“Disability, attitudes and stigma in Greek society”: Exploring the perceptions of caregivers and professionals regarding the repetitive behaviour of children with vision impairment and children on the autism spectrum
(a comparative study)

By

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A Thesis Submitted to

The University of Birmingham

for the Degree of

DOCTOR OF PHILOSOPHY

Disability, Inclusion & Special Needs Department
School of Education
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University of Birmingham

June 2022

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ABSTRACT

This comparative case study explores the perceptions of caregivers and professionals, regarding the repetitive behaviour (RB) in their 4-to-13-year-old children/ students with vision impairment (VI) or with autism spectrum disorder (ASD). The study was conducted in Greece, as no related research has been conducted in the country.

Research questions: This research aims to address the types of RBs observed by adults in children with VI or ASD, the explanations the adults employ to interpret these behaviours and the impact RBs have on the child, the caregiver, the professional and society. The underlying reason for this is an attempt to discover any potential differences between two different disabilities in a comparative fashion. The research questions that support the study are: 1. What are the RBs that caregivers and professionals observe in children with VI and children on the ASD? Does the child's individual characteristics such as their age or ability have an impact on their behaviour? 2. What explanations do caregivers and professionals attribute to these behaviours? and 3. What is the impact of these behaviours a) on the child, b) on the caregiver/ professional, c) on others?

Design: This study is based on interpretivist paradigm and followed a qualitative approach. A comparative case study design based on the ecological systems theory (EST) was adopted. 35 caregivers and accredited professionals were recruited (17 for the VI group, out of whom 8 were caregivers and 9 were professionals, and 18 for the ASD group, out of whom 9 were caregivers and 9 were professionals). Following the completion of a pilot study, all participants were interviewed regarding one specific child – their own child/ student – via semi-structured interviews. During the interviews, the researcher used a research diary as a methodological tool and video elicitation as a facilitation tool. A cross-case analysis was conducted and data was analysed according to the method of thematic analysis.

Results: A link has been indicated between VI and ASD, which concerns perceptions about the socially constructed manner in which an RB is perceived. ASD is perceived by the participants as a disability with challenging characteristics, such as an RB. The ASD group perceived RB as linked to ableism, social stigmatisation and taboo, in contrast to VI, where the existence of RB seems to be a consequence of sensory loss. Bi-directionality of EST seems to have been lost completely and the macrosystem seems to drive the interactions between the ecological systems. School policy and practical implications are discussed.

Keywords: repetitive behaviour, vision impairment, autism spectrum disorder, caregivers and professionals’ perceptions, social stigma, ableism

To Dimitrios Drakopoulos,

an enlightened academic, an inspiring teacher, my beloved grandfather…

Στον Δημήτριο Δρακόπουλο,

έναν φωτισμένο ακαδημαϊκό, έναν εμπνευσμένο δάσκαλο, τον αγαπημένο μου παππού…

Acknowledgements

To my magnificent ***parents Ioannis & Eyfrosyni****.*
You instilled in me a passion for lifelong learning.
Your love is always endless and your patience inexhaustible.

To my beloved ***sister Konstantina****.*
You were always so steadfast during all my efforts in this work and your faith in my abilities is unwavering.

To my ***lead supervisor Dr Liz Hodges****.*
From day one of this journey and until the last you were always the beacon showing the way. The teacher who with her honesty, consistency, firmness and humanity taught me how to remain strong and calm inside Academia.

To my ***supervisors Dr Prithvi Perepa & Dr Kerstin Wittemeyer****.*
You believed in me. You helped me. You supported me. You guided me. You kindly put up with me and my messy thoughts. You saw me cry. You heard me laugh. In one way or another, you were always 'there'.

To my ***sponsors.***
The ***"Leventis Foundation" (Switzerland) &***
The ***"Bakalas Foundation" (Greece)****. This thesis would have been impossible without your financial contribution. Special thanks to you!*

To the ***caregivers &*** *the* ***professionals*** *involved in this research study.*
I greatly appreciate the consideration and time you offered in participating in this scientific journey. Your energy, your thoughts and concerns are an integral part of these pages.

To the ***Headteachers Dr Philippos Katsoulis & Mrs Afroditi Bekiari, &***
the personnel *of the* ***"Special Primary School for the Blind" in Athens, Greece*** *& the* ***"Special Pre-Primary School for the Blind" in Athens, Greece****.*
For your willingness to participate in the present study. You all hold a special place in my heart, since the early idea for this doctoral thesis was the result of our earlier collaboration.

To the wonderful ***Mrs Lemonia Aidonidou & Mrs Dionysia Vasilara. Psychologist & Social worker*** *at* ***"Amimoni, the Panhellenic Association of Parents, Guardians and Friends of Visually Impaired People with Additional Disabilities"*** *respectively.*
I could not have made it without your support. Your appreciation and trust in me and my work was profound ever since our first meeting, which was even greater an incentive for me.

To the ever-creative ***Mrs Adamantia Psallidakou, Headteacher of the "Piraeus Special Primary School for Autistic Individuals" in Athens, Greece.***
You helped me in recruiting participants for the research.
I am very grateful for your generosity in rendering this study possible.

To the ***colleagues*** *who eventually became* ***friends*** *and my* ***dear friends:***
Dr Alexia Achtypi, Dr Hayrunisa Pelge, Dr Wen-Yu Wu & Dr Kubra Akbayrak. *For your help in making this thesis more reliable and my PhD daily life more bearable.*
And to ***Mrs Photini Valiakou, Mrs Alkisti Mona, Doc.dr Marija Andjelkovic, Dr Angeliki Bistaraki, Mrs Elizabeth Panjarian & Mrs Soumi Papadopoulou*** *for the positive criticism and reflective conversations; you push me to always be the best version of myself.*

To my ***colleagues*** *in study rooms* ***G5 and G47****.*
It has been my joy and privilege to walk this path with you. Thank you for keeping me and each other strong at various times throughout this long process.

To ***my mentor Dr Despina Papoudi****.*
My 'reference point', from my first steps in Special Education in Greece up to those that lead me to this day, in the United Kingdom.

To ***Prof. Vassilis Argyropoulos, Mr Panagiotis Markostamos, Prof. Angeliki Gena & Mr Nikolaos Kavourinos****. You encouraged and supported me in challenging moments of this journey and the preparation stage that preceded it.*

Last but not least, to ***Prof. Graeme Douglas****.*
It was that day in July 2013 in Istanbul, when a brief conversation with
you during the "8th ICEVI European Conference on Education and
Re/habilitation of people with visual impairment", changed my entire life.
Thank you, just to express my gratitude!

Ευχαριστίες[1][2]

*Στους σπουδαίους **γονείς** μου, **Ιωάννη & Ευφροσύνη**. Με διαποτίσατε με πάθος για τη δια βίου μάθηση. Η αγάπη σας είναι πάντοτε αστείρευτη και η υπομονή σας ανεξάντλητη.*

*Στην πολυαγαπημένη μου **αδερφή Κωνσταντίνα**. Παρούσα με σταθερότητα και ακλόνητη πίστη στις ικανότητες και τις ακαδημαϊκές επιλογές μου ˙ πίστη συχνά μεγαλύτερη κι από τη δική μου.*

*Στην κύρια επιβλέπουσα **Δρ. Liz Hodges**. Από την πρώτη ημέρα του ταξιδιού αυτού και μέχρι την τελευταία, ήσασταν πάντοτε ο φάρος που φώτιζε την πορεία. Η δασκάλα που με την ειλικρίνεια, τη συνέπεια, την αυστηρότητα και συνάμα ανθρωπιά της, μου δίδαξε πώς να παραμένω δυνατή μα και ψύχραιμη μέσα στην Ακαδημία.*

*Στους επιβλέποντες **Δρ. Prithvi Perepa & Δρ. Kerstin Wittemeyer**. Με πιστέψατε. Με βοηθήσατε. Με στηρίξατε. Με καθοδηγήσατε. Με ευγένεια δείξατε κατανόηση απέναντι στο χάος των σκέψεών μου. Με είδατε να κλαίω. Με ακούσατε να γελάω. Με τον έναν τρόπο ή τον άλλο, ήσασταν πάντοτε «εκεί».*

*Στους **χορηγούς** μου. Το **«Ίδρυμα Λεβέντης» (Ελβετία) &** το **«Ίδρυμα Μπάκαλα» (Ελλάδα)**. Αυτή η διατριβή θα ήταν αδύνατον να πραγματοποιηθεί δίχως την οικονομική σας ενίσχυση. Ειδικές ευχαριστίες σε εσάς λοιπόν!*

*Στους **κηδεμόνες & επαγγελματίες** που συμμετείχαν στην παρούσα ερευνητική εργασία. Εκτιμώ βαθιά το ενδιαφέρον και τον χρόνο που επενδύσατε με τη συμμετοχή σας σε αυτό το επιστημονικό εγχείρημα. Η*

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[1] In a gesture of respect towards all those who aided me in the preparation and conduction of this research study, but who do not speak English well; and given the fact that this is a comparative study taking place in Greece, I considered it sensible and important to thank them in their mother tongue, by providing my acknowledgements in the Greek language too.

[2] Σε ένδειξη σεβασμού προς τα άτομα εκείνα που με βοήθησαν την περίοδο της προετοιμασίας και κατά τη διάρκεια της πραγματοποίησης της δεδομένης έρευνας, αλλά δεν είναι εξοικειωμένα με τη χρήση της αγγλικής γλώσσας; και δεδομένου ότι πρόκειται για μία συγκριτική μελέτη η οποία λαμβάνει χώρα στην Ελλάδα, θεώρησα λογικό και σημαντικό να ευχαριστήσω τους ανθρώπους αυτούς και στη μητρική τους γλώσσα, δηλαδή την ελληνική.

ενέργειά σας, οι σκέψεις σας και οι προβληματισμοί σας θα αποτελούν πάντα αναπόσπαστο μέρος των σελίδων αυτών.

*Στους **Διευθυντές Δρ. Φίλιππο Κατσούλη & Κα Αφροδίτη Μπεκιάρη, & το προσωπικό του «Ειδικού Δημοτικού Σχολείου Τυφλών Καλλιθέας» στην Αθήνα & του «Ειδικού Νηπιαγωγείου Τυφλών Καλλιθέας» στην Αθήνα** αντίστοιχα.*
Για την προθυμία σας να συμμετέχετε στην παρούσα εργασία. Όλοι σας καταλαμβάνετε μία ξεχωριστή θέση στην καρδιά μου, αφού η πρωτόλεια ιδέα από την οποία ξεκίνησε αυτή η διδακτορική διατριβή ήταν το αποτέλεσμα της πρότερης συνεργασίας μας.

*Στις υπέροχες **Κα Λεμονιά Αηδονίδου & Κα Διονυσία Βασιλαρά. Ψυχολόγο & Κοινωνική λειτουργό** αντίστοιχα στην **«Αμυμώνη», τον «Πανελλήνιο Σύλλογο Γονέων, Κηδεμόνων και Φίλων Ατόμων με Προβλήματα Όρασης και Πρόσθετες Αναπηρίες».***
Δε θα τα είχα καταφέρει δίχως εσάς. Η εκτίμησή σας στο πρόσωπό μου καθώς και η εμπιστοσύνη που επιδείξατε στη δουλειά μου ήταν φανερές από την πρώτη μας κιόλας συνάντηση, γεγονός που αποτέλεσε επιπλέον κίνητρο για εμένα να προχωρήσω.

*Στην πάντοτε δημιουργική **Κα Αδαμαντία Ψαλλιδάκου, Διευθύντρια** του **«Ειδικού Δημοτικού Σχολείου Αυτιστικών» Πειραιά.***
Για τη βοήθεια που μου προσφέρατε, στα πλαίσια της αναζήτησης συμμετεχόντων για την έρευνά μου. Αισθάνομαι ευγνώμων για τη γενναιοδωρία που δείξατε, προκειμένου να καταστεί δυνατή η εκπόνηση αυτής της μελέτης.

*Στις **συναδέλφους** που με το πέρασμα του χρόνου έγιναν φίλες, καθώς και στις **αγαπημένες μου φίλες:***
***Δρ. Αλεξία Αχτύπη, Δρ. Hayrunisa Pelge, Δρ. Wen-Yu Wu & Δρ. Kubra Akbayrak.** Για τη βοήθειά σας στο να αποκτήσει η εν λόγω διατριβή μεγαλύτερη αξιοπιστία και η συχνά προκλητική καθημερινότητά μου να γίνει πιο υποφερτή. Καθώς και στις **Κα Φωτεινή Βαλιάκου, Κα Άλκηστη Μόνα, Δρ. Marija Andjelkovic, Δρ. Αγγελική Μπισταράκη, Κα Ελισσάβετ Panjarian & Κα Soumi Παπαδοπούλου** για την εποικοδομητική κριτική και τις αναστοχαστικές συζητήσεις˙ με ωθείτε πάντα να γίνομαι η καλύτερη εκδοχή του εαυτού μου.*

Στις συνεργάτιδες *στις αίθουσες ομαδικής μελέτης* ***G5 & G47.***
Ήταν χαρά και τιμή μου να διανύσω το μονοπάτι αυτό μαζί σας. Ένα μεγάλο ευχαριστώ που κρατήσαμε η μία την άλλη δυνατή, τις στιγμές εκείνες που μόνο εμείς γνωρίζουμε, καθ' όλη τη διάρκεια της μακράς αυτής διαδικασίας.

Στη ***μέντορά*** *μου,* ***Δρ. Δέσποινα Παπούδη****.*
«Σημείο αναφοράς» για εμένα, από τα πρώτα μου βήματα στον χώρο της Ειδικής Αγωγής στην Ελλάδα μέχρι εκείνα που με οδήγησαν στη σημερινή ημέρα στο Ηνωμένο Βασίλειο.

Στον ***Αναπληρωτή Καθηγητή Βασίλη Αργυρόπουλο, τον Κο Παναγιώτη Μαρκοστάμο, την Καθηγήτρια Αγγελική Γενά & τον Κο Νικόλαο Καβουρίνο****.*
Επειδή με ενθαρρύνατε και στηρίξατε σε πολύ συγκεκριμένες και προκλητικές στιγμές της διαδρομής αυτής, καθώς και της προετοιμασίας που προηγήθηκε.

Τελευταίο, αλλά εξίσου σημαντικό,
στον ***Καθηγητή Graeme Douglas****.*
Ήταν εκείνη η μέρα του Ιουλίου του 2013 στην Τουρκία, όταν μία σύντομη συζήτηση μαζί σας στα πλαίσια του «8^{ου} ICEVI Ευρωπαϊκού Συνεδρίου για την Εκπαίδευση κι Αποκατάσταση Ατόμων με οπτική αναπηρία», άλλαξε τη μετέπειτα ζωή μου. Σας ευχαριστώ, απλά για να εκφράσω την ευγνωμοσύνη μου.

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ACCESSIBILITY

Needless to say, the general focus of this research study is on children with vision impairment or with autism spectrum disorder and the families/ professionals associated with them. It goes without saying, therefore, that the study should be accessible to the people in question. According to Vigo et al. (2007), the first out of four accessibility characteristics (POUR: perceivable, operable, understandable, robust) is for a written source to be perceivable and in this case this would be achieved only if the thesis could be easily read by all types of potential readers. This study has been organised with people either with vision impairment or on the autism spectrum in mind and is also addressed to individuals with vision impairment or with autism spectrum disorder as well. Thus, in view of my intention to be inclusive and in order to make my thesis openly available and accessible, I kept the Accessibility Checker of Microsoft Word running while writing and working on this text.

Moreover, I decided to use MS Sans Serif, that is considered the clearest font in terms of writing options for people with low vision (partially sighted). To be precise, Buultjens et al. (1999) spoke in support of the clearness of the Helvetica font followed by the Arial font for print users. Because, however, the Helvetica font is not included in the Windows 10 list which I use, it was replaced by MS Sans Serif, which, according to the online Windows 10 guide, is considered the alternative typeface to Helvetica. In what concerns font size of the main text, No.12 was maintained, exactly as the University guidelines recommend and bearing in mind the wide usage of CCTV by people with low vision. I also aligned my content with the left margin (even if it is not so common), in order to make my thesis accessible to screen readers.

I initially tried to create figures and tables in strong colour contrasts for people with low vision, as well as alternative/ simplified tables and figures accompanied by a thorough description and a label which was placed before, rather than after them, with the purpose of making every table and figure accessible both to readers with any type of disability and those using a screen reader. In other words, I wanted to present my tables and figures in a more simplified way and provide them in the Appendices along with a proper description, in order to make access to them possible. Finally, though, I decided to have all the aforementioned accessible material within the main body of the thesis, as this will be helpful for all. In any case, it has to be mentioned that “no one font, size, style, or combination suits every person with low vision” (Buultjens et al., 1999); however, providing at least a strong support through this typical choice, optimum reading prerequisites for the reader with low vision are created (Buultjens et al., 1999).

ON THE CHOSEN TERMINOLOGY AND ABBREVIATIONS

Abbreviations used

The abbreviations I used throughout the thesis are presented alphabetically in *Table 1* below. Please note, however, that in the main body of the text each term is written out in its full form upon first appearing, and from that point onwards in the form of an acronym. The abbreviations used are internationally recognisable.

Table 1 consist of two columns and 16 rows. The first column provides all the abbreviations mentioned in the thesis, while the second column provides the full form of these abbreviations.

Table 1: All abbreviations used in the thesis

ADOS	Autism Diagnostic Observation Schedule
ADI-R	Autism Diagnostic Interview-Revised
APA	American Psychiatric Association
BST	Bioecological Systems Theory
CVI	Cerebral/ Cortical Visual Impairment
DSM	Diagnostic and Statistical Manual of Mental Disorders in the United States, published by the American Psychiatric Association
DSM-III	3rd edition
DSM-IV	4th edition
DSM-V	5th edition
EGA	Extreme Groups Approach
EST	Ecological Systems Theory
ICD	International Classification of Diseases and Related Health Problems
ICD-10	10th revision
ICD-11	11th revision

ICF	International Classification of Functioning, Disability and Health
IRR	Inter-Rater Reliability
NCDP	National Confederation of Disabled People in Greece
NFB	National Federation for the Blind of Greece
NVivo	NUD*IST Vivo computer software pack for organising data and for data analysis mainly used in qualitative and mixed methods research
RB RBs	Repetitive Behaviour Repetitive Behaviours
RNIB	Royal National Institute of Blind People in the United Kingdom
RRBs	Restrictive, Repetitive Behaviours

Terminology selected

Whether spoken or written, the language in which people refer to other people reflects their perceptions regarding the latter and may sometimes influence the way others perceive them (Auslander and Gold, 1999). Language allows for personal and professional communication but also reflects "societal trends" (Hayton and Dimitriou, 2019, p.3). From another point of view, language influences societal perceptions, public policy, clinical practice and research directions (Vivanti, 2020), as well as shapes how people think, feel and act toward others, including people with disabilities (Caplan, 1995). Negative references concerning people with disabilities have been termed "disabling language" (La Forge, 1991, p.1395) and may be used by caregivers, practitioners or people with disabilities themselves. The question, however, is whether specific terms are considered acceptable or not in the context of different societies and personalities. People develop different views depending on their experiences, their training, their own personal preferences, even the society/ country in which they have been raised (Dunn and Andrews, 2015, Graby, 2016). All these affect the way they speak, as well as what is offered or sought.

More precisely, the debate concerning terminology with regards to vision impairment and autism is ever relevant, since the language used to define and describe disability has evolved and is still evolving (Dunn and Andrews, 2015). Language is not static but changes inevitably (Aitchison, 2001) as exactly do people and their beliefs. It is my obligation to respect those beliefs; it is my obligation to respect practitioners, parents, caregivers, children and adults with vision impairment and autism spectrum disorder. That is the reason why I aim to present my rationale, to state and justify the perspective on which I will develop the writing of my thesis.

The language that accompanies vision impairment is not consistent and globally accepted. Graby (2016) and Woods (2017) argue that it is mainly person-centred or child-centred (Hayton and Dimitriou, 2019), favouring terms such as “a person with vision impairment”. Person-first language was originally proposed in the 1970s as an alternative option to the terms ‘disabled’ or ‘handicapped’ in general, so as to signify that disability is only one component of a person’s identity, rather than the only defining feature (Vivanti, 2020). An approach like that emphasises the individual over the disability; indicates the need for people to be focused on the personhood and not the characteristics that come along with that disability. By literally placing the person before the disability, attention is drawn to the individual’s unique strengths, needs and experiences, both related and unrelated to their disability. It is also an acknowledgement that these personal characteristics might differ across individuals with the same disability (Vivanti, 2020).

However, upon studying the terminology that associations organised by people with vision impairment themselves are using in practice, one may also observe identity-first use of language. For instance, the "Royal National Institute of Blind People (RNIB)", one of the United Kingdom's leading sight loss charities and the largest community of blind and partially sighted people in the country, refers to people with vision impairment as "blind people" even in its official title. In 1993, the American "National Federation of the Blind (NFB)" adopted a resolution opposing person-first language and branding it as "unacceptable and pernicious" (Jernigan, 1993). The NFB claimed that person-first language is defensive and "implies shame instead of true equality, and portrays the blind as touchy and belligerent" (Jernigan, 1993, p.2). In Greece, the "National Confederation of Disabled People (NCDP)"[1], as well as practitioners in the public and private sector promote and teach person-first language. It is something of an unspoken rule that follows a generally accepted practice, aligned with the social model of disability. However, individual denominations of associations of people with vision impairment, such as the NFB or chartered organisations like "Schools for the Blind", the "Center for Education and Rehabilitation for the Blind", "The Lighthouse for the Blind of Greece" or the "Panhellenic Association of Parents, Guardians and Friends of Visually Impaired People with Additional Disabilities" all refer to "blind" or "visually impaired" people and community as a whole; namely, they use identity-first language in the official denomination found in their websites. The variance observed between the official stance of organisations on the use of language and the terminology used in institution titles highlights that there is a contradiction within Greek society regarding the use of terminology and perhaps a certain lack of clarity regarding the use of appropriate

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[1] English term retrieved from the website of the EUROPEAN PATIENTS FORUM, E. *NCDP – National Confederation of disabled people* [Online]. Available: https://www.eu-patient.eu/Members/The-EPF-Members/Full-Membership/NCDP/ [Accessed 29th January 2021]., and that of the EUROPEAN DISABILITY FORUM, E. *National Confederation of Disabled People (NCDP)* [Online]. Available: https://www.edf-feph.org/our-members/account-national-confederation-of-disabled-people-ncdp/ [Accessed 29th January 2021]., where NCDP has a full membership.

terminology. The issue here is whether they are using identity-first language due to reasons of political correctness, or opting for the old-fashioned way, where a person was known by their disability (e.g., blind person) through the use of an adjective, but not necessarily because they were proud of their blind identity. I am trying to be critical regarding this issue, as it is part of the education I have gained in the United Kingdom, where I currently live. As a matter of fact, I may now be looking at things through a British lens – a way of regarding diversity developed in a country where using a politically correct language has become "a battleground", perhaps due to the great number of migrants who reside in it (Blackledge, 2009, p.6) and caused implications even in the field of disability. From a Greek point of view, however, things might be simpler; people just use a very specific terminology in the written word, just because they tend to do it traditionally; because for instance, all the associations for people with vision impairment have a long history that might make their renaming an unpleasant and difficult process, which means it is perhaps not based on the identity first philosophy. This is undoubtedly an attitude that might be reflected in people's perceptions in Greek society.

Personally speaking, I am a keen exponent of the person-first approach, as it conforms with my professional experiences with children with vision impairment and their families, as well as adults who had total vision loss or were partially sighted, both in Greece and in the United Kingdom. Another reason for making such a decision, is that my research study concerns children and social perceptions focused on disability, that seem to have an impact on the children's and their families' lives. Person-first language is intended to shift that focus from the impairment to the social barriers that impede full participation in the community. Thus, for these reasons, I will from this point onward refer to individuals/ children with sight loss as individuals/ children 'with vision impairment'.

With regard to the debate around autism, this has been more complex. Woods (2017, p.1091) argues that autism, as is the case with most disabilities, is seen as being different from; “the norm”, which is probably why “negative language” is used against it. This indicates the different ways in which people cope with autism spectrum disorder (Milton et al., 2016a) and the need for a common line to follow. Consequently, by focusing on eliminating the negative discourse of autism, Woods (2017) suggests the aim should be to achieve positive societal attitudes towards autism, initially by using the appropriate language and terminology. No such thing could be achieved without first consulting the autism community (people on the autism spectrum, their families, friends and broader support networks), exactly as in the case of vision impairment. Indeed, Milton (2014b), being a person with autism himself, who defines himself as an autistic man, argues that the answers to questions regarding terminology have been mistakenly given by people outside the autism community. This statement fills me with great concern regarding the tendency to neglect the importance attached to the perceptions and attitudes of people with disabilities, something that I will try to avoid in the present research study.

In Greece, the politically correct way is to use person-first language, according to the social model of disability. There has been no official resolution regarding the matter, however. As has already been mentioned regarding vision impairment, the “Greek National Federation of Individuals with Disabilities”, to which individuals with disabilities and professionals as well resort, has adopted person-first language. However, one can see no common approach between the denominations of public schools for children on the autism spectrum and those for children with vision impairment. For example, in Athens there is a “Special Primary School for Autistic Individuals” and there is also a “Special School for the Autistics”, according to the naming found on the official websites of the schools in question. As I have already said, I am not absolutely sure that the naming of the schools has been influenced by a conscious use of identity-first or person-first language. In any case, though, this is an attitude that may reflect the way in which people perceive disability and how they conceptualise it. It could be seen as a norm that possibly affects the way they perceive repetitive behaviours as well.

Consequently, in some areas the autism community perceives people as 'autistic', rather than as 'having autism spectrum disorder'. Therefore, some would say "my autistic child" while others would say "my student with autism spectrum disorder" or "a person on the autism spectrum". The person-first approach, therefore, has been challenged by the identity-first approach, namely through terminology such as 'autistic', 'autistic person' or 'autistic individual' (even if I am still not sure they are consciously thinking of identity first language when they use these phrases in Greece). This is because supporters such as Gernsbacher (2017) and Robertson and Ne'eman (2008) consider autism as an inherent part of an individual's identity. They believe that if an 'autistic person' is seen as a person pretending that autism is not there, then they are not being seen as a whole personality and a very important part of that individual's personhood is denied. Being 'autistic' is at least as much a part of someone's unique personhood and it is not removable or replaceable. The rationale is that 'non-autistic people' need to be reminded that 'autistic people' really are people. Because otherwise a problem emerges: that the disability is seen as separate from the individual. Therefore, it appears as if the diagnosis is so terrible as to be inconsistent with personhood, and that the only way to acknowledge that people are humans is to separate them from their disabilities. This is the same argument as with vision impairment which I presented above.

On the other hand, exactly as in the case of vision impairment, many parents and practitioners of children on the autism spectrum favour person-first language: they consider ‘person with autism’ preferable. It is because they do not think the disability is the only identity of the person and do not want their children to be identified or referred to as ‘autistic’. The rationale here is that “the centrality of the person” (Vivanti, 2020, p.692) goes first and it acknowledges that beyond the autism diagnosis there exists an individual with rights that has to be respected.

Therefore, in my writing (and thinking and speaking), I need to decide whether to use Person-first or identity-first terminology. Although a definitive mandate for writing and speaking about autism might be desirable, like Dunn and Andrews (2015), I believe that flexibility is an appropriate and respectful response, since disability has been perceived differently in different times. Although both person-first and identity-first language reflect a common intention to de-pathologise disability, they do so through the lens of two different approaches (Vivanti, 2020). Since there is no universally accepted guideline regarding the language and terminology used (Kenny et al., 2016), I would expect people simply to justify their choices in writing and speaking while simultaneously being respectful of other people’s opinions. In the interests, therefore, of not diverging in terms of the rationale underlying my approach towards both types of disability in the present research, I have chosen in this case to adhere to the same decision as the one I made regarding vision impairment, i.e., to use person-first language (an individual/ a child with autism spectrum disorder or on the autism spectrum).

First and foremost, and as has already been mentioned briefly above, the conceptualisation of autism in Greece, where my research took place, is very specific: although the terminology used is often identity-specific, the quality of special education as well as the manner in which individuals with a disability themselves wish to be referred to, is person-first oriented. Furthermore, the fact that most identity-first language research in autism does not include children, is an additional reason why I chose not to use identity-first language. To be more specific, Dunn and Andrews (2015), who have reviewed the evolution of disability language conclude their work with the major models used to characterise disability and people in general, without focusing on children at all. Therefore, both as a researcher and a practitioner in the field of disability, inclusion and special needs, I know how important all the developmental stages through which a child with or without a disability goes are. This entails that no safe generalisations can be made, unless research more focused on childhood takes place first.

Apart from the above, there is one more concern in relation to the use of the term 'vision or visual impairment'. 'Vision impairment' is the now recognised term that the World Health Organisation (2018) uses, and that the RNIB, as well as the Association of Blind Citizens of New Zealand (which promotes politically correct language) accept. This is because people with a vision impairment do not always look physically different. Therefore, they are considered not 'visually impaired'.

A similar concern emerged regarding the use of 'autism spectrum disorder' (in the singular) or 'autism spectrum disorders' (in the plural). Oberman and Kaufmann (2020) assert that the use of the singular term "autism spectrum disorder" is suggested alternatively to the plural term "autism spectrum disorders". The use of the plural term "autism spectrum disorders" is according to Oberman and Kaufmann (2020) also problematic in clinical practice, as on the one hand the DSM-V framework takes into consideration the range of impairments and severity in autism, while on the other, if autism is considered a broad behavioural syndrome with as yet unspecified causes and multiple mechanisms, this suggests that there is no need for a plural term.

There is also a debate on whether the term 'disorder' should be used or not. According to Singer (1999), Robertson (2009) and Nicolaidis

(2012), autism is considered to be a neurological form within the human mind. The debate concerns the neurodiversity movement that eschews negative language expressed through terms such as “disorder”, “deficit” and “impairment”. More precisely, Baron–Cohen (2000) suggested that the term “condition” replace the term “disorder”. There is also, however, the other side, whose supporters emphasise the term “disorder”, advocating “ways to ‘treat’ the condition, with some pursuing a ‘cure’ or ways to prevent it” (Kenny et al., 2016, p.443). The only thing that can be acknowledged without a doubt is the different preferences people hold about the terms they use to refer to autism, based on their beliefs, perceptions and attitudes. At the moment, though, there is no clear picture as to the autism community’s attitude towards this concern, especially in a Greek context. For this reason I will continue to use the term “disorder”, exactly as it occurs in the latest edition of both the American Diagnostic and Statistical Manual of Mental Disorders (DSM-V), as well as in the International Classification of Diseases and Related Health Problems (ICD-11) (Doernberg and Hollander, 2016).

Hence, taking into consideration the above concerns regarding the way in which reference would be made to vision impairment and the autism spectrum, the following abbreviations in *Table 2* were constructed. This is another table consisting of two columns and three rows. The first column includes the abbreviations via which reference either to autism or to vision impairment was made (shown in the second column).

***Table 2**: Abbreviations relating to the two disabilities discussed in the study*

ASD	Autism Spectrum Disorder
AS	Autism Spectrum
VI	Vision Impairment

Another point I have to mention here is the issue of referring to the names of the schools that were involved in this research study. The question arose of whether they should be translated literally or in a way that is politically correct: to mention some examples, "School for the Blind" vs "School of the Blind" or "School for Children with Vision Impairment" and "School for the Autistics" vs "School for Children on the Autism Spectrum" or "School for Children with Autism Spectrum Disorder". Ultimately, I opted for literal translations or chose to employ the terms that the institutions themselves use in the English versions of their websites.

The same concern also arose in relation to certain interviewees' statements. In this case as well, and because my main aim was to reflect the participants' perspectives, words were reproduced verbatim, and not using free translations at will.

PROLEGOMENON

Conducting a PhD, I would say, is like being in a relationship. A relationship that begins with the best of prospects; with enthusiasm, joy, and love; with dreams, ideas and thoughts that can be nothing but positive. It is a relationship that continues, despite encountering difficulties, problems and concerns. One cannot predict its final outcome, yet something drives them on, to live and experience it. One learns, grows, loses, finds, matures. Hence, I would like to begin with an excerpt from the first book I ever read as a child in the English language, "Oh, The places you'll go!", by Theodor Seuss Geisel (1990, pp.24-25), whose words have stayed with me well into adulthood:

"You will come to a place where the streets are not marked.
Some windows are lighted. But mostly they're darked.
A place you could sprain both your elbow and chin!
Do you dare to stay out? Do you dare to go in?
How much can you lose? How much can you win?

And IF you go in, should you turn left or right . . .
Or right-and-three-quarters? Or, maybe, not quite?
Or go around back and sneak in from behind?
Simple it's not, I'm afraid you will find,
For a mind-maker-upper to make up his mind."

Chapter 1
INTRODUCTION

1.I Chapter overview

After having defined the abbreviations which will be used in a table of abbreviations, as well as the perspective from which certain concepts are viewed, this first chapter opens with an introduction to the study and its background. A brief presentation of the chapters of the thesis then follows. The chapter is structured in the following way: in the beginning there is a section dedicated to the context and the scope, which is followed by the significance of the research study. A structure of the thesis is then presented in summarised form, before the chapter concludes with its own summary.

1.II The context, the scope and the significance of the research

This research study investigates the perceptions of caregivers and professionals concerning the repetitive behaviours (RBs) presented by their children/ students, either with vision impairment (VI) or on the autism spectrum (AS). Extensive reference to RBs and the way in which they are linked to the two aforementioned disabilities will be made in 2.V. However, to clarify the focus of this study, I would like to start this section with a brief explanation of how RBs are defined throughout the bibliography and how common they are in children with VI or with autism spectrum disorder (ASD).

RBs are described as a heterogeneous group of behaviours which, however, present homogeneity with regard to their clinical characteristics (Bodfish et al., 2000, Cuccaro et al., 2003, Lam and Aman, 2007), which is basically present in pervasive developmental disorders like ASD (Carcani-Rathwell et al., 2006). RBs appear as restricted, stereotyped patterns either of behaviours (e.g., repetitive vocalisations) or interests (e.g., an intense hobby) or activities (e.g., fixation with sameness in play) (Georgiades et al., 2010), or even harmful behaviour (e.g., cutting skin) (Stone, 1997). There is no mention in the bibliography regarding the absolute frequency of existence of RB in children on the AS. However, both of the two official diagnostic criteria (Wilson et al., 2013), namely the "American Diagnostic and Statistical Manual (DSM)" of mental disorders published by the American Psychiatric Association (1987, 1994, 2013) and the International Classification of Diseases and Related Health Problems (ICD) published by the World Health Organisation (1993, 2018), make mention of RB as one of the diagnostic criteria for an individual being on the AS.

On the other hand, people and more specifically children with VI may be characterised by a RB in a stereotypical sense, namely that of "improper behaviours such as atypical movement of arms, wobbling, putting their fingers into their eyes" (Wrzesińska et al., 2017, p.350), or a lack of direct stimulation from the environment (Fraiberg, 1977). Moreover, children with VI may present intense interests or activities, or even verbal repetitiveness (Abang, 1988, Leonhardt, 1990), that are considered as RBs. In contrast to the case of ASD, though, RB does not constitute an official diagnostic criterion for VI. Repetitive behaviour is sometimes presented as a result of VI (Warren, 1994), as a lack of interaction with the surrounding environment or even as an overstimulation from it (Charman and Stone, 2008, Stone, 1997). It might also be seen as a potential indication of autism as a coexisting disability

(Brown et al., 1997). Actually, according to Wrzesińska et al. (2017), 11-40% of children with VI present autistic features and this information has to be used, in order to make the diagnostic process easier, in case of a dual disability.

The current study seeks to redefine the concept of RBs in VI and the AS, as well as the way in which research tends to address it. The study begins with an inquiry of whether children with ASD or with VI exhibit RBs according to their caregivers and the professionals working with them. It continues with the investigation of what the RBs observed by the same adults in the same groups of children are (and how they vary across situations). Furthermore, the explanations that the caregivers and professionals attach to RBs are sought, and the study finishes with the question of whether RBs have an impact on the children's surrounding environment or not.

The reason I initially decided to place my focus on the two aforementioned disabilities was initially based on my work experience. It was a need that has developed through my working experience and the knowledge I have gained through my studies. However, this need was undoubtedly finalised and crystallised by my reading of the literature. The literature review made me feel that there are unanswered questions and much uncertainty in terms of the comparison between VI and ASD, and specifically with a focus on RBs presented by children of these groups and the perceptions adults (caregivers and professionals) have adopted. In other words, my personal research journey seems to have followed different stages before I came to focus on the area in question. What I initially hoped to achieve when I started to focus my attention (via the use of the research diary) on the behaviours of children, the interventions of my colleagues, the approaches of the parents, as well as my own actions and reactions, was to promote my educational practices, my relationship with my work environment and by extension, my personal growth. With the passage of time, however, my interest shifted quite a few times; for example, in the direction of children with VI and ASD, or in that of the manner of decoding RBs. The notes in my research diary also contributed to this, along with the continuous study of primary as well as secondary sources and the gaps in such literature as I had located. This trajectory resulted in the changing of my attitudes that as a matter of fact impacted my teaching focus, as is going to be discussed further down, in the Discussion chapter.

My professional background is in special education, education and human rights, and educational psychology and music, achieved both in Athens, Greece and in London, United Kingdom. My specialised training initially focused on ASD and then on early intervention and VI, which means that I have worked as an accredited special education teacher, VI practitioner and educational psychologist. At the beginning of my career, I worked at special primary and at special pre-primary schools (for children with multiple disabilities) where I was actually the Headteacher, responsible for reporting to the Greek Ministry of Education and Religious Affairs on a daily basis. My working conditions often included limited staff members at the setting and pupils from different socio-economic and ethnic backgrounds, as well as with different types of disabilities. It was a challenging start at a young age, which, however, armed me with an interest in disability, special and inclusive education, and the desire to contribute to it. As the years went by, I took part in various research projects, which enabled me to travel to many different countries in order to present research findings.

As a result, my interaction with other practitioners and the contact I had with researchers in the field challenged my understanding of my own lived experiences, yet reinforced my curiosity for research, as well as my observation skills. I therefore started keeping a research diary and observing my colleagues’ behaviour and my own inside the classroom, my own attitude and the children’s actions and reactions. For example, the following extracts from the diary I kept at the time, capture this process: *2/ 4/ 2015 - During the interdisciplinary team meeting today, the nurse complained that the children stereotype during their sessions; that the educators need to be stricter: "Our blind children should not appear like autistic ones", she said. I disagree! I think that these movements are an effort to communicate something. 6/ 10/ 2009 - I honestly have doubts regarding the diagnoses I read: pervasive developmental disorder and blindness. Is it possible that there are so many children with multiple diagnoses, or is it perhaps a case of overdiagnosis? Also, must I allow their enrolment at our school or not? The law states that a child is admitted on the basis of the child’s primary and most serious diagnosis. How does one define "primary and most serious"? 25/ 11/ 2013 - AV (diagnosis: autism) hit me today. He put my hair in his mouth and bit me on the head. I called to my assistant for help. We must discuss what is wrong with this child. What are we doing wrong for him to be reacting like this? What is he trying to tell us? How can we protect his classmates from potential attacks? I am not sure he understands Greek*. In the meantime, through my specialisation in VI, I acquired the position of Headteacher of the "Special Pre-Primary School for Children with Vision Impairment" in Athens and later that of a VI practitioner in the "Special School for Children with Vision Impairment", also in Athens. In parallel, I was running my own private practice: the "Special Education Centre for the Child, the Adolescent and the Family", focusing on children and adolescents with learning disabilities or multiple disabilities, as well as their families. I also visited the Moorfields Eye Hospital in London, supporting and preparing my own students for their eye surgeries, leading and following a psychoeducational programme. I was the link between the child and the anaesthesiologist in the anaesthetic room and between the child and the glaucoma specialist ophthalmologist in the recovery room, during all the necessary post-surgical examinations before the child went back in Greece.

At some point in the middle of my career, then, I observed through the notes in my research diary that students with VI and children on the AS were presenting similar RBs, and that the adults working with them almost always had the same reaction: *"Stop it!".* Actually, an extract from my diary, records this: *26/ 6/ 2006 - "Stop it!" It's what I heard all day today. Or otherwise, I saw silent therapists holding the children's hands or shutting their mouths with their own hands. "Autistic ones must curb such socially unacceptable behaviours", they explain*. My initial research idea was to explore ways of interpreting such behaviours, in the form of something like a dictionary which would include every possible interpretation, to which any interested parties could refer. Similar research – which interpreted the RBs presented by children with ASD – has actually already been conducted. However, I questioned myself regarding the useful of such an exercise and its practical implications. Therefore, and for the reasons which will gradually become apparent in the course of this thesis, my eventual choice of subject was the one mentioned above.

I feel the need to mention that my studies abroad, my volunteering work with the RNIB and especially my work in the United Kingdom in the last approximately five years have significantly contributed to the data analysis process. The handling of my data, its codification and the detection of categories and then themes would certainly have been an entirely different reality, had I not decided to move to the United Kingdom and to further develop the manner in which I perceive and process information, through being a member of an academic society, and of a society different from the one I originally come from.

In line with the bibliography, researchers such as Gense and Gense (1994), Gibbons (2005), Hobson (2005), Jordan (2005), Tager-Flusberg (2005) and de Verdier et al. (2018), linked autism and VI together and ended up conducting research which pertains to these two disabilities, exploring similarities and differences, cause-and-effect relationships, and behaviours that sometimes contrast and sometimes do not. Moreover, Bodfish et al. (2000)'s, Gal and Dyck (2009)'s, Georgiades et al. (2010)'s, Honey et al. (2012)'s studies on RBs in VI and in the ASD basically focus on the definition of RB, its description, the reason why it manifests and the negative impact it has on the child and the social environment, along with the measures that have to be taken to eliminate it. Thus, as will be revealed later on, comparative studies on the research in question were not in existence and as Baron-Cohen (2002, p.792) has remarked concerning the link between VI and ASD, "might this be no more than a surface similarity? We should be careful not to assume that just because two church bells are ringing simultaneously, they are causally connected by the same rope". Inspired, therefore, by the slogan of the The National Autistic Society (2002) in the year of their 40th anniversary, "The problem is understanding", and bearing in mind that the problem is not just understanding, but comprehension as well (Johnston and Hatton, 2003), I began to find meaning in the way people perceive the experience of a RB, either in the case of VI or in the case of the ASD. The investigation of the way in which these people were assigning meaning to a RB and how this meaning was sometimes affecting their own behaviour, marked the start of my journey of discovery into these attitudes.

Discovering the way in which caregivers and professionals (people who are mainly responsible for the edification and education of a child with disability) perceive the RB their child/ student might have, may provide answers regarding the collaboration of caregivers and professionals and the impact it might have on a child on the AS or with VI.

On the one hand, it is not only the way the child is treated that is important, but also the way the caregivers perceive that treatment and how they themselves are treated by those who are involved professionally with the child, and vice versa. On the other hand, "if you want to understand what a science is, you should look in the first instance not at its theories or its findings, (…) you should look at what the practitioners of it do" (Lincoln and Denzin, 2003, p.145). Practitioners working with children with disabilities and more specifically with children on the AS or with VI, daily put in to practice through their work what research speaks about in theory. It is, therefore, of great importance to take their opinion into serious consideration, for effective intervention for the students to be planned.

The study has revealed interesting insights into RBs presented by children with VI or with ASD, the attitudes towards these behaviours (and, as a matter of fact, these disabilities) and the connection of these disabilities with social stigma in Greece. Suggestions based on the results of the study are also proposed in the conclusion chapter.

1.III Reflections on the use of first-person language

The realisation of a goal is a personal affair; in the present case, it is that of a doctoral thesis. Elliott et al. (1999, p.221) argue that a thesis "owns" the researcher's perspectives. In particular, then, the study owns my perspectives and my preconceptions, by disclosing my values, interests and assumptions and the roles these played in researching my chosen topic. I even translated all the 35 interviews I conducted in Greek into English – and this translation is a bit of my involvement too – so as to analyse them properly using a software with an English layout. This is the reason why I chose to make use of the first-person singular throughout the writing of this thesis.

This is a conscious choice I have made, being fully aware of the debate among those who support this type of writing and those who argue that the use of first-person pronouns renders academic writing informal (Hyland and Jiang, 2017). Hyland (2012) states that an academic text not only persuades, but also engages the reader. He also argues that research is developing inside a very changing and competitive environment; thus, the use of first-person pronouns is a powerful means of establishing the authority of the writer, that is considered as important to her/ his uniqueness (Hyland, 2001, Hyland and Jiang, 2017). In addition, first-person language highlights the importance of the author's independent voice in academic writing (Hyland, 2001).

The methodological self-consciousness of social sciences researchers and the emotions that they have about their own study is discussed by Davies (2012). She claims that adopting a personal narrative (use of "I") in academic writing is not an easy process. It is a difficult as well as a challenging way of writing, because the writer needs to be reflective about methodology and considerate in terms of the lived experiences she/ he is arguing about and the emotions they may give rise to. First-person language communicates the aims and the scope of an academic text more easily to the reader, than if they had been communicated "in a more traditional, abstracted and dispassionate manner" (Davies, 2012, p.750). I hope, therefore, that by writing in the first-person, I have produced a more effective piece of writing. This way, on the one hand I recognise my "self-referential emotionality" (Davies, 2012, p.750), but on the other hand I acknowledge either the positive or the negative impact the emotions regarding the study/ social interactions might have on me, something that I need to take into consideration and reflect on considerably.

1.IV The structure followed

The main core of the thesis begins with Chapter 1. Chapter 1 is concerned with familiarising the reader with the story of the study, the thinking behind the study and its core idea/ main purpose. This first chapter tells the reader in summary what is likely to be coming and together with the preliminary chapters (i.e., Accessibility, On the chosen terminology and abbreviations) clarifies matters such as accessibility of the thesis, as well as the reasons behind the use of person-first pronouns and certain terminology.

Chapter 2 focuses on the way I went about finding and justifying the most adequate literature, as well as the means I used. The literature review and a discussion concerning it are presented somewhat like a story. It is a sensible story that my reasoning followed, moving from the general (e.g., VI, ASD) towards the specific (e.g., displaying of RBs by children with VI or on the AS in a Greek context).

The important element in Chapter 3 is the attempt to demonstrate the link between the theoretical framework and the methodological framework. In other words, what is attempted is the clarification of both the dated and the updated model of Ecological Systems Theory and the reason the initial version was considered appropriate for the current research study. This is the theory on which the theoretical discussion will later on be based, as well as part of the results, suggestions and implications.

What follows is Chapter 4, which attempts to present the research design framework and the methods used. More importantly, though, the chapter specifies the reason why I decided to use these methods to answer my research questions and clarifies how I ultimately reached the final version of the research questions. My ethical consideration, as well as matters of credibility, trustworthiness and reliability are also illustrated.

The results of the research study are prefaced analytically in Chapter 5. These results are also accompanied by some initial thoughts about them and followed by a discussion, justification and exposition of the data, codes, categories, cross-categories and themes which led to them.

A theoretical discussion with a focus on the Ecological Systems Theory is the core subject of Chapter 6. The structure of the chapter is that of a dialogue based on the research questions placed in Chapter 2. In other words, a theoretical explanation of the findings through a microsystem/ mesosystem/ exosystem/ macrosystem/ ex-macrosystem and chronosystem lens is attempted.

Approaching the end of the study, I drew my conclusions, synthesised the findings, and appraised the work I had done, noting its strengths and weaknesses. The above, along with any reflections and implications constitute Chapter 7 – the conclusion.

In addition to the conclusion, I decided to include an epilogue in my thesis; an epilogue that is used to bring closure to my work. What is special about an epilogue is that it wraps up the doctoral experience process in a reflective way, while also serving as a continuation of the prolegomenon.

Summary

This has been an introductory chapter whose purpose was to contextualise and provide a general idea for the research study, after presenting the rationale and reasoning behind the terminology and abbreviations used, which were discussed right at the beginning. In light of this, the chapter began with providing a few features regarding the aim of the study, the development of the present inquiry and the importance of this study in terms of altering the perceptions of caregivers and professionals concerning the RB that children with VI or with ASD exhibit. Then followed an overview of my education and work history, including the challenges I faced, how these factors influenced my thinking on issues faced by individuals either with a VI or with ASD, and the decisions I initially made. After this, I gave some brief information about the literature review, and a detailed section regarding the use of first-person language throughout the thesis. Finally, I briefly described each chapter of the thesis. The next chapter describes the exploration of the literature on the various categories, sub-categories and themes regarding the Greek, but mainly also the international context.

Chapter 2
LITERATURE REVIEW

2.I Chapter overview

Davies (2000) and Green et al. (2006) very interestingly argue that practitioners read reviews to keep up to date with their field and researchers carry out literature reviews in search of justification for further research. As a matter of fact, this chapter is concerned initially with a review of existing literature relevant to the subject of this study. Essentially, it summarises the key points of study on which researchers who have conducted similar research have focused. At the same time, it outlines gaps in the existing literature.

The literature review method I decided to use is that of a narrative. Narrative reviews illustrate what is already known and also what is missing (Green et al., 2006). They are generally comprehensive and cover a wide range of issues within a given topic, related mostly to human science, as well as its implications and conclusions that may be put into practice (Collins and Fauser, 2005, Yuan and Hunt, 2009). There were limitations, though, that I had to address with regard to the question of the suitability of the narrative review process as the most appropriate one. Sources on the subject were limited and many of them were dated too. Given the fact, then, that this is an exploratory paper with limited literature and topics, I made the decision to be critical instead of descriptive. As Ferrari (2015) indicates, when the purpose of the review is clear, then a qualitative approach (i.e., narrative) is preferable. Characteristically enough, he also pinpoints the fact that the narrative literature review is the "cornerstone" (Ferrari, 2015, p.234) of the synthesis of social science literature, provided that it concentrates on a specific topic and establishes a relevance for the criteria of literature selection.

To put it briefly, the main aim here is to gradually develop the argument of how my findings could contribute to the existing literature (Wisker, 2001). Throughout the chapter I will try to narrate a story. It is the story of the logical progression of my argument, which is divided into four different parts: one for VI, ASD and the reason I compared those fields, one for RBs, another for perceptions and finally one for any potential research that has been conducted in Greece, in relation to the subject of the current thesis.

2.II Literature search strategy

The underlying aim of choosing to compare VI and ASD, in the context of RBs is the acquisition of a better understanding of the content of an RB and its connection with VI and ASD. The ultimate goal of this effort is to record the perceptions of the individuals most involved in the lives of the children who present RBs; that is, caregivers and professionals.

I had started gathering information on the subject even before the starting date of my PhD studies. Given the fact that my studies were part-time and that I submitted my thesis after having completed my sixth year, my literature review had started two years before the official beginning of my doctoral journey (i.e., 2013) and finished on the last day before the final submission (i.e., 2022). My initial reading guided my professional interest, eventually enabling me to arrive at my key terms and the topic of my PhD. In the end, I came up with an idea based on my experience and my previous reading that I wanted to explore in more depth. Doubtlessly, that initial idea and initial focus changed several times before

I had arrived at the final key terms and research questions, as I will discuss later on.

The exact timescale of the collection of my literature was from 2013 until the beginning of 2022. Initially, my interest was focused entirely on the subject field of autism, as I was conducting research that was to be presented in various European conventions, as part of a wider team. Later, I started focusing on the subject of VI, again spurred by research work, as well as by the cases of my own clients (i.e., students with disabilities under my own care and responsibility). My initial criteria focused on the educational/ emotional/ cognitive/ social needs of the students, but after becoming aware of the existence of a connection between the two disabilities, I tried to demarcate them even further (e.g., RBs, comparative studies). For example, at first, I tried to arrive at the final subject of my research influenced by my professional background and the intention I had always had to find and use the most appropriate type of intervention for my students; thus, I thought about developing a diagnostic tool for RBs. This would be a tool, based on which a practitioner or a caregiver could assign meaning to the potential RB of a child either with VI or on the AS. The time, however, that I spent on research and reading helped me to move on to a point of view less influenced by practitioner bias, or in other words a point of view less traditional in terms of my status as a practitioner; a view that would offer me the chance to discover people’s attitudes and how they impact on or impacted by children’s RB.

To be more precise, I used the following keywords: “repetitive behaviour”, “repetitive movement”, “ritual behaviour”, “stereotypy”, “mannerism”, “challenging behaviour”, “attitudes”, “perceptions”, “impact” along with the key terms that follow: “vision impairment”, “visual impairment”, “sight loss”, “blindness”, “autism”, “autism spectrum disorder”, “autistic”. I also searched for related theoretical frameworks (i.e., "Ecological Systems Theory", "Ecological Systems Theory and disability" or methodological designs (i.e., "case study in education", "case study in social sciences"), even from research projects with a medical, philosophical or neuroscientific background.

I found references sourced via online databases, academic libraries and physical libraries in the United Kingdom and in Greece. More specifically, I used *Sci-Hub, EthOS, European E-Theses, ProQuest Dissertations, ProQuest, ERIC*, *ScienceDirect*, *PubMed* and the Serbian *KoBSON* databases. Apart from the databases, I tried a manual online search using *Google Scholar* and the University of Birmingham's *FindIt* as my main catalogue search tools. I have also visited council libraries such as the Birmingham Library, the Worcester Library and the online library of RNIB in the United Kingdom. This was a kind of physical search that I carried out, in order to be sure that I had not missed any sources in the course of my online pursuit. Moreover, I searched for information in the National Library of Greece, the Eugenides Foundation Library and the "Library of the Lighthouse for the Blind" in Greece.

There were plenty of references to ASD, so I needed to place a limit on the number I would use. My criteria for inclusion were first and foremost the relevance of the content of each book or academic paper, and whether it was focused on RBs or on drawing comparisons between ASD and VI. Whether a piece was relevant or not was decided mainly on the basis of whether it focused on the issue of behaviour in the context of autism. Furthermore, the context in which a research study was conducted or a book was written, specifically in the country of Greece, was another key aspect of choosing that literature, regardless of whether it was a qualitative or quantitative research study. In terms of any Greek sources, these were scarce and scant when it came to my key terms, thus causing me to include all of the ones I had detected, regardless of publication date. More precisely, bibliography on VI was mainly old, so I tried to make proper connections to the present and choose seminal older works on a one-off basis. However, with regard to RBs and the perceptions of people concerning VI and ASD, I had great difficulty in locating sources. The date of publication was another criterion; I initially tried to keep the most recent references, namely those of the last ten years, but without dismissing earlier ones. As I mentioned above, my intention was to focus on bibliography of the last decade or less, as suggested by Paul and Criado (2020). This was only possible in the subject of ASD (with the exception of one dated reference in my effort to cite the very first reference regarding autism) and methods/ methodology. According to Furrer et al. (2008), literature reviews can cover 20, 25 or even 30 recent years; while Paul and Feliciano-Cestero (2021) go as far as to mention the possibility of 50 years as being common. However, in my case I exceeded the limit of 30 years in an effort to record the perceptions and attitudes in the field in question; that of 40 years in the case of RB and the existing diagnostic manuals; even that of 50 years, when trying to cover specific features of my theoretical framework (comparing old and most recent versions), VI and comparative research between VI and ASD.

Sources related to people's perceptions about disability in general, as well as about VI and ASD in particular, were a component on which I focused during the last two years of my research study and after I carried out the interviews. The reason behind that decision was that I did not want to put myself in a biased position towards my interviewees, before meeting with them. When my limitations in literature and key terms did not produce any results, I then broadened the scope of my research, in order to obtain more relevant evidence. As a matter of fact, the literature did not point me to other literature, since I had reached what I would call a saturation point. I knew this had happened, when no further details were forthcoming, in the sense that I could not come across any new information related to my research topic. The literature review process gradually came to an end after the completion of the research study, when I tried to look back on the references and double-check if any relevant knowledge had come up in the meantime.

After the start of my studies, I was trained in using the EndNote software tool for publishing and managing bibliographies, citations and references, which I found deeply useful in terms of gathering and citing the sources I considered beneficial for the outcome of the research in question. As a matter of fact, I had a bibliography pool that was systematically created and revised as the years went by, in the manner described above.

This, therefore, is the literature search strategy that I employed. Moreover, I had to resort to 'grey literature', which can be personal experience (such as biographies, autobiographies or memoirs) but could also be, for example, practice records. The manner in which I selected 'grey literature' was based entirely on whether the author made reference to key terms of the research questions, such as RB (or similar, as described in the previous chapter), perceptions about RB and disability, impact of RB, or explanation of RB. The reason behind this action was that I appreciate the valuable perspective it brings to my review to take into consideration the views, experiences and perceptions of people who are directly involved with the subject I am researching (VI, ASD, RB), whether from the viewpoint of an individual with a disability, or from that of a parent or a professional. For instance, as McWilliam (2011, p.480) states in her memoir: "I want to share something (…) If it isn't a life itself – (…) well, then, let it be a sentence". What crystallises in this sentence is the importance of the individual voice, to which I tried to give space and value in my research.

2.III Approaching vision impairment and autism spectrum disorder

Before focusing on perceptions around RBs, it would be useful to identify the current definitions of VI and ASD and make a brief mention of their historical roots. This would shed light on the process which gave birth to the differentiating characteristics of the two disabilities, which simultaneously, however, cause many people to perceive the two as interdependent.

2.III.i Clarifying vision impairment

Various governmental agencies have formulated different definitions in order to legally define blindness, that can vary internationally and institutionally. Current definitions of blindness and VI are mainly used "to classify the level of visual dysfunction on the basis of visual acuity and visual field" (Kran et al., 2019, p.25). Nowadays, VI is defined internationally according to the International Classification of Diseases 11/ ICD-11 (World Health Organisation, 2018) criteria for the better-seeing eye. ICD-11 classifies VI into two groups: distance and near presenting VI. Distance VI is divided into mild (presenting visual acuity less than 6/12), moderate (presenting visual acuity less than 6/18), severe (presenting visual acuity less than 6/60), blindness (presenting visual acuity less than 3/60). On the other hand, near VI presents near vision acuity worse than N6[2] or M.08[3] at 40cm with existing correction.

The ICD-11 criteria for an individual with VI are based on the ICD-10/ Classification of Mental and Behavioural Disorders: diagnostic criteria for research (World Health Organisation, 1993) and the Global Initiative

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[2] "Normal near vision" is known as "N6", where 'N' means 'near' and '6' refers to the size of the letters used to test vision.

[3] The viewing size in meters.

for the Elimination of Avoidable Blindness (World Health Organisation, 2000). Both manuals have been based on the International Classification of Handicaps and Visual Impairments (World Health Organisation, 1980), according to what Fazzi et al. (1999) claim. In either case, the World Health Organisation (WHO) divides VI into five levels: moderate low vision, severe low vision, profound vision loss (central visual acuity from 20/500 to 20/1000 or visual field < 10 degrees), near total vision loss, and total vision loss, in which what is clinically recorded is "no light perception". The last three levels (profound vision loss, near total vision loss, total vision loss) are defined as blindness, but the first two (i.e., moderate low vision, severe low vision) do not meet the criteria for a diagnosis of blindness. Since 1934 though, North America and most of Europe have used the previous definition of legal blindness by the American Medical Association (Ray et al., 2016, p.2), which is as follows: "central visual acuity of 20/200 or less in the better eye with corrective glasses or the widest diameter of the visual field subtends an angular distance no greater than 20 degrees in the better eye". However, in the United Kingdom, the Certificate of Visual Impairment characterises blindness as visual acuity of less than 20/400. There have also been recent calls by the International Council of Ophthalmology to define VI according to their own standards, parts of which involve visual substitution skills employed by persons with visual disabilities (Colenbrander, 2002).

Therefore, VI is frequently encountered as a result of loss of visual acuity secondary to conditions such as cataract, diabetic retinopathy, glaucoma, macular degeneration, and retinal degeneration (Liu et al., 2018). Sapp (2010) asserts that blindness technically refers to a total absence of vision, either referring to congenitally blind or late blind persons, as suggested by Fielder and Proulx (2019). Nevertheless, the term is often used to refer to severe VI that results in a need to primarily use non-visual sensory information. She also asserts that low vision refers to VI that is less severe than blindness but still might impact a person’s ability to complete daily activities. People with low vision may need to use tools and techniques to enhance their ability to use their limited vision, or they may need to use aids or non-visual means (e.g., multisensory approaches) for completing tasks (Sapp, 2010).

Even though this research in question does not concern children who have been diagnosed with cerebral visual impairment or cortical visual impairment (CVI) – as can also be found in the bibliography (Kran et al., 2019) – it would be an omission not to include a reference to their case at this point. There is no common definition of CVI which is accepted by researchers (Ravenscroft, 2017). Even among official manuals such as the ICD, DSM or the International Classification of Functioning, Disability and Health (ICF), a generally accepted definition or a type of diagnosis cannot be found (Ravenscroft, 2016). Although CVI appears to be the most common cause of VI in children in the developed world, it still continues to be an underrecognised cause of VI. CVI refers to the visual impressions that a person develops because of the ability she/ he has to view the world, influenced by several forms of input such as experience, attention and environments. In this case, measure of visual acuity (ability one has to see according to the official manuals) is not the only criterion for the characterisation of a person as an individual with VI and the delivery, or not, of vision services (Kran et al., 2019). More precisely and as Kran et al. (2019, p.25) assert, CVI is related to a visual dysfunction caused “by injury to the retrogeniculate visual pathways and brain structures which subserve visual processing” and people are acknowledged as having a brain-based VI. In addition, CVI seems to be prevalent in children with additional disabilities (Gorrie et al., 2019). The reason, therefore, that I do not include CVI in my definition of VI is dual. On the one hand this is because there is no recognised definition as I mention above and on the other hand because CVI is not a commonly recognised term in Greece.

It might be historically interesting and sometimes helpful (from an intervention point of view) to define what VI is and which acuity measures there are. However, these "are not necessarily the sole or main driver to understand the nature of each person's visual impairment" (Ravenscroft, 2019, p.3). A more holistic approach to understanding VI is required, which might lead to the creation of appropriate conditions and an assessed environment for people with VI, inside which they can cope with their weaknesses and develop their strengths (McLinden et al., 2016).

Children with VI are a small but diverse population (Hobson and Lee, 2010) with different types of needs. VI often creates challenges to learning that can only be addressed through the specialist knowledge and understanding of professionals. Flanagan et al. (2003) demonstrate that there has been a decrease in the number of children who only have VI without any additional disability, in contrast to previous work carried out by Robinson et al. (1987) and Robinson and Jan (1993). Instead, there is an increase in the numbers of children with VI and multiple disabilities (Flanagan et al., 2003).

2.III.ii Defining autism spectrum disorder

Autism discourse is dominated by notions of autism being a disorder and a deficiency (Graby, 2016), a fact which has given rise to debate. One school of thought is that autism is believed to be a developmental disorder that is now considered to be congenital but begins to be noticeable in childhood (conditions are mostly apparent in the first five years of life) and is a lifelong condition (Lord et al., 2018). It is a disorder, then, that lasts for a lifetime and there is often developmental impact on the characteristics associated with autism. In other words, children with ASD behave in different ways, depending on the skills each of them has acquired, as well as often in ways not typical of their chronological age (Distelhurst-Hunter, 1997, Papoudi, 2008, Toth et al., 2006, Wing, 1996).

Another school of thought is that some consider it to be a deficiency relating to behavioural and cognitive tasks. Lord et al. (2018, p.508) argue that ASD is a condition with "a strong genetic component", used to describe "a constellation" of early-appearing deficits, such as social communication and RBs. For instance, even when exploring the difficulty individuals with ASD might have with social interaction, demonstration of ability on tasks has been crucial to defining the nature of a specific behavioural or cognitive deficit that exists behind the difficulty (Bishop et al., 2006, Happé, 1999).

However, a third school of thought is also the argument consistent with the broader "neurodiversity perspective" that sees autism as an expression of cultural diversity (Robertson and Ne'eman, 2008, p.691). ICD-10 (World Health Organisation, 1993) and ICD-11 (World Health Organisation, 2018) refer to a range of conditions characterised by some degree of difficulty with regard to social interaction, communication, language and behaviour. In some cases, ASD is present along with other conditions, such as attention deficit hyperactivity disorder, epilepsy, depression and anxiety. The level of intellectual functioning varies, extending from profound impairment to high ability levels.

Boucher (2017) suggests that a range of scientists have tried to provide answers in relation to matters pertaining to the causation of autism, arguing that autism is a brain-based, neurodevelopmental condition, which is characterised by a distinctive set of behavioural difficulties. This view had been considered valid for the last approximately 50 years, namely after 1970 and the appearance of Kanner' s original view, which was the first comprehensive instance of clinical observation in the 20th century (Kanner, 1943). Asperger (Asperger and Frith, 1991) conceptualised ASD as including people with typical language and intelligence; a view, though, that only became known to the English speaking world after 1980 when his work was translated from German (his work had already been read in the German speaking world) into English. Kanner and Asperger identify ASD as a condition distinct from mental health conditions and intellectual disabilities (Lyons and Fitzgerald, 2007, Perepa, 2019). Their view focusing on the association of ASD with language and learning difficulties, is still the dominant one (Nadesan, 2013).

2.III.iii Vision impairment and autism spectrum disorder: Reasons for study

ASD and VI have been regarded as closely related (Cass, 1996, Hobson and Lee, 2010); a relation that can be characterised as debatable as well (O'Hare, 1996). Researchers such as Tager-Flusberg (2005, p.182), argue that "there are striking similarities between autistic and blind people"; similarities that "reveal important insights into the development of communication and social cognition". For instance, Leekam and Wyver (2005) refer to the sensory difficulties that children of both groups experience. VI and ASD are displayed with varying behavioural symptomatology and aetiology, occurring at all levels of intelligence and at multiple degrees of severity. They can occur as a single disorder, together or as part of a multiple disability. This is an important point, since an individual with a dual diagnosis (VI and ASD) is clearly different than one having only one of these two disabilities. Having VI and ASD is considered a multiple disability that may require different (or additional) identification and/ or interventional approaches, in the case of children with ASD but without VI, or vice versa (Kancherla et al., 2013).

According to Hobson and Lee (2010), the number of children with dual diagnosis increases by the year.

Both VI and ASD have significant effects on the ability to process information from the environment, which typically partly relies on visual information (Jordan, 2005). The behaviours observed in infancy in both disorders vary throughout a person’s lifespan. Multiple causes may exist behind these behaviours. They are also both disorders that have an impact on those who live with and care for the individual (Jordan, 2005).

Few past research studies have focused on determining the way in which congenital blindness predisposes to features of autism. According to Hobson and Bishop (2003), researchers are trying to trace the developmental pathways that lead to the syndrome in children with congenital blindness, hoping that their research will yield insights into the nature of autism itself. Similarly, Hobson (2005) and Hobson et al. (1999b) suggest that researchers should link congenital blindness to autism, in order to explain the prevalence of RBs in children with VI that are similar to those in children who do not have VI but are on the AS. More specifically, researchers were aiming at an in-depth exploration of autism, focusing however on the characteristics it shares with congenital blindness and on the data extracted from children with VI (Brown et al., 1997, Cass et al., 1994, Chess, 1971, Chess, 1977, Fraiberg, 1977, Keeler, 1956, Rogers and Newhart-Larson, 1989, Wing, 1969). What they mainly assert is the existence of homogeneity “which is not found in the child but rather in the dysfunction of the system constituted by child-in-relation-to-other” (Hobson and Bishop, 2003, p.9).

Likewise, researchers are focusing on the hypersensitivity to a visual stimulus that both groups of children might present. More specifically, mention has been made by Tager-Flusberg (2005), of understanding sensory processing in ASD via understanding how the senses of an individual with VI work. Years later though, Leekam et al. (2011) claim issues such as hyper- and hypo-sensitivity in vision, touch and hearing remain to be settled, in the sense that all sensory modalities can be affected by sensory symptoms, which means that no reliable conclusions in relation to autism could be drawn. I can detect a contradiction here, between Tager-Flusberg (2005) and Leekam et al. (2011), believing the latter's argument to be stronger for two reasons; one based on the literature, another based on my clinical experience and practice. According to Slimani et al. (2013), the absence of vision from birth induces a hypersensitivity to stimuli (e.g., pain). On the contrary, though, I have observed, through my experience with children with VI, a certain deterioration of the senses (e.g., taste and touch), owing to the medication they were receiving and the effects that it has on the sensory receptors. I also observed that the children often present a 'sensory defense', particularly regarding their contact with new materials. The sense of the unknown is what acts in an inhibitory manner, as well as a psychological factor related to the possible contact of children with doctors in hospital rooms where they might be hospitalised and where intervention on their bodies for medical reasons is common and probably painful (Tavoulari et al., 2015). As a result, therefore, it is not possible to arrive at a reliable conclusion in what concerns hypersensitivity or hyposensitivity in individuals with VI, and hence no such relationship can be observed regarding the same issue in people on the AS, as Tager-Flusberg (2005) would suggest.

What is evident, therefore, is a tendency on behalf of the research community to focus on the exploration of VI and ASD, thus indicating the need for further investigation of the two disabilities on a comparative basis. RB is one of the shared behaviour pattern in both the conditions and therefore needs further investigation.

2.IV The concept of ableism and the link with disability

On this point, the concept of ableism needs to be introduced. Ableism has been approached by different researchers, each one of whom highlights it from a different point of view.

Campbell (2009, p.4) speaks of “sameness” and “abled(ness)” (Campbell, 2009, p.11). These two terms refer to whether one is “a fully human” (Campbell, 2009, p.6) or in “a diminished state of being human” (Campbell, 2009, p.5).

Disability is also present in the ableist discussion of normalcy, normalisation and humanness by Campbell (2009), as well as by Goble (2014). On the one hand, Goble (2014, p.41) discusses “the concept of normality” in relation to ableism and justifies it by saying that these ideas have been historically developed in the context of the emergence of industrialised society. This society is characterised by specific rules, developed for those without a profound disability (Sapey, 2010, Singer, 1999). On the other hand, Campbell (2009, p.11) approaches disability speaking of “disablism”, as a set of conscious and unconscious perceptions that promote inequality towards people with a disability or a presumed one. Disability is an “inherently negative”(Campbell, 2009, p.17) notion, “shaped and formed by the politics of ableism”. Thus, disablism is opposed to normalcy and the sense that one is healthy and functional, but reflects the process through which disability refers to “inferior, blighted or in deficit second-class” people (Swain et al., 2013, p.56).

Normality is also related to ableism according to Ho (2008, p.198), who conceptualises it as an attitude that devalues or differentiates disability through the valuation of what is equated to “normal” or “standard”. Therefore, it seems impossible to speak about “difference” without ableism (Campbell, 2009, p.6).

Another crucial point of debate is the meaning of dependence and independence. Independence is another notion to which ableism is connected, that reflects the sociocultural view of disability and supports that a person with a disability is differentiated from one who has a functional difficulty (Goble, 2014). Similarly, dependence and independence are mentioned by Morris (1993) cited in Priestley (2004), as well as by Barton (2013) in relation to the fact that people with disabilities are in need of care. This sounds like a "benefaction as anathema" to people with disabilities (Drake, 1999, p.162). Barton (2013, p.24), more precisely, talks about " the pejorative mythology that disability is necessarily a form of dependency" and a fabrication of ableism as a result of the "medicalization" (Barton, 2013, p.33) of disability.

2.IV.i Ableism, vision impairment, autism spectrum disorder

Shyman (2016, p.367) connects "abnormality" with ASD as "it causes risks" and makes "tragic both the condition itself and (…) the individual who possesses it". According to Shyman, what intervention should be aiming for is minimisation -if not elimination- of the ''autistic symptomatology''; therefore, bringing the individual closer to normality. An extension of this conceptualisation is the notion of ableism, or in other words the idea that characteristics associated with autism are considered inferior and that they need to be minimised in order for one to be part of society and adhere to social norms. From this perspective, the goal should be to increase one's chances at inclusion, based on their ability to meet the acceptable standards of normality. In addition, Bottema-Beutel et al. (2021) approach autism from another ableism point of view, where the language used to communicate about autism and do research about autism can reflect perceptions and attitudes that discriminate against people with disabilities. In other words, ableist language refers to language that assumes people with a disability are inferior to people without one.

No similar conclusions have been encountered in relation to VI, apart from Bogart and Dunn (2019), who suggested that ableism is a means of discrimination and social oppression toward people with disabilities. They further argue that disability is a social construct or, in other words, a construct that is socially desirable (including sensory disabilities).

In addition, Mik-Meyer (2016, p.1356) links ableism with any "visible disability", arguing that, even when talking about "inclusiveness", that produces a type of "othering process", thus "difference".

2.IV.ii Ableism, children's rights and the connection to repetitive behaviour

When it comes to children, they are more vulnerable to the views of society and their parents might be "unwitting oppressors" (Swain et al., 2013, p.96), since their beliefs and expectations are sensibly shaped by the professionals they defer to (Swain et al., 2013). This means that ableism clearly also applies to children, but in this case, I wonder whether the notion of children's rights is powerful enough to fit RB into a childhood rights framework. The Convention on the Rights of the Child in 1989 (UNG Assembly, 1989) was an important milestone in history reflecting the changing image of children, regardless of the existence of a disability (Hammarberg, 1990, Verhellen, 2000).

Given the fact that RBs "appear functionless to an observer" (Collis et al., 2022, p.1), it would seem, then, that what is different is highlighted as abnormal (Campbell, 2009). Characteristically enough, Goble (2014, p.41) states that ableism "institutionalises" and "medicalises" disability but “normalises” behaviours that are not “tragic”. According to that and given the fact that RBs have been characterised as lacking rationality (Boyer and Liénard, 2006) - rationality being the main “quality” of a human being (March and Simon, 2005, p.201) -, then a RB cannot be considered as “normal” (Goble, 2014). As a matter of fact, RB would fit the ableist argument, as it is seen as a characteristic of ASD or VI and therefore needs to be eradicated.

This seems a little contradictory, because as it has been discussed, RB could also be part of the development of a child without any disability. That is to say, it is considered as a norm, but not in ASD or in some cases of VI. Hence, based on my own point of view and in relation to existing trends, I feel obliged to clarify my position towards an ableism perspective and education. I remember myself as a professional, trying to teach children to fit into society, but I realise that this is a discriminating position or even an ableist one. This is a tension and I do understand that some people still hold a similar view. Doubtlessly, these concepts inform my current research work and the lens of equality through which I am ideally obliged to view students with or without a disability, with or without an RB. In this context, my current lens of equality and equity means that there should initially be an understanding of RB and not an immediate intervention. In other words, recognising ableism means that children with VI or ASD should not have any intervention at first instance, as it is trying to normalise them, but a try to explain a RB and what a child is trying to address.

2.V The definition of repetitive behaviour

Taking into account definitions about RB, it is commonly accepted by researchers such as Amaral et al. (2011), Gal and Dyck (2009), Hattier et al. (2012), Honey et al. (2007), Leekam et al. (2011), Stronach and Wetherby (2014), Tröster et al. (1991a) and Whitehouse and Lewis (2015) that RB is a heterogeneous set of responses associated with a range of conditions. It is considered to comprise restricted repetitive patterns of movements (such as hand-flapping, body rocking, spinning objects, sniffing), compulsive and obsessive behaviour, as well as ritual habits, repetitive vocalisations or speech which do not appear to have a clear functional purpose (echolalia), persistence on sameness, tics, self-stimulation or self-harm. Apart from heterogeneous, the definition of such movements is also often controversial, since multiple terms other than "repetitive behaviour" may be encountered (Wolff et al., 2016), such as stereotyped behaviour (Nind and Kellett, 2002), ritualistic behaviour (Zohar and Felz, 2001) or compulsive-like activity (Evans et al., 1997). Nevertheless, all RBs are recognisable by their "stereotypy, rigidity, repetition and apparent lack of rational motivation" (Boyer and Liénard, 2006, p.595).

2.V.i The relationship between early childhood development and repetitive behaviour

RBs are common in adults around certain stages of the life-cycle (Boyer and Liénard, 2006), as well as in typically developing children (Baranek et al., 2006, Evans et al., 1997, Langen et al., 2011, Oakley et al., 2015). Children might engage in a significant amount of repetitive, ritualistic and compulsive-like activities as part of their early development (Evans et al., 1997). This is a phase characterised by perfectionism, attachment to a favourite object, preferred routines, concerns about cleanliness and dirt, rituals for eating or bedtime (Boyer and Liénard, 2006). In the past, Gesell (1946) and Evans et al. (1997) made mention of RBs in typically developing children, while more recently Boyer and Liénard (2006, p.596) did as well, interpreting them as an attempt on behalf of the children to achieve a "calibration of the system" and the surrounding environment. It has actually been noted that sometimes, depending on the society in which an RB is observed, it can be interpreted as either attention-grabbing and compelling (Boyer and Liénard, 2006) or as a cause of prominent difficulties in the daily life of affected individuals (Langen et al., 2011).

2.V.ii The relationship between early childhood development, repetitive behaviour and disability

Whereas RB is adaptive in typical development, it was pathologised in disabilities such as mental disorders and schizophrenia in the 18th century as asserted by Grew (1701) in Langen et al. (2011), in the 19th century in catatonia and dementia as claimed by Kraepelin and Kahlbaum (1874) in Langen et al. (2011) and finally in the 20th century in ASD and its first reports by Kanner (1943) and Asperger and Frith (1991). Although Gal and Dyck (2009, p.762) argue that each disability is linked to a specific pattern of RB, they do believe that their functions remain the same in all cases: to assist the person to "maintain an optimal level of internal stimulation".

Young children often show a high degree of RBs that may trigger a degree of alertness with regard to the potential existence of autism in the child. These behaviours, however, diminish over time as other skills develop – but not if the child is on the AS (Honey et al., 2008, Zandt et al., 2007).

As a matter of fact, an RB is something pathologised that has an impact on the early development of a child. For example, according to Gesell's developmental scales, a child with RB could never be considered "normal" (Nadesan, 2013, p.85) but presents a delay in their cognitive and social development or else a failure to reach the appropriate developmental milestones. Thus, a proper educational or psychological intervention must be proposed (Nadesan, 2013).

There is also, however, the approach according to which a RB is a catalyst of "the development of autistic symptomatology" as mentioned by Nash and Bonesteel (2002) cited in Nadesan (2013, p.155). In this case, a child's early development is linked to "abnormal patterns of brain growth early" (Nadesan, 2013, p.154) which are responsible for behaviours such as repetitive ones.

Finally, there are manuals that define the early development of a child (Eisenberg et al., 2009) and which observe specific developmental stages with specific characteristics. If that is not the case – the manifestation of RB being one such contingency – then the parents are encouraged to turn to experts in order to assess the child's development, whose delayed nature is taken for granted.

After identifying the importance of the relationship between early childhood development, repetitive behaviour and disability in general, I move on to define RB in VI and in ASD. I am also going to discuss the connection between early childhood development, RB and VI as well as ASD.

2.V.iii Through the lens of vision impairment

Viewed through the lens of VI, RBs do not seem to occupy a specific position in the context of its diagnostic procedure or that of an early diagnosis that is based on official diagnostic tools. Even though it is not part of the diagnostic criteria, RB displayed by individuals is described as a potential characteristic of the disability; a characteristic that is taken into consideration in early childhood development.

To be precise, specialists focus more on characteristics of visual acuity and contrast sensitivity, especially in the case of children, for whom the most reliable method of diagnosis (given that sight has not fully developed), are the Teller Cards Test (Zimmermann et al., 2015), Lea symbols (Elgohary et al., 2017, Repka, 2002), as well as the Snellen charts that have been superseded by the logMar chart design and measures (Oluonye and Sargent, 2018).

Seeking a proper definition

For decades, researchers have tried to reach an agreement on a common terminology regarding RBs presented by children with VI. Such behaviours are mentioned in the literature under various terms, such as "blindisms", "mannerisms", "autistic behaviours", "autistic tendencies", "autistic features", "autistic patterns", "obsessive behaviours", "stereotypies", "stereotypic behaviours", "stereotypical mannerisms", "stereotyped movements", "stereotyped behaviours" and "repetitive behaviours" (Brambring and Tröster, 1992, Brown et al., 1997, Eichel, 1978, Keeler, 1956, Murdoch, 2000, Pérez-Pereira and Conti-Ramsden, 2005, Smith et al., 1969, Traynor et al., 2018, Tröster et al., 1991a, Warren, 1994, Whitehouse and Lewis, 2015). Such an effort might potentially be linked to the researchers' own perceptions concerning the behaviours children with VI display, in the sense that, underlying each definition there is a specific explanation which focuses on a different factor. For example, it focuses either on the child's behaviour (e.g., stereotypies), or the disability which may explain an RB (e.g., blindisms), or on another disability (e.g., autistic pattern), or even on the conjecture concerning the emotional state of the person who exhibits such repetitive behaviour (e.g., obsessive behaviour).

Seeking an adequate description

A plethora of research has also focused on the description of RBs exhibited by children with VI. These RBs range from whirling or spinning around, to flapping arms and hands, hand clapping, running or walking on toes, head or body rocking, head banging or head-wagging/ weaving, headshaking, eye poking either pressing or rolling the eyes back, eye flicking with fingers, light gazing, flipping the upper lips with the fingers, body twisting movements of the upper extremities, bouncing and twirling, which are exhibited in a repetitive way (Boyce and Hammond, 1996, Brambring and Tröster, 1992, Dumont and Markovits, 1982, Gal and Dyck, 2009, Hobson, 2005, Kingsley, 1997, Pinquart and Pfeiffer, 2012, Stone, 1997, Webster and Roe, 1998). Dale and Salt (2008) claim that an RB could appear in the early developmental stages of a child with VI, even from the first months of birth, while Tröster et al. (1991b) observe an increase of RBs from the first to the second year of life and then, after peaking, decreasing in the second to up to around five, when the child goes to school. Brambring and Tröster (1992) note that there is a decrease of RBs generally as the individual grows, with the exception of pressing the eyes with the fingers and swaying the body, that remain relatively the same from the age of one to six years old.

Seeking the cause of repetitive behaviour Apart from concerns relating to the definition and description of RB in children with VI, many researchers have pointed out hypotheses regarding the reason children with VI exhibit RB. Throughout time, there have been environmental causes that have been proposed as contributors to the persistence of the RBs, such as sensory deprivation, restricted locomotion, social deprivation, inadequate primary caregiver-child relationships, photophobia, limited motor/ physical activity, lack of ability to imitate, lack of variety of activities (Gense and Gense, 1994). Thus, it seems that interaction with the environment can be a source of challenges for the child with VI either due to hyperstimulation or hypostimulation (Charman and Stone, 2008, Stone, 1997). RBs may help over- or under- stimulated children to maintain an optimal or homeostatic state of stimulation (Gal, 2006, Miller, 2005), if they may have difficulty in regulating their responses to sensory input from either the body or the environment (Miller et al., 2007). This is called “sensory processing” and has been mentioned by several researchers (Gal et al., 2010, Miller, 2005, Miller and Lane, 2000). In that case, the function of RBs would be to increase stimulation in an hypostimulating environment (Mason, 1991) or to block hyperstimulation (Wehmeyer, 1990), so as to let the person keep her/ his physiological and psychological limits (Fraser and Broom, 1990).

Other factors that contribute to the persistence of RBs according to researchers (Abang, 1988, Bak, 1999, Tröster et al., 1991a, Warren, 1994), are an indication of boredom, constraint, communication difficulties, arousal, demand or overwhelming social demands. RBs could increase with anxiety and with stressful situations as well.

It is also believed that developmental factors (i.e., severity of VI), could affect the intensity of an RB. Some supportive evidence of this has been found in the work of Cass et al. (1994) and Gal and Dyck (2009), who believe that the higher the degree of VI, the more children try to obtain visual stimulation in the form of the light-and-dark effect, through movements of their hands or fingers directly to their eyes or by moving their heads in front of a source of light. It is thus seen as an expression of hyperkinetic behaviour on behalf of children with low vision, whereas Webster and Roe (1998), as well as Banda et al. (2014), De Vaan et al. (2013), Gense and Gense (1994), Li (2009) and McHugh and Lieberman (2003) suggest that it is possible that younger children with congenital blindness or with multiple disabilities (e.g., VI and ASD) exhibit RB as a self-stimulating activity, in cases when they cannot cope with an overstimulating environment.

More specifically, Dale and Salt (2008)' s observations highlight that some children with VI experience "some unusual early social and linguistic behaviours" such as RB, that can be noted as "autistic like behaviours" (Dale and Salt, 2008, p.136). That observation alerted practitioners to the social developmental risks for children with VI, which in turn led to the reinforcement of the process of designing and implementing early intervention (Wiley et al., 2016). The intention was to develop the child's strengths and increase the ability to overcome any constraints due to the lack of vision (Preisler, 1991, Sonksen and Stiff, 1991, Sonksen and Dale, 2002). These constraints might be related to the fact that vision drives the integration of input from other senses, or in other words that vision presents the child with VI with significant challenges when it comes to making sense of what is heard, what is touched (Oluonye and Sargent, 2018) and what is tasted or smelled (Tavoulari et al., 2015).

Consequently, and as Oluonye and Sargent (2018) maintain, VI has an important impact on early childhood development and it would be beneficial to think of it as a potential neurodevelopmental disorder, which requires ongoing input from an interdisciplinary team. What they more precisely suggest is that vision matures rapidly within the first year of life as the eyes, visual pathways and brain mature. VI might impact on all aspects of early development in the sense that skills may emerge much later than in children without VI. A very specific mention is made to echolalia, where for example the process of making requests could be prolonged, compared to children with no VI.

Young children often show a high degree of RBs that may trigger an alertness with regard to the potential existence of autism in the child. These behaviours, however, diminish over time as other skills develop.

Actually, around the second year of life, some children exhibit a “developmental setback”, that might include loss of skills (Oluonye and Sargent, 2018, p.382). Children with VI, then, are at greater risk of a developmental setback, because of the limited or total loss of sight (Oluonye and Sargent, 2018).

For many years, it has been proposed that congenital VI can seriously disrupt infant and early development; therefore, early intervention and counselling (Fraiberg, 1977, Sonksen and Dale, 2002) have been a priority for children and parents respectively since the 1970s and have undoubtedly had an impact on the general developmental patterns in young children with VI and their caregivers (Pérez-Pereira and Conti-Ramsden, 2001, Pérez-Pereira and Conti-Ramsden, 2005). Although every case is different compared to another, in congenital VI early development is affected to a greater extent and what is proposed is a further development of research on early intervention that might minimise or prevent any developmental difficulties (Dale and Sonksen, 2002, Sonksen and Dale, 2002). Thus, a relationship could be noted between vision and the early psychological childhood development of children with VI, as well as a link between this relationship and RB.

Finally, Warren (1994) interprets RBs based on the motor activity which occurs in the attempt of the “non-seeing child” to activate some of the senses that are still available to them. People without a VI construct their self-identity and the understanding of other people mainly based on vision. Babies and pupils with no VI use sighted behaviour (i.e., eye contact, joint attention, gaze following) to interact with others, especially during the pre-linguistic stage (Dale and Salt, 2008). Therefore, vision seems crucial for the child’s early development, since the child tries to see and respond to social signs. Lack of vision might result in hindering the social development of a young child, who tries, as Bigelow (2003) and Urwin (1983) have noted, to use and compensate with the other senses (i.e., touch, olfactory, taste, hearing). That lack of mutual gaze between the baby and the caregiver was believed to have as a consequence an "asocial behaviour" expressed as RB and characterised as "autistic" (Fraiberg, 1977, Keeler, 1956, Wills, 1979b), since similar behaviour is also observed in children on the AS.

It would be an omission not to mention the case of those individuals with VI, who eventually develop their skills in otherwise typical ways. For example, Bosman et al. (2006) reach the conclusion that low vision affects the reading process quantitatively but not qualitatively. Wolffe (2019) asserts that literacy, mobility, independent living and working, as well as socialization are successfully achieved by individuals with VI, provided that specific training suggestions are followed. An example of such an individual would be Kapperman (2019), a person with VI himself, states that he achieved a high academic level after long hours of studying, he is still handling written work and he has also been awarded very competitive grants as an academic.

Likely impact of repetitive behaviour on individuals

With regard to the impact RB might have on children's families and their educators, there is no specific research evidence, but contextual evidence could arise from content-related research studies. Nevertheless, data exists that concerns the impact on the development of other sensory pathways through which the child with VI interacts with the external environment. The basic reason why this occurs is that on the one hand environmental stimuli are limited for the child with VI, yet on the other hand the quality of non-visual stimuli differs from the visual ones (Stone, 1997, Warren, 1994, Webster and Roe, 1998). Therefore, due to the reduced stimulation of the optical nerves, the child tries to increase the stimulation of the other senses, such as smell and hearing (Gal and Dyck, 2009, Li, 2009, Smith et al., 1969) and as a consequence the behaviour can be perceived as socially unacceptable.

It has also been asserted by Stone (1997) that RB frequently has as a consequence both the reduction of personal effectiveness and that of social exclusion. More specifically, she says that the world is very demanding for individuals with partial or total vision loss, thus making them choose retreat, passivity and withdrawal by indicating “socially unacceptable” behaviour such as flicking fingers in front of the face, rocking and twirling on the spot, and even harmful ones like eye-poking (Stone, 1997, p.95).

Interventions suggested

All the above are mainly described in the VI literature as socially unaccepted repetition of phrases, gestures or actions that have to be eliminated if they emerge (Brame et al., 1998). Actually, one of the early attempts at addressing the RBs of children with VI, suggested that the RB be curbed even through the use of pain or the introduction of new behaviours which would gradually replace the repetitive ones (Hayes and Weinhouse, 1978, Miller and Miller, 1976). Later, arguing that RBs do not seem to have a precise purpose, researchers (Brambring and Tröster, 1992, Gal et al., 2009, Tröster et al., 1991a, Warren, 1994) suggested that there are compelling grounds to discourage, prevent or redirect them, so that they become socially acceptable. Moss and Blaha (1993) make mention of prejudice that seems to exist in people’s thinking about RBs and the fact that society needs to understand what an RB is and what kind of purpose it serves, and address this behaviour accordingly.

Some RBs though, are not only considered as socially unacceptable, but can be harmful as well. For instance, Stone (1997) observed a child with VI, who had frequent episodes when he became very agitated at his play school, constantly poking at his eyes with his fingers. It took a while for the staff to realise that it was the central heating boiler coming on that was upsetting the child and unfortunately the noise was so much part of their environment that they did not notice it. This kind of behaviour can be characterised as self-harming (e.g., eye poking, pressuring the eyeball) and has been recorded in children with VI frequently by Gal and Dyck (2009) and this is a case where RB should be stopped according to their suggestion. However, Singer (2009) and Stone (1997) highlight the need for distraction every time a child with VI presents a self-harming RB. Kingsley (1997) suggests distraction as well, referring to the RBs that an individual with VI often adopts. She holds that a self-harming RB looks alarming and might socially stigmatise the individual.

2.V.iv Through the lens of autism spectrum disorder

In the context of ASD, RBs seem to be a part of the diagnostic criteria for the disability, while this is not the case in VI, as seen above. RBs form a core symptom of the diagnosis, which has been considered from the time ASD was first described by Kanner and until more recently as a sign for children who go on to develop ASD (Barber et al., 2012, Morgan et al., 2008) or as an identification of early ASD diagnosis (Landa and Garrett-Mayer, 2006, Ozonoff et al., 2008, Watt et al., 2008). More specifically, circumscribed interests are first mentioned by Kanner (1943) in the form of restricted patterns of interest and activity persistence on sameness. Kanner had difficulty understanding a boy's "fascinating peculiarities", namely making "stereotyped movements" either with his fingers or with his head. Most of those actions are "repetitions" carried out in exactly the same way in which they were performed originally (Silberman, 2017, p.169).

Later on, in 1952 and 1968, the 1st (DSM-I) and the 2nd (DSM-II) edition of the Diagnostic and Statistical Manual of Mental Disorders (compiled by the American Psychiatric Association-APA) sub-categorised “early infantile autism” under “schizophrenia, childhood type” (Nadesan, 2013, p.11). It was not until 1980, when ASD was formally distinguished from schizophrenia and its first official diagnostic criteria were published as part of the DSM-III (American Psychiatric Association, 1980) and the DSM-III-R (American Psychiatric Association, 1987), that this was extended to include “bizarre responses to aspects of the environment” (Boucher, 2017, p.10). Such behaviour may include limited interests, rigid adherence to routines, repetitive motor movements, repetitive vocalisations, rituals and rote conversational exchanges (Frith, 2008, Happé, 1995, Leekam et al., 2011, Leekham et al., 2011). In the 4th edition of the DSM (American Psychiatric Association, 1994), RB is one of the constituents of the triad of feature characteristics (related to social interactions, communication deficits, restrictive/ repetitive behaviour) which are considered prerequisites for the diagnosis. RBs comprise a single category, which suggests there is sufficient homogeneity in their manifestation. However, there are studies (Bodfish et al., 2000, Cuccaro et al., 2003, Georgiades et al., 2010, Lam and Aman, 2007, Lewis and Bodfish, 1998, Papageorgiou et al., 2008, Szatmari et al., 2006) that have provided evidence of RB heterogeneity.

Some years later, changes were made to the diagnostic criteria and in 2013 the APA released the 5th edition of DSM, DSM-V. This is now the standard reference point that healthcare providers use to diagnose mental and behavioural conditions, including ASD. Therefore, according to the DSM-V (American Psychiatric Association, 2013), one of the diagnostic criteria for ASD is still RB. The diagnostic triad, however, is reduced to two feature characteristics: impaired social interactions/ communication and restrictive behaviour (Matson et al., 2012). The fact that they have merged communication and interaction but kept RRBs as discreet, highlights how important it is as part of the diagnostic criteria for autism.

The APA is not the only association which has adopted an internationally recognised classification scheme and diagnostic criteria system for ASD. The WHO edited the ICD-10 in 1992 for use by clinicians and another edition in 1993 providing diagnostic criteria for use by researchers (World Health Organisation, 1993). According to Boucher (2017), between the DSM and the ICD there are more similarities than differences; however, the DSM recognised autism as a condition before it was recognised by the ICD. The criteria for ASD in ICD-10 are more detailed than in DSM-IV. In general, the DSM covers mental disorders and is mostly used in the United States and other English-speaking countries. The ICD covers all kinds of disorders and is mainly used by medical and health policy professionals worldwide. Actually, because of the wider usage the DSM has in English-speaking countries, the historical definitions of ASD are based mostly on the definitions provided mainly by the DSM (Boucher, 2017). The original publication date for ICD-11 was meant to be 2011-12 but delays postponed it to 2015-16 (Frances and Nardo, 2013, Hyland et al., 2016); finally, ICD-11 was released in 2018 (World Health Organisation, 2018) and as researchers advised (McCabe and Widiger, 2020), it is now more in line with DSM-5 (not entirely though), concerning ASD diagnosis.

Apart from the DSM and ICD diagnostic manuals, there are more screening and assessment tools that focus on early diagnosis/ early intervention concerning ASD, which take into account the RB area, as well as social communication and social interaction. Such tools are the Modified Checklist for Autism in Toddlers (Robins et al., 1999, Robins et al., 2001), the Childhood Autism Rating Scales (Schopler et al., 2010) , the Autism Diagnostic Observation Schedule (ADOS) (Lord et al., 2000, Lord et al., 1989) and the Autism Diagnostic Interview-Revised (ADI-R) (Lord et al., 1994). The ADOS and ADI-R, though, are not necessarily focused only on early intervention, as they can be used for later diagnosis too (Perepa, 2019).

Seeking a proper definition of repetitive behaviour

Many efforts have been made in order to find the most suitable term for the RBs of children with ASD. Throughout the literature there is a wide range of terminology, which refers to such behaviour, such as "stereotypic movement", "oscillations", "spinning", "stereotypic behaviour", "stereotyped patterns of behaviour", "mannerisms", "self-stimulatory behaviour", "unusually restricted movements", "strange repetitive movements", "behavioural inflexibility", and "repetitive behaviour" (Donvan and Zucker, 2016, Grandin and Scariano, 1995, Mazefsky et al., 2008, Sethi et al., 2019, Synodinou, 1999, Tröster et al., 1991a). Moreover, mention is made through the use of terms such as "ritual behaviour" (Hsu and Ho, 2009, Whitman, 2004), "back-and-forth activities" (Paul, 2008, p.95), "abnormal stereotypies" (Baranek et al., 2008, p.113). By considering all these different terms used to describe RB, one can understand the researchers' persistence in coming up with the optimal terminology, based on which it could then be determined whether a child meets the behavioural criteria to be considered as being on the AS or not. Thus, there is little consensus regarding the terminology used by researchers (Bodfish et al., 2000), who try to classify and quantify RBs, hoping to gain insight by observing behaviours (Langen et al., 2011).

Seeking an adequate description for repetitive behaviour

Beside the search for a 'proper' term, researchers have tried to describe the nature and the content of RBs, with the aim of achieving a correct and timely diagnosis. As a matter of fact, a range of similar behaviours has been recorded over the years in children with ASD, which pertain to a range of behaviours from repetitive movements of the body to more cognitively demanding behaviours, such as intense hobbies (Chess, 1971, Dale and Salt, 2008, Hobson and Bishop, 2003, Hobson et al., 1999b). In other words, there are two broad categories of "restricted, repetitive behaviours (RRBs)" as mentioned in Lam and Aman (2007, p.855), Sethi et al. (2019, p.1236) and Wolfe et al. (2014, p.180): "repetitive sensory-motor stereotypies and insistence on sameness". Even more specifically, Mullin (2014) in her very interesting book titled "Drawing autism", devotes an entire chapter (Mullin, 2014, p.49-67) to the description of imagery and repetitiveness found in all the artwork of the artists with ASD she researched.

Researchers also refer to "behavioural inflexibility" (Sethi et al., 2019), "restricted repetitive and stereotyped patterns of behaviour" (Kogan et al., 2008, p.1149) and "inappropriate body language" (Carrington and Graham, 2001, p.45) as a result of stress due to unpredictability, that either have to be eliminated or stopped. Still, the attempt to fully describe the RBs manifested by children on the AS, shows that RBs are part of the diagnostic process for ASD.

In the context of trying to correctly describe the RBs of children on the AS, ritual behaviours occupy a substantial place in the literature, often named as a proposed subgroup of the complex RB. They are recognised as a repetitive activity; sometimes functional (e.g., used to manage stress), sometimes purposeless and problematic (e.g., excessive head shaking). Ritual behaviours often occur at high frequency (Whitman, 2004) and can be categorised into high-level and low-level behaviour (Turner, 1996). In Turner's system, high-level behaviours include rituals, rigid routines, circumscribed interests, and resistance to change; while low-level behaviours refer to repetitive motor actions. Similarly, Carcani-Rathwell et al. (2006) propose three subgroups; namely, repetitive movements (e.g., thumb sucking), sensory behaviours (e.g., hand flapping), and cognitive rigidity (e.g., resistance to change). Rituals might be highly extended to many areas of everyday life (e.g., dressing, eating, travelling routines) and are linked with high stress in individuals. Finally, as Hsu and Ho (2009) and Loh et al. (2007) conclude, ritual behaviours are not well understood and there is disagreement as to whether they should be considered as purposeful or non-purposeful behaviour.

Another attempt at describing RBs in ASD is made through the obsessions that have often been said to identify individuals with ASD. Actually, Sheila Barton, as the mother of a boy on the AS, quotes the words of her own child, who says that "they are obsessions that use (…) repetition to manage a chaotic world (…) to filter sensation and block out frightening or unmanageable sensory input" (Barton, 2012, p.231).

Finally, another description of a potential RB presented by a child on the AS is provided by DSM-V (American Psychiatric Association, 2013). According to DSM-V, then, RBs can have impact on movements, on objects and on speech. As a matter of fact, an RB may be linked to the movement of a part of the individual's body (e.g., hand-flapping), may refer to the use of an object (e.g., lining up toys) or is likely to involve repeating words/ phrases/ sentences (e.g., echolalia) on behalf of the child.

Seeking the cause of repetitive behaviour The third point of focus for researchers, is the proximal cause or triggers for a child with ASD presenting an RB. Behavioural reasons (stress, anxiety, unpredictability, pain), environmental factors in tandem with genetic – neurobiological factors (sensory overwhelming in lighting, touch, smells, noise), cognitive barriers (communication issues, interference with educational achievement, attention, learning difficulty) or social situations (crowds, maintaining meaningful interpersonal relationships) could be the reasons for a child with ASD to manifest an RB (Charman et al., 1997, Leekam et al., 2011, Rogers, 1998, Sigman and Capps, 1997). An additional cause might be the lack of understanding language as part of communication issues, so it is possible that the child does not understand what the other people around them are trying to say, especially when they are not using simple/ direct words or visual schedules, hence causing her/ him to resort to an RB. Whenever this happens it is because the child struggles to communicate with the surrounding environment and that causes her/ him high levels of stress, anxiety and aggravation (Boucher, 2017).

Additionally, there is an indication of difficulty in the process of thinking, which might affect the behaviour of a child on the AS. Children with ASD engage in activities, which can be categorised, as Gena (2002, p.28) argues, by “absence” or the “redundancy” of behaviour. More precisely, redundancy of behaviour refers to RB in situations involving visual stimuli, speech, olfactory, taste, touch, motion and daily routines (Gena, 2002). This seems to be a difficulty for children with ASD, who experience the senses as fragmented; thus, they plan and implement their thinking and behaviour in a fragmented way too (Frith, 2008).

What needs to be underlined is the need to decipher such behaviours. The aim would be to understand the reason for their existence in the case of each individual with ASD respectively, thus reducing the amount of social stigma towards them. Besides, the origin of social stigma remains unknown (Amaral et al., 2011), that is the reason why it is still being reviewed (Bogart and Dunn, 2019). However, it would be difficult to focus on a single reason, because the actual cause is still not clear and the field deserves more research (Gottlieb, 2007). Similarly to the case of VI, so in ASD I would again like to conclude this chapter by highlighting the link between the disability in question, RB and early childhood development. From the 1950s onwards, there is evidence of concern on behalf of scientists regarding children at their early developmental stages presenting an RB. Scientists tried to fit such cases into existing categories of disorders, to no avail. That is the reason behind Kanner's (Boucher, 2017, p.5) first reference to "early childhood autism".

Likely impact of repetitive behaviour on individuals

Research on the impact of RB on individuals with ASD and their families remains scarce, as asserted by Sethi et al. (2019). Leekam et al. (2011) claim that RB is a core feature for ASD that sometimes constitutes a major barrier to social adaptation. This is something that Kanner (1943) and Asperger also maintained years ago, as cited in Frith and Mira (1992). In some cases, actually, RBs are thought to be so disruptive for children, that medication is considered, even though, as Milton et al. (2016b, p.9) argue, there is no medication to "treat challenging behaviour".

What is very characteristic is Paula Johnston's mention in her own biography, where she points out that she was labelled "disruptive, attention seeking, rude, cheeky and deliberately awkward", every time she was indicating an RB (Johnston and Hatton, 2003, p.11). From an educational point of view, Sue Hatton (Paula's teacher) says that even if children on the AS are not the same, many of them act in similar ways in particular situations and as a matter of fact it seems so difficult for educators and people in general to stop making assumptions and to learn to think with real awareness and more understanding (Johnston and Hatton, 2003).

Another personal testimony of a child with ASD in Simmons and Sicoli (1996, p.4)'s book, regarding the "strange" sense people have about him presenting an RB is the following: "They call it 'stimming'. All I know is that it makes me feel good even though mom says most people think it is strange". As in the previous case, so in this, an assumption is expressed by the child’s mother, regarding another assumption that people around them have.

RB has also been linked to elevated levels of parental stress (Orsmond et al., 2007). That does not imply that the parents should be blamed for their child’s behaviour, but the other way round; that an RB might also cause high levels of parental stress (Boucher, 2017).

Self-harming behaviour is not mentioned in the DSM-V, however it is considered to be a really important RB by Boucher (2017), which might have impact on the child and her/ his social environment. It is usually expressed in the form of head banging, self-biting, self-scratching, self-pinching and self-hair pulling (Rojahn et al., 2016). In some cases, self-harming behaviour is even worse, such as in the example of Edgar Schneider talking about himself in his book “Discovering my autism” (Schneider, 1999, p.78) regarding an RB that occurred every time he becomes agitated: “My first nervous breakdown (…) I slashed my forearm with my straightedge razor. (…) I and everyone else took it as a suicide attempt. (…) I did not want to die. Whenever I got angry, I would hurt myself before I would hurt anyone else”. Besides, some research studies (Bodfish et al., 2000, Mooney et al., 2009, Turner, 1999) include self-harming behaviour as an RB, while some others (Bishop et al., 2006, Cuccaro et al., 2007, Cuccaro et al., 2003, Richler et al., 2007, Shao et al., 2003, Szatmari et al., 2006) do not consider it at all, or just consider RB as a precursor to self-harming behaviour (Rojahn et al., 2016).

Interventions suggested

RBs may inform intervention decisions (Wolfe et al., 2014) and sometimes can interfere with socialisation, learning and behaviour. If the RB is curbed, then the child’s adaptability and flexibility could potentially increase, which will in turn enhance the overall trajectory of adaptive behaviour development and functioning (Amaral et al., 2011). A very interesting view is that of Sethi et al. (2019), who suggest that an intervention for eliminating RBs might not be the solution to the case, but accepting and adapting RBs on the part of family members could be as important as providing strategies to decrease RB when it becomes challenging. Based on this, I would like to personally pose the question of why RBs have to be eliminated, since it is social stigma that defines intervention methods through people’s choices; there is something deeper here, which is probably linked to people’s mentality, rather than simply the containment of RBs as they manifest. It seems, actually, that this was the case even when Schneider (1999, p.65) clearly introduced it in his story about himself, while recounting that sometimes while exhibiting an RB “I was (…) treated as a pariah, and was subjected to epithets such as, ‘ You Nazzi bustard [sic]’ ”. Thus, the aim would be not necessarily to eliminate RBs; this would be the only option in the self-harming RB case. The goal would basically be to understand and probably change people’s perceptions and attitudes towards RBs. One cannot disregard those cases when RB is an indicator of stress levels, communication difficulties or sensory overload. Then, the professional or caregiver would certainly want to address those and help the person, something that could then lead to reduction of RBs in itself.

2.V.v Are repetitive behaviours the same or different in children with vision impairment and children on the autism spectrum?

It is apparent that great efforts have been made in terms of discovering the correct terminology, the correct definition, the cause and the interpretation of the various motives behind the RBs exhibited by children with VI. However, as a practitioner, what I would like to find out is how RBs could be perceived by the caregivers and professionals who are the individuals closest to the children in question; I would also like to find out if those people's perceptions may affect their life or the life of a child with VI and if this is the case, how I could intervene in an appropriate way.

As in the case of VI, so in the case of ASD, most of the research effort has focused on the attempt to construct a proper definition and how the RB can be measured, on the description of RB (what it looks like, potential causes) and on the effort of pinpointing the most efficient way of addressing the issue, since the behaviour is socially unacceptable, which in any case also belongs to the diagnostic criteria for ASD. Undoubtedly, the above factors could guide research effectively in areas such as an early diagnosis and early intervention. However, this should not be the only point of interest and as Leekam et al. (2011) claim, a broader focus is needed (in infancy and early development of infancy when the RB could still change), so that interventions can be put in place.

According to the data presented in ASD and VI-related literature, Jure et al. (2016) and Molinaro et al. (2020) hold that Keeler (1956) was the first to speak of the link between the two populations, claiming that children with VI present RBs just like children with ASD. In addition, in the 60s-70s, Burlingham (1965), Nagera and Colonna (1965) and Wills (1979b) relate that similarity with the fact that lack of vision produces difficulties in personal development and social interaction, just like the behavioural elements observed in children with ASD. Later on, Fraiberg (1977) and Fraiberg and Adelson (1973) hold that lack of vision impacts on the self-image and self-representation of a child with VI, and thus has consequences on the ego that are externalised in the form of RBs. More recently, Brown et al. (1997), Hobson and Lee (1999a), Hobson et al. (1999b), Hobson and Bishop (2003), Hobson (2005) and Minter et al. (1998) focus on children's socio-emotional experiences, identifying similarities between the two disabilities in question, which require more investigation.

In contrast, Pérez-Pereira and Conti-Ramsden (2005, p.99) assert that children with VI do not have “autistic features”. They argue that their difficulties are related to the peripheral nervous system rather than the central and as a consequence they need more time to develop certain capacities such as the Theory of Mind and Shared Attention Mechanism. Research in the VI field though, has shown that similar patterns of behaviour, namely RBs such as spinning or head banging, occur in children with total vision loss and children with ASD (Cass, 1996). What is worth mentioning, however, is that according to the observation of Bogdashina (2005, p.23), RB is interpreted as “strange”, “bizarre” and “obsessive” with regard to children on the AS, whereas for children with VI it is thought to be “typical”. The answer then to why such an expression of social stigma is more intense in ASD and why RBs are perceived differently, is because of a potential relationship between diagnostic criteria and peoples’ perceptions.

However, (Bogdashina, 2005) does not provide an explanation of the reasons behind such an observation. She believes that children with VI are characterised by emotional and psychological difficulties because of the different set of sensory information they receive and which are therefore expressed as RB. Following this reasoning, however, children with ASD should not be characterised either by emotional or by psychological difficulties, which, however, Gray et al. (2012) and Maskey et al. (2013) have reported at elevated rates. Thus, the evidence seems to suggest that Bogdashina’s statement may not be the case and this is the reason why I disagree with her.

I would also like to express my disagreement with Bogdashina’s following notion. That children with VI can rely on their remaining senses (touch, smell, taste, hearing, but not sight) in order to perceive the world, in contrast to children with ASD (who are not able to), whose senses are all affected. The reason is that, as has already been said at the end of section 2.V.iii, a child with VI has senses (even sight itself) that can be affected too. Undoubtedly, for the pupils who lack the ability to mainly use vision to recognise their surroundings, the great challenge is to develop the other senses (touch, smell, hearing, taste). Gould and Sullivan (1999) argue that the hands are, for students with partial sight or complete loss of vision, the main source of empirical knowledge of the world, because with their help they can touch objects and persons, in order to construct images of the world that surrounds them. However, they often present a sensory defence, particularly regarding their contact with new materials, which is related to a sense of the unknown, that acts as an inhibitory factor, as well as to a psychological factor.

In addition, it has been claimed that children with ASD manifest RB reminiscent of that of individuals with VI, due to hypoactivity towards sensory input (Bogdashina, 2005). At the same time, mention is also made of hyperactivity towards sensory input, which, however, cannot possibly be true in the case of individuals with VI. As has already been suggested in section 2.V.iii (Leekam et al., 2011, Slimani et al., 2013, Tager-Flusberg, 2005), one cannot express a definitive opinion regarding the hypersensitivity or hyposensitivity of individuals with VI. Therefore, Bogdashina’ s argument fails. What emerges perhaps is that the causation of RB differs between the two cohorts or simply just that perceptions about the behaviour could differ based on the diagnostic label.

2.V.vi Emerging perceptions on repetitive behaviour

In the results of the aforementioned studies one can observe that RBs are considered part of the diagnostic criteria for ASD, while this is not the case in VI. In some cases, RB is considered as a prediction for developmental outcome and in some other cases as the severity of "autism symptoms" connected to communication delays (Watt et al., 2008). For some researchers, RBs could distinguish ASD from other disabilities (Bartak and Rutter, 1976, Bodfish et al., 2000, Smith and Van Houten, 1996), while for others RB is commonly observed in developmental conditions in general (Powers, 2010) or in Rett syndrome and cerebral palsy (Frith and Done, 1990, Hattier et al., 2012, Turner, 1996, Whitehouse and Lewis, 2015).

What is certain, however, is that children with VI present behaviours that are linked to similar ones in those with ASD and vice versa. On the one hand, there is also a tradition in research regarding the presence of ASD in children with VI (Hobson et al., 1999b). On the other hand, VI in the sense of decreased vision acuity could be identified in children on the AS. What I am saying then is that sometimes there is a disparity between research and reality. Overlap, then, of behaviour patterns does not mean someone has VI or ASD; there could be someone with both conditions too. Moreover, children with ASD might use peripheral vision to an unusual extent (Lord et al., 2000). Oversensitivity to vision stimuli may also occur, as well as impaired processing of vision motion (Gepner and Mestre, 2002, Milne et al., 2005). In that case too, however, this does not mean that VI can be diagnosed in children with ASD.

But aside from the various studies, RB is used as a basis for ASD diagnosis in both the ICD-11 (World Health Organisation, 2018) and the DSM-V (American Psychiatric Association, 2013). This has already been mentioned in 2.IV.ii, but at this point a further and more detailed reference to the actual part of the diagnostic criteria is going to be made. The DSM-V stipulates that a diagnosis of ASD requires that the individual exhibit symptoms from a dyad of social communication and interaction as one area and repetitive, ritualistic behaviours as the second. In ICD-11 though, the criteria are stipulated by the WHO. According to DSM-V (Wiggins et al., 2019, p.696):

> “restricted, repetitive patterns of behaviour, interests or activities comprise some of the criteria according to which a child is diagnosed with ASD. In more detail, mention is made of:
>
> 1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypes, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
> 2. Insistence on sameness, inflexible adherence to routines, or ritualised patterns of verbal or non-verbal behaviour (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).
> 3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
> 4. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/ temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).”

Another important consideration is the way in which caregivers might perceive their children’s behaviours. This is because interviews with family members often comprise part of the diagnostic process and more specifically of the Differential Diagnosis in Preschool Evaluations as pointed out by Crowley (2015), as part of relevant professionals training in Greece. Parental interviews are at the core of standardised tests such as the ADI-R (Lecavalier et al., 2006a) or the Diagnostic Interview Schedule for Children (Shaffer et al., 2004) which are used by authorised diagnostic bodies globally, Greece included (Papanikolaou et al., 2009). This is a fact that might affect the diagnosis itself. Characteristically, Haney et al. (2018b) highlight the important role that perceptions play in the caregivers' descriptions of their children's emotions and behaviours in areas that may include the diagnostic setting. That factor has also been indicated by Perepa (2019), who pinpoints possible implications for the reliability of the diagnostic process.

Furthermore and according to Doernberg and Hollander (2016), Lauritsen (2013) and Rutter (2011), the age at which an RB first appears, as well as its level of frequency (Fecteau et al., 2003) are factors that differentiate a child without any diagnosis from a child with ASD. The idea is that infants are more likely to exhibit a motor and sensory RB (Stronach and Wetherby, 2014), whereas older children are likely to manifest more complex RBs (Militerni et al., 2002). Likewise, Durand and Carr (1987), and more recently Baranek et al. (2008), believe that the persistence of an RB beyond early childhood or the change in their functions over time are factors that indicate a disability or predict autism severity in adolescents (Shattuck et al., 2007). However, taking into account what has been presented in section 2.V concerning the fact that RBs are observed both in children and adults, one cannot help but wonder why they are noticed and considered a diagnostic criterion in children on the AS. The answer would be, because they are considered as a distinctive feature of autism along with communication and social differences. I wonder, then, what is it that causes this categorisation of RB and if the case would be different, if these children did not have an official diagnosis. I hypothesise that the behaviour is pathologised and considered problematic, once other things are observed as being atypical. Due to the notion of ableism, an RB exhibited by a child with a disability is not acceptable (Friedman and Owen, 2017). I assume that this attitude might be stronger in cases where an RB is part of an official diagnosis (as in ASD); it is as if the 'abnormality' of such a behaviour is 'legalised'. Actually, Campbell (2009, p.17) very distinctly mentions that disability is "inherently negative" and that it is "shaped and formed by the politics of ableism". Therefore, in the current research the focus is placed on adults and the fluctuation of their perception, rather than on the children and the reason they present an RB. These thoughts spurred me to undertake this research to review this kind of stigma (Bogart and Dunn, 2019) more and develop my research questions, which I aim to answer throughout the present research study.

With regard to VI though, RB does not comprise a diagnostic criterion. In neither of the two official diagnostic manuals (DSM-V and ICD-11) is any mention made to a potential behaviour of such a nature. To be precise, the criteria focus is not on an individual's behaviour, but on her/ his pathology. This interestingly contradicts what Bogdashina (2005) says about RB being considered as a normal characteristic of children with VI. What is more, there are children with VI, who do not have noticeable RBs (Pérez-Pereira and Conti-Ramsden, 2005), as well as others who have none (Warren, 1994). It is more likely, though, for children with severe VI to present a "behavioural difficulty" (Dutton and Bauer, 2019, p.59) that might be an RB (Gal and Dyck, 2009). There are no related findings in literature, but it might be interesting to find out if there is a difference in the presence of RBs in children who acquire VI at a later age (e.g., 3, 5, 9 years).

In any case, differences between VI and ASD in diagnostic practice may have important implications, both for clinical prevalence rates, as well as for the individual's care options (Wilson et al., 2013).

2.VI Perceptions

Prior to discussing perceptions, it is essential to introduce a working definition of this term. Perceptions are defined as a subjective experience and an entirely subjective process (Solms and Turnbull, 2010). Hopp (2011) claims that everybody has a “second nature”, by which is meant their upbringing, cultural perceptions, practices and language. That “second nature” enables people to perceive facts instantly and passively (but not unconsciously) and this might impact on how they respond to them. There is a reason-giving relation between experiences and beliefs that explains why a person finds something to be as she/ he thinks it to be. In other words, individuals see different views, although they might believe that they see the same version of reality as others (Hopp, 2011).

Over the years, researchers have conducted extensive research on the perceptions and attitudes of various groups towards people with any type of disability (Dequin, 1988, Yuker, 1976). Still, the investigation of perceptions is important for the understanding of disability and also for organising the most effective ways of intervention; because, if there is extensive research, then it could alter the way according to which intervention programmes have been organised until now. Therefore, in order for intervention programmes in general to become more effective, understanding peoples’ perceptions is vital. In particular, it is the people (policy makers, practitioners, parents, caregivers) by whom the programmes are designed whose adopted perceptions we need to understand. This would entail recognising whether the strategies I am proposing would be relatable to the caregivers based on their perceptions of the causes of RBs or their social role.

2.VI.i Caregiver and professional perceptions of repetitive behaviours

Little attention has been given to the perceptions of people regarding ASD and VI in general. More specifically, in terms of ASD, the research that has mainly been carried out focusing on people's perceptions concerns two things: on the one hand the parental perceptions of support that suggest the need for early intervention identifying the aetiology of ASD and informed family planning (Chen et al., 2013, Hanish et al., 2018); on the other, professional perceptions that are mainly influenced by the medical model paradigm, meaning that professionals view RBs as a medical condition with symptomatology and ways of treatment (Draaisma, 2009, Haney, 2014, Krcek, 2013, Muskat, 2017, Owren and Stenhammer, 2013).

Concerning the caregivers' perceptions, Newsome (2001) expresses the need for using them in support services for families with children on the AS, who, as has been noted by Sioutis (2012), face the most difficulties in comparison to the families of other children with disabilities. Actually, when the perceptions of parents are taken into consideration, it results in their own learning and in valued outcomes for their children (Beatson and Prelock, 2002). As a matter of fact, some authors suggest that support services should consider parent perceptions when developing interventions to assist with the children's emotional and behavioural challenges (Haney et al., 2018b). With reference to VI, Lairy and Harrison-Covello (1973) and Warren (1994) suggest in their research studies that the parents' perceptions and attitudes towards their child with VI and the nature of their interaction should be taken into account by professionals. This argument still seems relevant to the topic in question, even if it has been extracted from rather dated research studies.

With regard to the perceptions of professionals, they relate RBs with behavioural inflexibility, arguing that there is impact on multiple areas of functioning such as communication (Sethi et al., 2019), while professionals also describe their experiences of the impact of a child's behaviour, and the stigma which it entails, with the aim of seeking more opportunities to develop their skills and their knowledge of ASD (Morris et al., 2018).

Following the literature search I undertook, no specific sources emerged with regard to the perceptions of people concerning RB that children with VI might present. The only interesting information that was found in relation to children with VI in general, was the fact that their caregivers react accordingly, depending on the way the surrounding environment handles the situation involving the child with VI (Sioutis, 2012). If the surrounding environment accepts the child's disability, then the family itself can accept her/ him more easily. No research evidence was found in relation to people's perceptions about the RB of children on the AS, either. This gap in the literature is commented upon by Fletcher-Watson et al. (2017), who very astutely observe that researchers should endeavour to continue to take community perceptions into account. This is the only way to shed light on the everyday communication between caregivers and professionals, which seems to not be well understood. If the quality of the relationship and communication between these groups of people was more clearly understood, then the community would be more accepting of them; as a consequence, they would enjoy a better "feeling of belonging" (McLeod et al., 2019, p. 2331) and as a result, their children/ students with VI or ASD would have less challenging situations to confront than, say, stigma and social rejection. Thus, progress will be made with respect to more inclusive ways of intervention through the participation of all of those involved (children, caregivers, professionals). I believe that a deeper understanding of groups of people who are involved in the field of autism and also in that of VI would be most helpful in terms of providing these children with the right knowledge and intervention. The participants' statements can potentially be linked to the perceptions they have and will be discussed through the Ecological Systems Theory (EST) later in the next chapter.

2.VI.ii The importance of understanding caregiver and professional perceptions

The answer would be that people experience a version of reality by relying on their senses, in order to interpret and make sense of the world around them. Perceptions are seen as a subjective experience; a completely personal process that depends on the sensory information received from the various sensory organs and processed in the various parts of the brain.

The examination of the perceptions of caregivers and professionals may make it possible for the need for dialogue between caregivers and professionals to be met, so that it can be professionally determined what kind of intervention is best for the child and for the adults themselves as well. After all, many of the existing research studies have been focused on the children rather than on adjusting the adults' behaviour (Bradshaw, 1998, Kossyvaki et al., 2016). Viewed from another perspective, the aim for the participants (caregivers and professionals) could be the alteration of their communicative and interacting style.

It is interesting to note the finding that children with ASD run a high risk of unmet service needs (Chiri and Warfield, 2012), since the rate of service used by their families is low. One hypothesis is their unmet expectations (Casagrande and Ingersoll, 2017), with respect to their relationship with the professionals they are working with. It would be interesting to see this relationship improve, driven by, for example, the existence of RBs, and to discover whether and if children involved in such behaviour are affected as a result.

According to the approach of Misailidi and Papoudi (2017), it is likely that, if an attempt at creating intervention programmes focusing on the children’s emotional development is made, it might aid the children themselves as well as their caregivers and professionals in handling the difficulties (e.g., RBs) that are often caused by the disrupted expression and perception of emotions.

More specifically, it is not only the way the child is treated that is important, but also the way the caregivers are treated by those who are involved professionally with the child, and vice versa. Bogdashina (2005, p.220) advises that “the experience of many parents shows that, the more you know about autism, the more you suffer at the hands of professionals who know less”; or, in other words, that as parental knowledge increases, they realise that professionals do not have sufficient understanding of autism. I am strongly opposed to this opinion, as I believe that the key for acceptance is not always knowledge, but the improvement of the opportunities offered. Therefore, knowledge about individuals on the AS rather than knowledge about ASD as a disability would be the key for achieving equal opportunities and collaborative relationships (White et al., 2016). Similarly, knowledge concerning individuals with VI rather than knowledge about VI itself would be important for identifying the similarities as well as the differences between those two disabilities, and providing children, their families and educators with the adequate support. Concerning RBs, this would be very important as well, in the sense that if the knowledge behind what an RB in the context of VI and ASD means for people can be identified, then a targeted intervention could offer effective support.

Eleftheriou (2009) asserts that different societies (e.g., countries) have different support and knowledge. She also claims that the offered knowledge and support reflect people’s perceptions, as well as any type of prejudice and social barrier. When societies offer their citizens better information in relation to diversity, then the social integration of people with disabilities turns into a process that is milder and smoother. For that to take place, however, the beliefs of the individuals that comprise the society need to change (Moss and Blaha, 1993). This knowledge could be obtained by collecting information from caregivers and professionals and especially by trying to understand and interpret their beliefs and perceptions, which determine the way in which they react and behave.

So, researchers need to be more mindful about perceptions which could be used to build a better and more collaborative partnership between caregivers and professionals, always for the children’s benefit. Undoubtedly, it might be difficult to expect adults to alter their perceptions, but I do believe that the educational appropriation of RB could be possible through this attitude.

2.VII Greece: Understanding repetitive behaviour in children with vision impairment and those on the autism spectrum

The research study was carried out in Greece for two reasons. Mainly because of my deep interest in finding out what happens in my country of origin and partly for pragmatic reasons which will be discussed in the next chapter. This is why studies that have been conducted in Greece are mentioned below.

Research relating to children with ASD from Greece that exhibit any kind of RB is limited, while there are no research attempts to be found concerning the RB of children with VI. The studies that have been carried out focus mostly on children on the AS, the nature of the RBs, their structure, their cross-cultural heterogeneity, as well as their impact on the children themselves and the way they are addressed.

More specifically, research conducted by Georgiades et al. (2010) has revealed “the factor structure” of RB in children with ASD in Greece, providing cross-cultural support for the distinction between a “high-order” factor representing RBs and a “low-factor” reflecting RBs and self-harming behaviours.

Papageorgiou et al. (2008) compare Greek and North American populations. Their findings provide evidence for the cross-cultural heterogeneity of the RB domain of ASD and the clear distinction between insistence on sameness and repetitive sensory and motor behaviours, and interests in individuals with pervasive developmental disorder. With their findings they expressed a desire to challenge the homogenous construct of RRBs as mentioned in the ADI-R and provide a reorganisation and re-conceptualisation of the RRBs in autism (two underlying dimensions of “insistence on sameness” (or Resistance to Change), and repetitive sensory and motor behaviours and interests) (Papageorgiou et al., 2008, p.558).

Finally, Synodinou (1999) notes a contradiction which characterises all people, with or without a disability: On the one hand there is the “rhythm” that supports the body and on the other the “rhythm” that oppresses and causes suffering. Thus, she argues that children with ASD are overcome by their own pace, which is also their freedom. But this rhythm is so persistent and pressing that it prevents them from communicating and causes them to become shielded in their loneliness.

This negative view of RBs might also be what has led researchers like Kaloudi et al. (2011) to conduct research with the aim of addressing and curbing RBs. That kind of RB contextualisation shows that the formation of the perceptions of researchers and practitioners tends to be heavily influenced by their subject specialism.

Regarding research that involves perceptions relating to the RB of children either with VI or with ASD, none seems to exist. Indeed, Mavropoulou and Sideridis (2014) say that it is difficult to measure children's perceptions and attitudes, while, on the contrary, other foreign researchers (Campbell, 2006, Campbell, 2007, Campbell et al., 2005, Campbell et al., 2004, Campbell et al., 2011, Magiati et al., 2002, Morton and Campbell, 2008, Swaim and Morgan, 2001), try to present different children's attitudes and perceptions toward their peers with ASD, depending on their gender, grade and socioeconomic status. This may be because who is diagnosed with ASD varies across countries, because the conceptualisation of what autism is may differ (Perepa, 2019).

Syriopoulou-Delli et al. (2012) suggest that the perceptions of Greek teachers regarding the management of children with ASD are relative to the teachers' level of specialisation. Proof of this has been found in previous research by Mavropoulou and Padeliadu (2000) which demonstrates that even the most specialised teachers mention the existence of RBs in their students, as well as how difficult it is to work with them because of their RB.

It is obvious that research done so far is fragmentary, so further research is necessary in order to establish whether there is consistency in the approach between VI and ASD. It is important that the impact which the behaviour of children with ASD has on the perceptions of the people around them be tracked. For the same reasons, I consider it important that the impact that the RBs of children with VI have on the life of the adults who surround them (caregivers and professionals) be explored, something which it would be possible to achieve, if the perceptions of the adults concerning the RBs are initially investigated.

2.VIII The gaps in the literature review and how they led to the conception of the research questions

On the one hand, the literature review revealed a tendency on behalf of the existing research studies to aim for better insights into the field of ASD via the exploration of VI, and to focus on dual diagnosis or for the common features found in both disabilities; therefore, a connection is seen between these two disabilities. On the other hand, though, the approach of examining potential RBs seems to divide researchers. In fact, few of those who work in the ASD research field talk about the social rejection of children with disabilities. At the same time, elements emerge that separate the two disabilities, but without explaining the case of RBs and the perceptions of the people involved.

Comparative studies on the subject in question cannot be found, while studies on RBs in VI and in the ASD do exist, but are fragmentary, in the sense that they mainly focus on the definition of RB, its description, the reason for which it is being displayed and the negative impact it has on the child and the social environment along with the measures that have to be taken to eliminate it. It could be elucidating if comparative studies on VI and ASD could be conducted, concerning in particular the link between VI and ASD, in the sense that has already been presented in 2.III.iii. Both disabilities share characteristics that could lead to important findings and insights about the impact they have on the people who live with or care for the children with VI or ASD. This kind of comparative study could be illuminating as well, regarding the way people conceptualise RBs. These findings might be used practically in order to develop further communication and collaboration between practitioners and the families of children with either of the two disabilities. Recent studies tend to concentrate either on comparison, aiming ultimately at better insight into the field of ASD via the exploration of VI, or on dual diagnosis or the common features found in both disabilities; however, different conclusions are drawn.

The perceptions of caregivers and professionals concerning children’s RB and its impact on the life of both the former and the latter does not seem to be a primary research aim and the reason for this is not clear. Only research regarding perceptions about the general behaviour of children with VI or the learning ability of children on the AS has been found. It is speculated that due to the fact that a correct diagnosis seems more important for a society that is obliged to offer adequate education and state financial aid to the children’s families, researchers are eager to pinpoint the characteristics of a proper diagnosis. Furthermore, there is a chance that researchers tend to avoid such a comparative topic. Most researchers are aware of the difficulty inherent in the process of decoding people’s perceptions and beliefs, which could be why this type of research is seen as an intimidating task.

Overall, I have gathered information about RBs, VI, ASD and I have tried to outline the perceptions people involved in these two disabilities have. The gaps that emerged from the literature review can be summarised as follows: First and foremost, the need to describe the interpretation of RBs manifesting in children with VI or ASD by the people in their environment. Then, the need to identify the background of this interpretation, of the perception that is hidden behind it and of the tendency to decipher RBs. All of the above could be investigated in the context of modern Greek society and given the fact that no comparative research study (in the field of VI and ASD) has been conducted regarding

Greek culture, the perceptions of people and the impact they suffer or cause. This topic is important to investigate, as caregivers and professionals work very closely with their children and students with VI and/ or ASD, as a result affecting them via their upbringing or teaching respectively.

Therefore, the following research questions aim to address the aforementioned gaps in the existing literature. These research questions are going to be further reviewed later on:

1. What are the RBs that caregivers and professionals observe in children with VI and children on the AS? Do the child's individual characteristics, such as their age, level of sight or disability, have an impact on their behaviour?
2. What explanations do caregivers and professionals attribute to these behaviours?
3. What is the impact of these behaviours a) on the child, b) on the caregiver/ professional, c) on others?

2.IX Rationale and development of the research questions

The procedure I followed in order to approach the research questions above, was based on the information that I had recorded in my research diary. As I previously mentioned in section 1.II, in this research diary I kept meticulous notes regarding the behaviours of my students my colleagues and myself, such as the following: *1/ 9/ 2018 - Classes have resumed and VS's RB has intensified. Particularly his echolalia. I wonder why this always happens after the summer (?); 25 /9 /2014 - "Our music-therapist is fantastic! She formed a band with VI students, they prepared a little presentation and are also preparing a CD. I cannot believe I am* *seeing NV and YF (diagnosis: MDVI) stereotype playing music and singing.”; 13/ 12/ 2008 - “The Institute’s interdisciplinary team meeting has just finished. It’s incredible how much time we end up spending each time on the autistics’ stereotypies. Are we always supposed to stop them? So that the children do not become upset, apparently? To make them return to the here and now? So that they don’t suffer abrasions? I don’t understand... I do not always agree... I often realise that the more I try to curb them, the more they flare up…”*. My notes were also related to those behaviours and incidents that involved the families of the children: *24/ 4/ 2017 - “TR’s dad came by today, raging. My son (diagnosis: autism) acts like a spastic at home!”, he screamed. “Do something! He is an embarrassment!”.*

An initial update took place after the first three years of record keeping, when, following a thematic analysis of the data I had collected, I arrived at certain common groupings of considerations. Those were reinforced or dismissed following considerable reading and spotting of gaps in the literature, before I could finalise my research questions. I maintained my research diary even after having conducted the interviews for the study, taking notes following my meeting with each interviewee. For example: *1/ 6/ 2019 - “I felt that they were trying to impress me with the various techniques they use in order to stop their ‘blind child’s autism’, as they said”*. This was a kind of reflection that helped me realise the existence of negative data which I will discuss further on. Most of the data in my research diary pertained to recurring issues concerning both disabilities, which struck me as, both from an academic and a professional viewpoint. For instance: *1/ 11/ 2014 - “I dare say that at the hospital we went to I observed repetitiveness even in the behaviours of adults with.”*. It did matter to me because as a specialist I was asked to give advice regarding RB presented by children either with VI or ASD. It did matter to the families, since RB was a subject of conversation throughout interdisciplinary team meetings in which I had participated, following a family's request. It did matter to other practitioners, because their views contradicted each other's and sometimes contradicted the literature as well. After focusing on my literature review, I also realised that there was a gap with regard to that issue, namely the displaying of RB by children with VI or ASD, the way this was perceived by those involved in it (children, families, professionals) and the question of how it could be addressed.

It is obvious that my initial ideas came from practice, as a need was highlighted for understanding the reason why VI reminded me so much of ASD, as can be seen through the notes made in my research diary: *"23/5/2011 - It is incredible how much AM's repetitive movements and echolalia remind me of those of the children in the autistic group with which I work on Tuesday evenings. His sister actually has the same blindness characteristics and the exact same reactions as him [i.e. AM]!"*. As has already been mentioned in Chapter 1, there was a need to decode the RBs of my students, and to relate them to the manner in which they were being addressed by parents and educators, based on their perceptions. It was (and still is) a very familiar field, yet at the same time very unexplored. After all, the scientific need for further comprehension and interpretation of perceptions that all people share, was pinpointed by Langdridge (2007). The conclusions that he drew also highlight how important this might be for knowledge production and science development.

More specifically, my scientific interest in RB began during my time as a special educator and an educational psychologist of children with VI and children with ASD in Athens, Greece. The fact that both groups of students presented repetitive movements (receiving similar reactions or/ and interventions by professionals), increased my awareness regarding RBs and the ways in which adults respond to them. I was mainly concentrating on how people perceive the experience of RB and what it means for them. My search for answers then, in conjunction with the literature review, as has been mentioned already, gave rise to my research questions.

However, I did not settle on the questions from the very beginning. "Answering a research question is a more challenging analysis objective than assuring the quality of the data to be analysed" (Guest et al., 2012, p.27), so I needed to be careful and accurate. The process was developmental and it evolved along with my own concerns and in tandem with the gaps I observed while conducting the literature review. My initial thoughts were descriptive (e.g., focused on a combination of detecting, describing and interpreting RBs in relation to both disabilities). Gradually, though, the need arose for the clarification of the manner in which RBs are interpreted, of whether this interpretation affects the lives of the people involved in them and whether the same interpretation is offered by all those speaking of an RB, after all. Caregivers and professionals always remained in the spotlight, since they are the people most directly involved with an RB, after the children themselves. There was also a thought of focusing on children's perceptions regarding the RB that they themselves display, the reason why they resort to it and the feelings that it might trigger. However, ethical considerations, as well as trustworthiness concerns, were issues that preoccupied me significantly.

Summary

This chapter initially presented the literature research strategy I followed in order to gather any literature information related to VI, ASD, RB, perceptions about RB, ableism, as well as early childhood development and its connection with disability in general and RB in particular. The main aim was to address the issues around RBs presented by children either with VI or with ASD, and the perceptions of caregivers and professionals in relation to the matter, bringing together related literature from previous sections from inside and mainly from outside of Greece. This chapter concludes with the gaps I detected during the literature review process and with the research questions to which I was finally led.

Chapter 3

THEORETICAL & CONCEPTUAL FRAMEWORK

3.I Chapter overview

The main focus of this chapter is to outline the rationale for my choice of theory, which aligns and supports the structure of the research project's purpose, its research questions, significance and design.

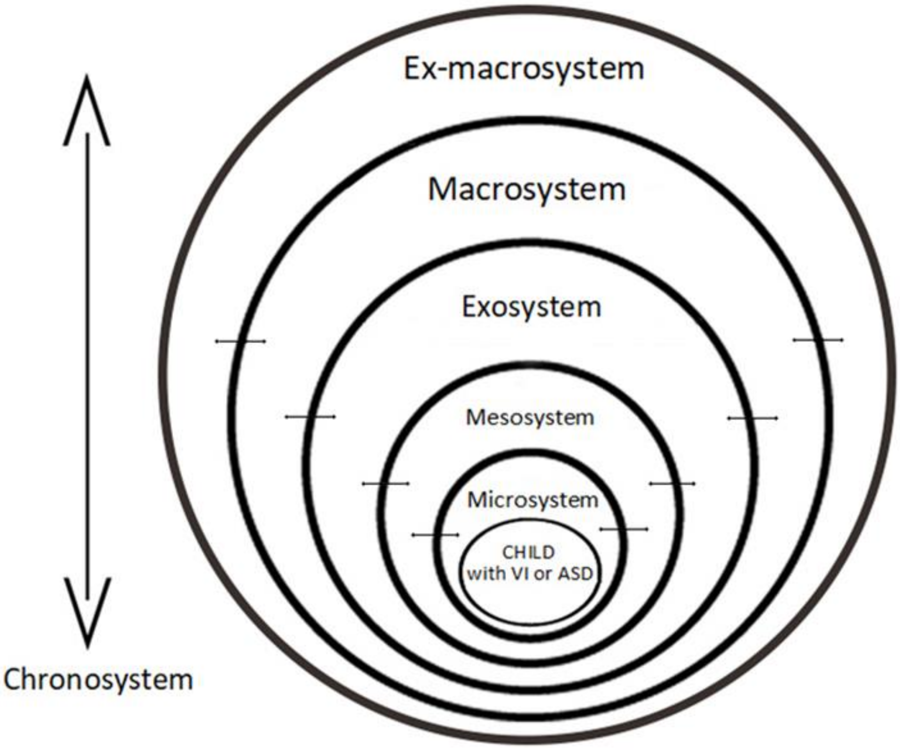
This chapter contains a section about the Ecological Systems Theory (EST) and its main characteristics; a section outlining other research attempts, where EST has been used so as to better understand matters related to perceptions and disability; a section featuring a critique of and reflection on EST and a final section where the reason why EST - and not the Bioecological Systems Theory (BST) - is relevant to my research questions is discussed.

3.II The framework behind the theory: My research design

In the context of a research study, a conceptual and theoretical framework has to be clearly defined from the very beginning. The purpose of the theoretical framework of the research study is to uncover and analyse the caregiver and professional perceptions about the RB children with VI and those on the AS may present. The theoretical framework determines the type of data to be collected, as well as the structure and the vision of the study, along with its key components such as the problem, the purpose, the significance and the research questions (Osanloo and Grant, 2016). Moreover, the theoretical framework offers a clear explanation of what has been found or of the researcher's risk of being burdened with the previously mentioned “limited uselessness of findings and conclusions” (Sarter, 2006, p.494). Qualitative researchers approach their studies with a basic set of beliefs that guide their inquiries. As such, it was important to examine my own epistemological beliefs when selecting a theoretical framework. My beliefs are influenced by assumptions, values and ethics that are all personal postulates. Therefore, I am trying to discover the lens through which I view the world, as well as the theory that underlies my thinking with regards to how I understood the subject and planned to research

Bronfenbrenner (1979)’s innovation for building context into research at the levels of theory and empirical work, is the EST. The EST is traditionally described using a nested systems metaphor (Anderson et al., 2014), to capture the idea of the multiple transactions within and between all the systems in the frame. However, it is usually presented as an overlapping configuration of interconnected ecological systems (Rogoff, 2003), as it is shown in *Figure 1*.

Figure 1: Nested model of Ecological Systems Theory (with all six levels)



This is a figure with six overlapping circles and a big vertical arrow on the left pointing in both directions. The smallest circle corresponds to the child. The next one is the microsystem, namely the family of the child. The mesosystem represents the interrelationships between the settings within a child's microsystem, while the fourth circle – the exosystem, is about the settings in which children do not directly participate but which are considered influential in a child's development (e.g., policy, school policy). Then, the fifth circle, or in other words the macrosystem, concerns the perceptions, attitudes and culture adopted by the society, while the ex-macrosystem is linked to the fact that many decisions are made outside the country's borders, by external legislative or administrative bodies (e.g., European Union policies). Small arrows from and towards each circle in relation to the next/ previous one depict the influence that each circle has on the others. The vertical arrow on the left represents the chronosystem, which pervades each of the overlapping circles to its right.

Unlike other statements of theory, Bronfenbrenner (2005) does not focus on a specific domain such as social relations or cognition or biological development, but on the natural environment in which the children need to develop (Darling, 2007). In other words, the EST examines the factors in an environment whose interaction affects a child (Walker et al., 2019). The theory, therefore, seeks to understand the influences on development "within the complex 'ecology' within which humans live" (McLinden et al., 2016, p.185). This is a dynamic context/ environment with an ecology, "rather in the way that a habitat for plants and animals is an ecology" (Thomas, 2017b, p.168).

The EST is presented as a network model in a graphical depiction of the variation that exists among four overlapping circles. Inside these circles there are dynamic relations within and across all of these systems: micro, meso, exo and macro, based on patterns of social interaction (Anderson et al., 2014) that reflect a complex and evolving ecology of human development (Shea and Bauer, 1994). The interaction of constructs within a circle and interactions of structures between circles is the key to the EST. This conceptual framework demonstrates an understanding of how situated dynamics in this study were connected and how the research was positioned.

The child is at the centre and the microsystem is the circle closest to the child. The microsystem encompasses the child and her/ his direct and immediate environment, such as their socio-economic characteristics, school, family, home, as well as neighbourhood and childcare environment (Berk, 2003). Bi-directional influences, as Bronfenbrenner (Härkönen, 2001, MacBlain and Gray, 2016, Ryan, 2001) calls them, are the strongest and have the greatest impact on the child. Ryan (2001) tries to explain Bronfenbrenner’s observation, by indicating that the interactions happen in two ways: from the child and towards the child. This kind of relationship is very intense and highlights what Härkönen (2001, p.7) mentions; that “the interaction within the layers of the structures and the interaction of the structures between the layers is the key to this theory”.

The second overlapping circle closest to the child is the mesosystem, which connects the structures of the child’s microsystem with each other. According to Davison and Birch (2001), the mesosystem represents the interactions and relationships between the major settings in which the child is immersed (parental dynamics, parent-teacher relationship). In other words, it describes how the different aspects of a child's microsystem work together for the child herself/ himself. For instance, the connection between the child’s teacher and the parent, the school and the neighbourhood or a workshop that a practitioner might attend and the upcoming benefit it will bring to the child, are some of the dynamics and relationships that might develop inside the mesosystem that mainly reflect the interaction between the microsystem and the exosystem.

What follows is the exosystem; this circle regards the social system with which the child seems to not be directly involved (such as the professionals, practitioners, teachers, education, curriculum and policy), but which still has a significant effect on/ caused by her/ him. However, the child does feel the positive and the negative force she/ he receives indirectly from this external circle (Ryan, 2001).

The macrosystem relates to the overarching culture in which the child lives (perceptions, attitudes, cultural values, laws, legislation, rules, customs, mass media). The macrosystem encompasses all major systems and institutions that govern and shape society (Bronfenbrenner, 1999, Bronfenbrenner and Mahoney, 1975). This means that, whichever the above principles may be, they affect all – and not only some – of the smaller circles: the exosystem, which in turn affects the mesosystem and ultimately the microsystem, which is directly related to the child (Berk, 2003, Bronfenbrenner, 1992).

Later on, Bronfenbrenner himself noted that there are changes that occur over time, represented by a further fifth time-related system aspect which he added and named "chronosystem" (Bronfenbrenner, 2005). It has been considered necessary for Bronfenbrenner to add more levels in order to give this theory an up-to-date structure (Drakenberg and Malmgren, 2013). The element of time is important and necessary. The concept of time is treated as being as important as the environment for human development and focuses on the changing relationships in an environment (Bronfenbrenner, 1992, Rosa and Tudge, 2013). The chronosystem can cover a short or longer period of time and can include roles that may have an influence on development, such as the influence of a professional on a caregiver or a child, after having supported the student for a long time. In other words, the chronosystem includes the experiences of the caregivers and professionals and the influences over their lives, "throughout their compulsory and post-compulsory educational pathway" as advised by McLinden et al. (2016, p.192). The chronosystem follows a developmental process that requires time. This may include changes to each of the systems (starting from society in this case – the macrosystem) which all potentially affect a child's (with VI or ASD) development.

Moreover, Drakenberg (2004) in Drakenberg and Malmgren (2013) advises one more level to the EST, called "ex-macrosystem", which is outside the macrosystem and influences it, as well as the underlying systems. The ex-macrosystem is the biggest ecosystem and the one the furthest away from the child, who is in the centre. It is linked to the fact that many decisions are made outside the country's borders, by external legislative or administrative bodies. This view has been further strengthened through the increasing number of multicultural citizens (Drakenberg and Malmgren, 2013) or/ and also perhaps by the empowerment of the European Union and the Europeanisation which seems to have a domestic impact on varying European policies (Pech and Kochenov, 2019).

3.III Bioecological Systems Theory

Smelser and Baltes (2001) mention that Bronfenbrenner updated his original model by acknowledging the role of the biological determinants of the individual; thus, a bioecological model was proposed. That updated model weaves together human social ecologies and individual human biological determinants into a more comprehensive whole.

More precisely, BST focuses on the understanding of genetic influences on development. In this case, Bronfenbrenner (2005) emphasises the interactions and demonstrates the complex relationships between influences on human development that are close to the learner (proximal influences) and those that are distant from the learner (distal influences) over a given developmental time span. He also highlights that the interrelationships between the different systems have to be respected and that “the association of processes and outcomes observed in different contexts and for different people [must] be lawful, not random” (Darling, 2007, p.210). Hence, the aim of the new model was to explain this “variability” (Darling, 2007, p.210) using specific and generalisable principles.

The main concern around this model is related to parental monitoring and knowledge. The focus is not on the latter concepts themselves, but on the sharing of information between parents and children that transforms sharing into effective socialisation. In addition, the ability of parents to gain information about their children becomes increasingly dependent on the children themselves. Hence, the child acquires an active and fundamental role within the BST (Darling, 2007).

Another central element of Bronfenbrenner's BST is the "Process–Person–Context–Time model" described in detail by Bronfenbrenner and Morris (2007, p.798). According to this model, there are four components that are necessary to incorporate when conducting developmental research within a bioecological systems framework: 1) the process or the recurrent interactions between a person and the surrounding environment, 2) the person or the individual and their unique set of characteristics (demand characteristics, resource characteristics, force characteristics), 3) the context or the nested settings as discussed earlier in relation to Bronfenbrenner's early work and 4) time (microtime, mesotime, macrotime) (Crawford et al., 2020).

Although BST is often used to examine human and specifically child development, it can be applied across various and different contexts, such as the perceptions of teachers concerning their students' competencies (Tudge et al., 2003); adolescent aggression (Benson and Buehler, 2012); early vocabulary development (Farrant and Zubrick, 2012); classroom quality, behavioural engagement and reading achievement (Ponitz et al., 2009); as well as war and terrorism (Masten and Narayan, 2012), poverty (Eamon, 2001), sexual behaviours (Lohman and Billings, 2008) and bullying (Lee, 2011).

As a matter of fact, my rationale for using EST and not BST, is that the latter focuses more on the particular individual and their biological determinants. In the present study, the child does not take centre stage in the research and this what I intend to explain later on. This is the reason why there is no theoretical focus on BST, but on EST. The lens through which I personally perceive EST focuses on ecology rather than on bioecology, because of the individuals' interactions with the child and the interrelationships among the systems. Interactions are the main concept of EST and these interactions might be what affects people's perceptions, and in this sense that the study is not looking at how caregivers and adults experience their children's/ students' RB, but at how they perceive it. To put it briefly, I am here using the EST in order to discover more about disability (VI, ASD) and how it is experienced by caregivers and professionals. Hence, the child is not at the centre and is not the only person responsible for her/ his own development, as Bronfenbrenner (2005) asserts in BST. In other words, BST cannot be considered appropriate for the research in question, since it focuses exclusively on child development, while my goal is not to understand the child but the tendencies of the adults towards them. However, the context of the ecological systems (circles) that EST creates and the interconnections between them comprise, in my opinion, the most suitable context for the presentation of my argument for a different interconnection between the ecological system and the fact that bi-directional influence could not only be a one-way concept.

3.IV Critique of the Ecological Systems Theory and the lens through which it is viewed in research

Regardless of its supporters, EST has been engaged in an ongoing reassessment and critique of its original model, something that over time has led to iterations of the latter. EST has been much questioned and this is something that needs to be highlighted.

Christensen (2016) criticises Bronfenbrenner's theory, initially by arguing that even if everything interacts with everything else in the theory, this happens to varying degrees and at different times. EST is presented as a theoretical and analytical framework, but in an experimental and descriptive way.

This concern leads to another one, related to time. Individuals and their social environments have a history (in the sense of expressing the past) and a future (by making choices about possibilities). An EST perspective has to be present-oriented; however, this appears as a limitation to practitioners for whom "the past roots and future solutions of problems are critical" (Rothery, 2016, p.92).

Another point is made by Christensen (2016) regarding interaction between individuals and the fact that this is seen as the main source of learning in EST. Hence, by using Bronfenbrenner's model, it becomes easier to see that the lives of all individuals are influenced by society – and, therefore, collectively by the people who comprise it – through the way in which the latter interact. This standpoint has again been criticised by Christensen (2016), in the sense that each individual needs to be seen for their individual characteristics. Then, the ability of individuals to influence their own lives should be at the forefront of the researchers' attention.

Resilience is one more aspect that is not included in Bronfenbrenner's theory, although it should have been integrated according to Engler (2007). He argues that adding resilience to EST can offer explanations as to the way in which individuals overcome trauma in their lives. Bronfenbrenner's theory focuses mainly on the negative effects of how an individual will develop if exposed to adversity. In other words, the theory cannot provide an explanation for how a person can be brought up in a negative environment but still survive within a "successful" (Christensen, 2016, p.25) life.

An additional point of criticism indicated by Christensen (2016), concerns the relationship a person has with other individuals, family or colleagues. These ties serve beneficial (i.e., long-term relations) and social (i.e., personal factors) aspects in relationships that ideally have to be closely connected, so as for the individual to be seen as a complete human being. As a matter of fact, it seems that there is a lack of that connection in the anthropocentric EST and particularly in terms of how individuals might strengthen each other, since in the theory the ties are never neither beneficial nor emotional. The point here is not to deny the complexity of human social, economic, and political system factors impacting especially children, but to argue for a more inclusive consideration of all factors.

Rothery (2016, p.92) also expressed concern about the theory's "open-endedness, which can be both good and bad news". The potential bad news is that when it comes to the holistic understanding of someone's life, then there is no end to the avenues that can be explored and that the researcher should ensure that they take an interest not only in individual aspects of the natural environment, but in said environment in its entirety should be accomplished (Ungar, 2002).

A further important criticism is that EST supports adaptation; as such, it can easily become a model through which practitioners encourage families or students to accommodate to challenging circumstances. For this reason, emphasis is placed on the fact that social realities are – and must be – part of the environment of an ecological system. EST can be misused if it is employed in the absence of social values; thus, an integration of values with EST is proposed (Rothery, 2016) .

More recently, Elliott and Davis (2020, p.10) question the focus of EST on "the person-process-context time" model, where the interrelationships between these concepts come to the fore. On the contrary, they believe that interrelationships are first framed as processes and that people interact intimately with the physical environment. In the same manner my intention is not that of understanding the cause of children's RB, but rather the reactions of the adults to RBs and their actual perceptions regarding them. My rationale behind this emerged on the basis of the information extracted from my research diary; for instance, on the notes I had made when I had the feeling that people were being critical of me and my teaching approach towards my students' RB: *"Today (31/10/2007) I tried to use imitation in order to stop FT's (diagnosis: pervasive developmental disorder) stereotypical movements. Must I, though? It seemed to calm her down temporarily, but then she had some unexpected outbursts. Is she repressed, perhaps? The headteacher looks at me askance. As if I am to blame for the child's movements. I don't want to always be stopping her"* or they looked afraid or irritated by students' RB: *"(29/3/2016) At the school play for the 25th of March celebrations I managed to get them to allow PK (diagnosis: autism) to play the national anthem on the keyboard. He made sounds at the same time – it was echolalia. I know him. He was singing. But the headteacher turned off his microphone*". Hence, a broader interpretation of the environment needs to be part of the systems of the theory.

In the context of the EST critique and although Bronfenbrenner updated his original model by acknowledging the role of the biological determinants of the individual, it is believed that this development is still not comprehensive enough for those advocating that childhood defines long-term intergenerational sustainable futures (Elliott and Davis, 2020). Stanger (2011) actually stated even before Elliott and Davis (2020), that the chronosystem must be extended to include evolutionary time scales. Further, Elliott and Davis (2020, p.11) discuss the nonhuman and/or physical environment potentially framed beyond these nested human systems, as well as the "all encompassing, or situated within and impacted by human social systems, or integral and across all nested systems" environment.

Overall, useful concerns have been raised in relation to EST and the limitations I have identified above regarding the lack of resilience in terms of time (it is a present-oriented theory), feelings (it does not focus on the feelings that arise within the context of relationships) and the influence of the person on their own life (it attributes greater power to the surrounding environment). Notwithstanding, it seems that the theory is robust enough to accommodate them and let researchers accommodate any further research studies (Rothery, 2016).

3.V Perceptions and how they can be developed according to the Ecological Systems Theory – Past research studies

At this point, I will try to find out how the EST can help one to understand the development of perceptions and their impact on children with disabilities and/ or their families. Although the EST has been invoked in the disability literature as a framework for child, classroom, and family investigations, few studies provide information about perceptions and how they can be developed according to the theory in question. This might be because of the restricted nature of that specific research area (i.e., perceptions – disability – EST). However, the way these studies employ the EST within their personal research study can be a source of inspiration regarding a potential conceptual framework that can act as a springboard for future research (like the present one).

Hong and Eamon (2012) studied students' perceptions regarding unsafe schools in the United States. Unsafe schools are an issue that concerns parents, practitioners, policy-makers, the school. Using the EST, the researchers examined the microsystem, the mesosystem and the exosystem factors, associated with the perceptions developed in unsafe school environments. This study identified several factors in all of the three ecological circles used, that influence students' perceptions of unsafe schools. Thus, it seems that all three of the ecological circles used impacted on children's perceptions.

Following an ecological perspective which spreads from the microsystem to the macrosystem, Drakenberg and Malmgren (2013) investigated school headteachers' perceptions about the Swedish compulsory education system. The researchers finally advised that additional circles should be added to Bronfenbrenner's original EST, based on the perceptions of the headteachers that seemed not to be uniform. In other words, they believe that the current ecological systems do not suffice and that it is necessary that more potentially influential ecological systems be examined. They actually suggest improving students' relations with their teachers and students' relations with the headteacher. This suggestion seems relevant for my own research and the importance of the relationship between children with ASD or VI and their caregivers and/ or the professionals working with them.

Ciero Paviot (2015) discussed a three-circle ecological perspective (macrosystem, mesosystem, microsystem) of private tuition and parent perceptions in terms of the educational situation in Kenya and Mauritius. The results focus on concerns regarding the mesosystem level (national education system), which seems to be greatly influenced by the microsystem (parent perceptions). In this case, then, it seems that perceptions are constructed at the level of the microsystem, which needs to change.

Kamenopoulou (2016) used EST with the aim of exploring the extent to which young people on the AS are socially included in the mainstream environment. She also tried to pinpoint any existing barriers to young people’s participation, which may be rooted in limiting perceptions. According to the EST, mainstream school is a system which interacts, communicates and influences social inclusion in a continuous way. As a matter of fact, the conceptual framework of EST explores the inclusion of individuals with a disability in education; this way, the researcher focuses on the interaction between the person and the context.

Similarly, McLinden and McCracken (2016) examined inclusive educational views through the EST. They identified multiple sources of interconnections between the ecological systems, in relation to the topic in question; therefore, a holistic approach towards children with VI was proposed.

In addition, McLinden et al. (2020) examined the influence of promoting curriculum access (exosystem) to children with VI, in a school and post education context, based on Bronfenbrenner’s EST. In that case, the child and the learning environment are characterised by a nature that changes over time (chronosystem).

It cannot be said that new theory was generated by the aforementioned studies, but the intention was that new knowledge, which would be useful in other settings and the field in general, would occur (Imenda, 2014). Thus, what emerges consistently, which could also be used as a basis for my research study, is that in all situations the interaction and interconnections between the ecological systems is possible and invaluable for the child occupying the centre. Depending on the case, one may observe the flow of influence from the inside of the ecological circles towards the outside, or in other cases from the outside towards the inside. What is important to record is in which ecological system a potential issue is observed each time, so that an effort is made accordingly to alter the interaction with the environment directly involved.

Applying Bronfenbrenner's framework in education seems a very interesting, very powerful and important process. Actually, education is considered a social matter that could be viewed through the EST (Yue-guo, 2005), so as to enable individuals to bring either their knowledge, or values or perceptions and emotions into every situation. The result is a thorough analysis and a more comprehensive plan for addressing VI and ASD practices in the current research.

Students, who are always placed in the centre of the EST, interact with individuals from the microsystem and are affected by their personal values. Likewise, there are dynamic relations across the ecological systems – and not only within each one of them – that can also bring about changes on the child who is in the centre. In other words, the EST prompts and highlights changes in education that involve what Cote and Nightingale (2012, p.475) advise concerning the importance of "human-environment dynamics" that could give rise to change and this is because everything about a child and their environment affects how that child grows and develops. This change could be very important because of the possibility to take "advantage of the opportunities created by change", as Berkes et al. (2008, p.376) argue. In addition, it seems important to state that according to Kamenopoulou (2016), policies (e.g., special education governmental policy, schools' policy on special education, WHO's diagnostic criteria for disabilities) are in flux as flexible frameworks that are continually being reconstructed to meet the professionals' requirements. As a matter of fact then, in turn, policies meet the students' needs too (Kamenopoulou, 2016). As a result, the change pinpointed by the EST at the beginning of the paragraph indicates that the challenge of this process is not insurmountable, given that reference has been made to the flexibility of the frameworks. What I would add to that justification is that policies could be in flux as flexible frameworks that are continually being reconstructed to meet the needs of caregivers as well.

3.VI Ecological Systems Theory, disability and the current research study

What has already been highlighted is that Bronfenbrenner' s theory has been applied in the contexts of education, childhood education, pedagogy and psychology, with a focus on the interaction of environments in child development. Although the theoretical framework outlined by Bronfenbrenner was not initially intended to be directly applied to children with disabilities, there is evidence in the literature that demonstrates the value of drawing on it, like for example for children with particular developmental needs (Bricout et al., 2004, Davis et al., 2015). Interestingly, the EST has been applied in addressing more special education and disability matters. For instance, Davison and Birch (2001) built an adaption of Bronfenbrenner's framework, by employing a disability lens in order to identify key factors of relevance for children with disabilities, placing the child in the middle and three overlapping circles (micro, meso, macro) around her/ him. In the case of a disability, then, Walker et al. (2019) advise that children must be considered within the context of their environment. The framework has also been applied within the field of sensory impairment support, in relation to both VI (Hewett et al., 2017, McLinden et al., 2017) and hearing impairments (McLinden and McCracken, 2016, Swanwick, 2014). Argyropoulos and Gentle (2019), as well as McLinden et al. (2016) implemented the theory in a more focused manner, in research, regarding people with VI; the former two by using the microlevel and the macrolevel approach, whereas the latter by using the initial model of the EST which was suggested by Bronfenbrenner.

For this study, the EST is considered an apt lens of a conceptual framework that guides this thesis and is inspired by a six-level ecological perspective. In the current example, I will focus on the updated version of the EST, the one with the chronosystem included. The impact of the chronosystem is an important factor and the reason why it might have an effect on perceptions over time. This is because society is a living ecological system that shifts and transforms along with the perceptions of the people that comprise it. With regards to the ex-macrosystem, it seems to have been a necessary level for Drakenberg and Malmgren (2013) and I believe it is an indispensable level for the current study as well. The reason is that if I follow their argument of ex-macrosystems existing outside the country and being connected to national guidelines (Drakenberg and Malmgren, 2013), then changes in terms of the DSM and ICD would fit into this description. This is also the reason why I consider that society's perceptions (macrosystem) do matter for individuals; because, even though this is the most distant environment, there are still people and situations that influence and affect a child.

As has been mentioned, Davison and Birch (2001) focus on disability; however, their suggestion does not include the exosystem. On the contrary, in the case of VI, McLinden et al. (2016) refer to the exosystem and the chronosystem, something that I consider important for the outcomes of the current study, for the reasons I will explain below.

My main focus engaged primarily with the macrosystem, since my aim was to discover the importance of considering people's perceptions about RBs. These perceptions (macrosystem) might then affect the content of policy and curriculum related to VI and ASD (exosystem), as well as the potential training caregivers or professionals might receive. The exosystem, then, is the one that affects the relationship between caregivers and professionals, their collaboration and interaction (mesosystem), a fact that would impact on the way caregivers and the family in general behave, as well as treat and help a child either with VI or with ASD (microsystem) to develop. The mesosystem and macrosystem as well as the exosystem and the ex-macrosystem might not directly involve the child (McLinden et al., 2016), but I believe it would not be possible to impose changes without leading to consequences in the ecology (Neal and Neal, 2013). Influence, however, is not a one-way concept; the macrosystem would also influence the ex-macrosystem and the philosophy based on which diagnostic manuals such as the DSM and ICD are structured. As a matter of fact, if changes could be achieved in terms of the macrosystem (perceptions, attitudes), then gradually via the exosystem (e.g., not employing RB as part of diagnostic criteria, or absence of instruction suggesting the curbing of RB) and mesosystem (collaboration between caregivers and professionals in terms of the RB of their children/ students) the developing child inside the family's microsystem would be affected as well.

At this point, I would like to stress again that the influence between systems moves in two directions. In other words, one can observe a 'flow' of influence both from the microsystem towards the ex-macrosystem (from the centre of the overlapping circles towards the outside), but also from the ex-macrosystem towards the microsystem (from the outside layer of the overlapping circles towards their centre), as has in any case been described above. Each ecological system acknowledges the others and development is seen as the result of an interaction between them. Interactions take place and show not only general-to-specific, but also specific-to-general progression as well.

Thus, this could be seen as a helpful framework for examining the caregivers' and professionals' role regarding the development of perceptions about children with VI or ASD who present an RB. Indeed, according to Bronfenbrenner (2005) and McLinden et al. (2016), a strength of the EST is that it focuses on the complexity of the influences between relationships in the environment, over a given period of time.

Locating the key issues raised in the literature review and using examples from the literature, I could go into more detail in terms of the reason for choosing to follow the EST framework. This will provide a stronger argument for explaining why I chose this theory to underpin my own research study and how this ecological framework was useful for understanding the significance of people's perceptions regarding RB, the impact they have on children's (with VI or ASD) life and how these perceptions could be used constructively in order to prevent any negative impact.

3.VII How the Ecological Systems Theory informed the study and its design

Given the results of the literature review, what is suggested is the investigation of the perceptions of the adults concerning RBs, so as to further explore the impact that the RBs of children with VI and ASD have on the life of the adults who surround them at most times (i.e., caregivers and professionals).

There is a high risk of unmet service need which is linked to the low rate of service used by families with a child on the AS (Chiri and Warfield, 2012), a fact that seems connected with the unmet expectations of the caregivers themselves (Casagrande and Ingersoll, 2017). In addition, RBs are seen as a result of disrupted perceptions (Misailidi and Papoudi, 2017) or in other words as knowledge offered to society – a kind of knowledge that reflects the beliefs of society itself; this is a knowledge that according to Moss and Blaha (1993) needs to change.

Given the fact that the ecological theory does not mention the characteristics of the child much, but focuses on the interactions among the environments, what matters the most is these interactions and the impact they have on the child's development. It must be clarified, then, that this is considered as a limitation of the study[4]; namely, the fact that I do not intend to focus on the child's characteristics. My main focus is not the child herself/ himself and the characteristics she/ he may have. My main focus is the surrounding environment of the child either with VI or on the AS, the impact that environment has on the child and the reasons why, as well as the way in which this could be made to change. More precisely, through the proposed ecological model, a holistic view of RBs is provided, in the sense that the surrounding environment (e.g., family, community, policy) is the one that is being influenced by the society's attitudes and this, thus, influences the child and the way her/ his RB is treated. This holistic approach comes from the necessity to understand how perceptions influence child development and how child development can be explored and explained through the relationship with the surrounding environment (Oswalt, 2008). As the creator of EST himself asserts in Bronfenbrenner (1979, 1999), and according to the ecological theory itself, the early years of a child's life are vital, since many interpersonal relationships are formed. The issue, however, is how to aid the child with disability and how to ensure that the optimal number of intervention methods and services is used for children with VI and ASD.

Looking, therefore, through an ecological lens, the focus shifts from the individual and moves beyond interpretations that hold her/ him responsible for her/ his behaviours (Rothery, 2008, Sallis et al., 2015). Surrounding environments have an impact on the child and might determine her/ his behaviour, in the sense that wider societal attitudes

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[4] A mention of this limitation is made in this section and not in section 7.III.i of Chapter 7, where the limitations of the study are discussed. The reason is because this serves the development of the justification.

impact on caregiver and practitioner views and the way they behave to the children, because of the RB the children might display.

From an ecological perspective then, the EST is characterised by a multi-dimensional and multi-layered nature (Lee, 2008) that links to the core of this study, since the study will employ the EST to explain how perceptions are constructed and impacted upon by different ecological environments. Consequently, multi-level interventions are important and considered to be more effective in changing behaviours (Sallis et al., 2015). Therefore, since all ecological systems interact with each other, every potential change in one may bring about improvement in the others (Hastie and Siedentop, 1999).

It would be an omission to not mention a form of criticism that has been made, in terms of the great importance that has been attached to the individual. McCuaig et al. (2016) stated that microlevel and macrolevel agendas produce unrealistic expectations for individuals and more specifically the children to become responsible for themselves. Hence, the EST was considered an appropriate approach because, even though the child is central, their behaviour is defined by their interaction with the individuals in their environment.

As has already been mentioned, the exploration of perceptions in VI and ASD is a complex issue that ideally has to be seen via the EST, since the EST approaches challenging matters in a holistic way. The case study, then, seems to be the most appropriate research method and this is one of the reasons[5] why it was chosen to be used. The case study "can be considered a robust research method, particularly when a holistic, in-depth investigation is required" (Zainal, 2007, p.1), just as in the case at hand. The case study is considered to be one of the methodological

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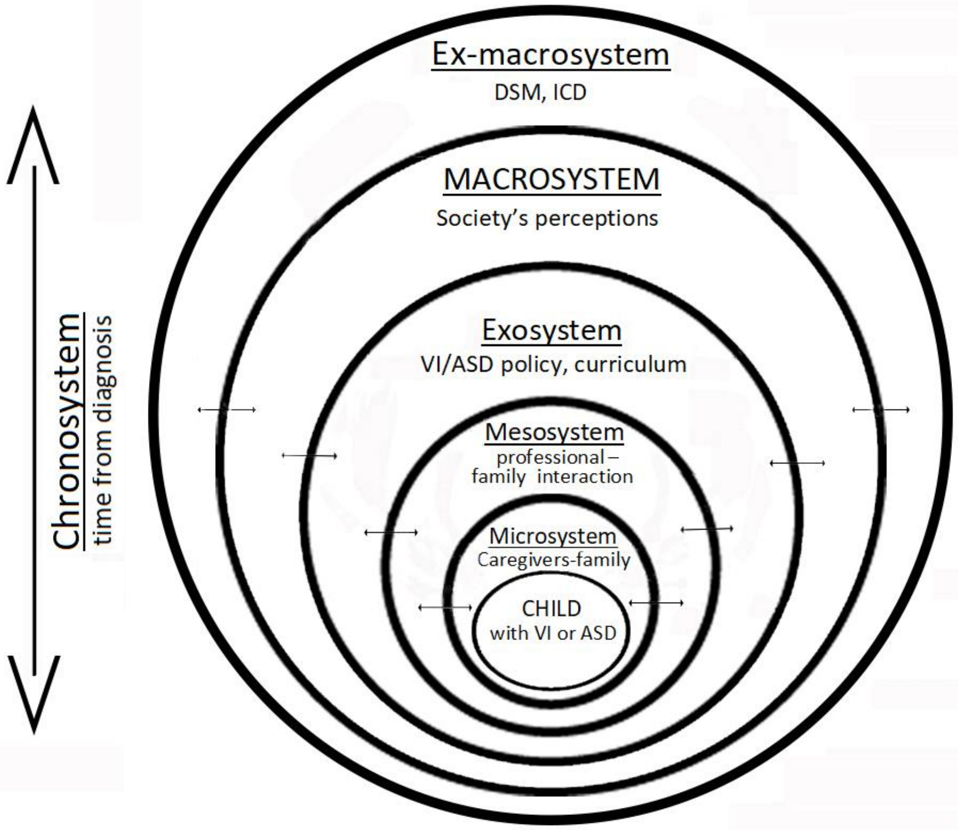
[5] More details may be found in the following chapter.

choices of that research study. Further discussion on methodological choices in detail, will be presented in the next chapter.

In *Figure 2* below, Bronfenbrenner's ecological framework is visualised as a model, so as to clarify how a person's (with VI or ASD) development can be explored and explained through the relationship she/ he has with the surrounding environment. Each environment connects to elements identified in the literature review as factors that need to be considered when designing diagnostic tools or intervention methods. As depicted in the same figure, the macrosystem strongly defines the way in which I view the interconnections between the different systems for my research.

__Figure 2:__ Nested model of Ecological Systems Theory adapted to the example of the present study



This is a figure with six overlapping circles and a big vertical arrow on the left that faces both directions. The smallest circle corresponds to the child either with VI or with ASD. The next one is the microsystem, namely the caregivers (family) of the child. The mesosystem is the third circle, which represents the interaction between caregivers and professionals, while the fourth circle – the exosystem, concerns VI and ASD policy and curriculum. Then, the fifth circle, or in other words the macrosystem, concerns the perceptions, attitudes and culture adopted by the society (the Greek society in the current study in question), while the largest one is the ex-macrosystem which concerns the DSM and ICD diagnostic tools that have been developed in a European context. The macrosystem (society’s perceptions) is written in capital letters, indicating the concern of this research regarding perceptions and the impact on the development of children with VI or ASD. Small arrows from and towards each circle in relation to the next/ previous one depict the influence that each circle has on the others. It is an influence that may be starting from the macrosystem and moving towards the inside of the circles – in other words, the child – or vice versa; that is, starting from the child and heading towards society – the macrosystem. The vertical arrow on the left represents the chronosystem, which pervades each of the overlapping circles to its right.

Summary

Overall, Chapter 3 presented the theoretical and conceptual framework of EST that demonstrates an understanding of how perceptions regarding RB in this study are connected with VI and ASD and how the research was positioned, informed and designed. As Kamenopoulou (2016, p.22) very aptly states, EST assisted me to provide "a logical attitude to a complex situation, which, therefore, informed the research design".

I have tried to explain what the ecological system is and how it has been used to facilitate the understanding of the interaction of environments in child development (a child either with VI or on the AS) and of how that development could be improved, based on perceptions that people hold. The chronosystem was mentioned as a key factor in this process, as perceptions are likely to not remain fixed, but change with the passage of time. Another important factor is the ex-macrosystem, which is not mentioned in EST-based research very often. However, in the present research the international diagnostic manuals that have been generated based on social perception and which continue to affect the individual on an exo, meso and micro-level appear to be important.

In the following chapter, Chapter 4, more practical aspects of the study are going to be presented, such as the methodological design and the methods that were followed.

Chapter 4

RESEARCH DESIGN & METHODS USED

4.I Chapter overview

The main focus of this chapter is firstly to present the rationale of how and why I conducted the study. What follows is the definition of the research aims and questions, as well as the development of the study's main idea and how it was transformed due to the ethical dilemmas that occurred. My position in relation to ontology and epistemology and how this led to a paradigm and a comparative case study is discussed, in order for the reader to acquire a sense of where I stand on the problem itself and how I tried to organise it methodologically, as well as how I tried to overcome any difficulties or obstacles arising. My views on the importance of theory are shared by Maxwell (2012, p.33-34), who wrote, that:

> "the function of this theory is to inform the rest of your design to help you to assess and refine your goals, develop realistic and relevant research questions, select appropriate methods, and identify potential validity threats to your conclusions. It also helps you justify your research".

Following that, clarification is also given regarding the sampling and the recruiting processes. Ethical concerns as well as details about the data gathering process, the materials used and the data analysis method I used, comprise three more points of the section. The chapter closes with a discussion of matters of reliability, credibility and trustworthiness.

4.II Aims of the study

The overall aim of the study is to examine and understand the commonalities and the differences in the RBs of children with VI and children with ASD, as well as the common and differing elements in the attitudes and reactions of caregivers and professionals towards such behaviours. RB is an issue already seen in the literature review that divides people involved with VI and ASD. These comparisons might afford knowledge that can be implemented into practice for the children's, families' and professionals' own benefit. Comparing data gathered from the groups does not seem an easy process. First and foremost, it is not easy to capture how a group interacts or overlaps. Nor is it easy to try to record and quantify how people feel and think about certain issues, as opposed to what they know or can do, especially when bearing in mind that even people's own perceptions of themselves change over time (Takala, 1999). Responses though are "indirect evidence, so it is necessary to ensure that these are a sound basis for inferring specific attitudes, opinions, perceptions or beliefs" (Black, 1999, p.215). However, as Black (1999) points out, all people are different and everyone is entitled to an opinion, so finding out what this opinion means is important. This is of great value, "simply because it is assumed that these attitudes will influence behaviour", as well as because "such discoveries might be the basis of further investigations of the nature of relationships" (Black, 1999, p.215).

4.III Justification of research approach

A qualitative approach was used for the research study, since I believe that as Castleberry and Nolen (2018) argue, qualitative research methods allow researchers to explore beliefs, values, and motives that explain the reason behaviours occur. The primary aim of qualitative research is to gain a better understanding of a phenomenon through the experiences of those "who have directly experienced [it]" (Castleberry and Nolen, 2018, p.807). In other words, qualitative methods are concerned with the interpretation of phenomena, regarding the meanings these phenomena have for the people experiencing them. The goal is to detect the "local experience" as Thomas (2017b, p.110) claims and this is what really does matter for the study in question; without aiming at generalisations or causation, without quantifying or counting things, as is usually the case in a quantitative study. I need to acknowledge, though, that I did draw on some quantitative terms (e.g., truth), as well as quantitative data (e.g., demographic information of the interviewees) I considered important for the better illustration of the study. This choice does not place my research within the category of quantitative or of mixed method studies, but it mitigates my qualitative approach.

"Qualitative researchers approach their studies with a certain paradigm or worldview (..) that guide their inquiries" (Creswell and Poth, 2017, p.74), through which the nature, the purpose and the thinking of the research is clarified. A paradigm[6] is a way of regarding and researching phenomena; it is a view of the world and of what counts as accepted (Cohen et al., 2018). This research study is based on the interpretative paradigm, as it is characterised by a concern for the individual, with the aim of understanding the subjective world of human experience (Cohen et al., 2018).

More specifically, the social world is seen as a social construction; the main aim is to analyse adult perceptions concerning RBs. The interpretation of these perceptions will be carried out through the collection of the adults' points of view and opinions. An interpretative paradigm takes the view that people might be different, yet the cause of a

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[6] From the Greek word «παράδειγμα» ('paradigma'), which means 'example'. It is based either on positivism or interpretivism. THOMAS, G. 2017b. *How to do your research project: A guide for students,* London, Sage.

behaviour lies in the past and focuses on action; namely, researchers set out to understand an individual's interpretations of the world that might have been influenced by experiences. Qualitative research may also be located in the critical paradigm, which focuses on criticism of an existing situation and offers possible suggestions for shifts (Denzin and Lincoln, 2005); however, this objective does not meet the purpose of this investigation.

Last but not least, the researcher's position is another important criterion regarding the methodology I wanted to follow. There is one more reason why the case study is the one that addresses "the 'how' or 'why' questions" (Yazan, 2015, p.135) concerning the subject of my interest. The researcher's obligation is to describe, understand, interpret and explain people's experiences, by identifying their meaning as viewed and understood by the participants (Cohen et al., 2018, Marshall and Rossman, 2014). There is an assumption in interpretative research made by Harraway (1988 cited in Schwartz-Shea and Yanow, 2013, p.111), according to which knowledge can be found in relations between people. This is called "situated knowledge" and exposes the researcher to multiple perspectives on the research questions she/ he is looking into. So, if this is taken for granted, then the researcher has a central role in the interpretation process. It is a position that represents subjectivity and Thomas (2017b) advises the researcher to accept it as it is. In other words, a researcher needs to recognise her/ his position inside a research process without feigning objectivity, but without losing thoroughness and balance either. This is called "positionality" and means that I needed to recognise my feelings and thoughts, likes and dislikes, preferences and predilections and recognise them all as important components which contribute to my study. Thomas (2017b, p.109) advises that the researcher's position might affect her/ his interpretation; thus, what she/ he would try is to act as a "participant". The value of the researcher's contribution is acknowledged in the context of interpretivism without, however, supplanting the participants' point of view. To be precise, it explores the participants' views and perceptions in the here and now, influenced by the researcher's worldview and dictated by the nature of the interaction between the researcher and the participants (Willig, 2013). In this case, reality is constructed by the participants involved in the research study (who usually provide evidence of different perspectives) and the researcher, since she/ he is the one who is going to interpret the data collected by the participants. With regards to the interpretivist side of my study, I would like to defend the fact that while quantitative data was used in the form of demographic information for example, as mentioned above, this was used to interpret the experiences of the individuals and not to generalise, as is done in positivist research.

4.IV Deciding on the methodology used

An initial phase of research design is to frame the study within the philosophical and theoretical perspectives that guide its design. Ontology and epistemology[7] are far from independent of each other; they lead into particular methodologies and together limit the appropriate methods for a research study (Braun and Clarke, 2013). The point is what kind of truth I am interested in hearing. There is no single theory that fits best with any inquiry. However, it is the researcher's responsibility to decide which lens to use or which blueprint to follow in order to build an argument, establish the context of the problem, and explain findings.

Ontology and epistemology are terms inextricably linked with methodology. Ontology defines a related theory that assists a researcher

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[7] Both terms end in 'ology', which stems from the Greek suffix «λογία» ('logia'), which denotes, among other things, 'speaking'. Ibid.

in acquainting themselves with the initial theory. In the case in question, the truth of the research is sought not only in what the participants have shared with the researcher, or in what the researcher has recorded in her research diary. The truth is a complex of social interactions that comprise interactions, connections, perceptions and expectations (Thomas, 2017b). The researcher has to make an effort and arrange the most appropriate procedures, in order to discover that truth (Thomas, 2017a). As has already been said, the truth is based on the interpretative paradigm by having the subjective world of human experience at its centre. Case study appears to comprise the most appropriate qualitative approach for the present research study (Clough and Nutbrown, 2012). The main reason is the one already mentioned above, in Chapter 3: namely, that a connection exists between the case study and the EST. In other words, there is a link between the theoretical framework (EST) of the study and the choice of the methodological framework, and one must inform the other. However, it requires a better focus, since "[when] aspiring researchers choose to use case study, what they usually come across is the multiplicity of approaches and a contested terrain marked by variety of perspectives" (Yazan, 2015, p.150).

The use of the case study in education research could be claimed to have been a reaction against the "quantitative bias in research in education (…) and the primacy of measurement" (Hamilton and Corbett-Whittier, 2012, p.5) as a means of collecting data. A case study might be applied to a person, a group, an institution, an event, a period of time, a country, a specific policy, a programme (Thomas, 2011) and as Bradshaw and Wallace (1991, p.155) assert, "case studies are not atheoretical". In this study then, I am focusing on two groups – one is of VI and another of ASD, both of them linked to caregivers and professionals connected to children with any of these two disabilities. So, each of these groups compounds a distinct case for the study.

Perhaps the most important way in which they contribute to general theory, is "by illuminating phenomena that challenge scholarly consensus on a particular issue". The case study approach cares about "a holistic view" (Denscombe, 2017, p.58) of what is going on in one specific social setting or more. This is what I am aiming for and this is the reason why I did not choose to undertake action research (its central aim is change and problem-solving), nor an ethnography (researcher becomes part of the situation she/ he is studying) or evaluation research (assesses how effective a programme or an intervention has been), an experiment (a test is done under controlled conditions) or a longitudinal/ cross-sectional study (which makes use of large numbers of participants, while a survey is used as the main method) (Thomas, 2017a, Thomas, 2017b).

Although case studies are sometimes considered less valuable because they cannot be easily generalised and theory-tested, as Thomas (2015) suggests, they are concerned with in-depth research, a detailed understanding of a phenomenon. The aim is rather "particularisation" than "generalisation" (Thomas, 2011, p.17); what is sought is the interpretation of a situation, rather than its general application to the wider population. Case studies are also commonly comprised of two parts: a subject (persons, place) and an object (analytical frame) that the subject explicates (Thomas, 2011) and which will be described in detail further on.

Case studies could be approached variously, depending on the researcher's intent concerning her/ his study. For example, during the 1980s and 1990s, Lawrence Stenhouse, Roger Yin, Saharan Merriam, Robert Stake and Andrew Pollard contributed by offering their own perspective on the matter. Stenhouse links the case study with anthropological and ethnographic research (Hamilton and Corbett-Whittier, 2012). Yin views it as a method and he identifies exploratory, descriptive and explanatory forms in it (Yin, 2012, Yin, 2017). Later on, Merriam describes particularistic, descriptive and heuristic types of case study and she was the first to introduce the interpretative case study, asserting that case studies must be based on the intention of the research (Hamilton and Corbett-Whittier, 2012, Yazan, 2015). Stake perceives researchers as interpreters, whose aim is to discover already constructed knowledge (Yazan, 2015) and Pollard uses the case study as a longitudinal strategy, trying to capture the nature of learning (Hamilton and Corbett-Whittier, 2012).

During the 20th century though, researchers mentioned by Bradshaw and Wallace (1991), such as Grimshaw (1973), Lieberson (1985), Smelser (1976) and Swanson (1971), debate the precise meaning and scope of the case study in relation to comparative research. With reference to the debate between case studies and comparative research, Bradshaw and Wallace (1991) and Thomas (2017b) argue that the case study constitutes an important type of comparative research; hence, it is a specific strategy used in certain circumstances, under the title of "comparative case study". These circumstances might be when the researchers' intention is to conduct a cross-national research or compare different and multiple cases, by explaining why particular things occur and how the main parts affect one another (Denscombe, 2014). Consequently, such a combination of a case study methodology and a comparative study methodology was chosen as the most appealing approach for the study in question that would help me to answer my research questions, for the reasons discussed below. I will also analyse the process I followed in order to achieve this kind of comparison(s) in section 4.VIII.

More specifically, what the case study truly aims at, apart from just describing what is happening in a social setting, is to focus on the explanation of the causes of the relationships within that setting, the exploration of the key issues affecting those in the social setting and the comparison of different groups in order to learn from the similarities and differences emerging from that comparison. I tried to present a multiple case study (perceptions regarding RBs exhibited by children with VI in comparison with perceptions concerning RBs manifesting in children with ASD), trying to place the emphasis more on the differences than on the similarities between the two case studies, exactly as Schwandt (2014), Thomas (2011) and (Yin, 2017) suggest. Comparison seems important, because it can shed light on perceptions of people connected to two different disabilities, something that has never been done before, neither in Greece, nor worldwide. The comparison already mentioned is general, and within it more comparisons (case studies) take place. For example, the first group is composed of caregivers and professionals of children with VI, and is compared with the second group that is composed of caregivers and professionals of children on the AS. Comparisons are expected to be made between caregivers and professionals or even among members of the same group (e.g., mothers and fathers, participants and others with or without VI, speech and language therapists, psychologists and musicians). It might be interesting to discover whether the participants' responses might differ from each other; whether the RBs might be seen differently from a VI point of view or an ASD one; whether the perceptions of people define the RBs or the RBs define the individuals' perceptions and, if this is the case, then how this affects children, their families, practitioners, and society.

Having chosen a comparative case study, as a researcher I still needed to generate rich descriptions of people's lived experiences of the world by understanding these experiences. I needed, however, to do it comparatively, as I was aware of the fact that the researcher might have preconceptions about a topic but must attempt to reflect on them and bracket them off.

Overall, methodology follows a specific approach to the inquiry. It is a way of acting, thinking, and speaking "that occupies a middle ground between discussions of method and discussions of issues in the philosophy of social science" (Schwandt, 2014, p.161). Methodology helps the researcher to frame an issue that could be investigated under a particular procedure; it is a kind of assistance for her/ him, so as to develop a sensible link: "problem-data-generation-analysis-argument" (Schwandt, 2014, p.161). Methodology and methods "display a synergetic relationship" (Schwandt, 2014, p.162), since methods are employed within a specific methodology.

Figure 3 outlines the main points of what has already been mentioned in relation to the theoretical framework of my research design and the research design itself. The same figure also makes mention of the ethos employed for the collection of the research data, in a way which will be described further down in 4.VII.

Figure 3: Theoretical framework of the study, research design and the tools used

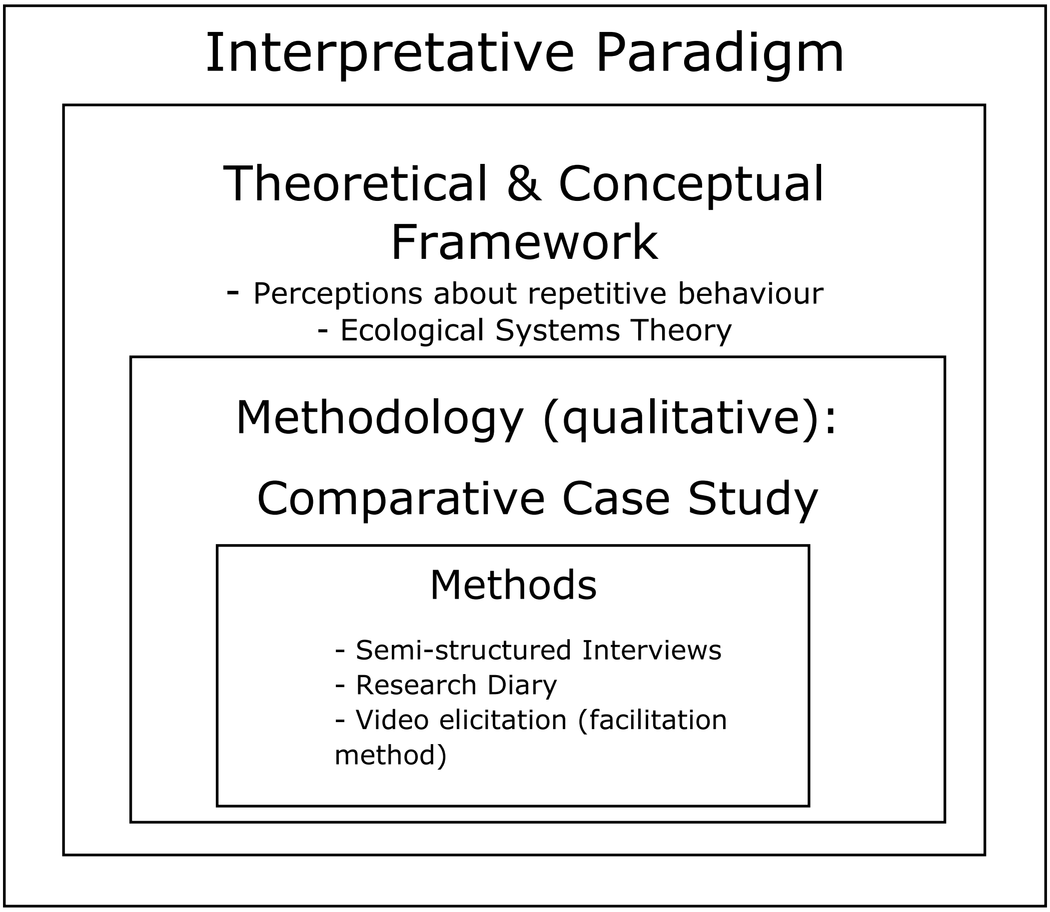

Figure 3 outlines the main points of the theoretical and conceptual framework of my research design and the research design itself. The same figure also makes mention of the tools employed for the collection of the research data. More specifically, these are four rectangles, each one inside a larger one. The largest one highlights the interpretative paradigm identity of the study. The next one shows the conceptual and theoretical framework of the study, which refers to the perceptions about RB and to the EST that the study is based on. The one inside of it represents the type of qualitative methodology that is followed and that this is the comparative case study. In the last and smallest rectangle, the one about the methods used, semi-structured interviews, video elicitation and research diary are listed.

4.V Sampling and access process

The reason I initially wanted to recruit participants from all over Greece was twofold. It was because my research interest – and therefore part of my research questions – was a result of my journey as a practitioner in my mother country, Greece. Another reason was the fact that as a Greek, I would be able to identify and analyse participant perceptions in a more meaningful way and in a way that could be used to make sense of the results of a qualitative research. However, the participants I finally recruited were from Athens for practical reasons, since I could not afford to travel all around the country. Thus, I initially got in touch with the Headteachers of the two "Special Schools for the Blind"[8] in Athens (Pre-Primary and Primary), as well as with the contact person of the "Panhellenic Association of Parents, Guardians and Friends

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[8] As already mentioned in "On the chosen terminology and abbreviations" section, the official denominations of the Associations and Schools are extracted from the English version of their official websites.

of Visually Impaired People with Additional Disabilities"[9], who agreed to give me access to their Organisations for the purposes of my research. At the same time, I contacted the Headteachers of the three "Special Schools for the Autistics"[10] in Athens (Pre-Primary and Primary), only one of whom responded to my request. The participants therefore, were recruited from the following four Schools/ Associations:

1. The "Special Pre-Primary School for the Blind" in Athens
2. The "Special Primary School for the Blind" in Athens
3. The "Panhellenic Association of Parents, Guardians and Friends of Visually Impaired People with Additional Disabilities: AMIMONI" in Athens
4. The "Special Primary School for the Autistic" of Piraeus[11]

In terms of participant numbers, there are some interesting points mentioned by Saunders and Townsend (2016) and Baker and Edwards (2012), who argue that the number of participants depends on the balance between representativeness and quality of responses, in order to enable solid understanding of the cases. Marshall et al. (2013) suggest 15-20 participants for case-study strategies, whereas Kuzel (1992) notes that for homogeneous populations 6-12 participants should be enough, while for heterogeneous groups 12-20 participants are likely to be needed. There is, however, also a more recent debate, according to Sim et al. (2018), whose overall conclusion is that the sample has to be determined a priori of the qualitative research study. More precisely, Sim et al. (2018) advise four general approaches towards determining qualitative sample size: 1. "rules of thumb", based upon a combination of methodological considerations and past experience of similar studies; 2. "conceptual models", focused on specific characteristics (e.g., aim, theoretical frame,

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[9] ditto

[10] ditto

[11] Piraeus is a port city located in Athens.

analysis intended) of the study; 3. “numerical guidelines” derived from empirical investigation and 4. “statistical formulae”, based on the probability of obtaining a sufficient sample size. The second approach regards the use of “shadowed data” (Morse, 2000), or, in other words, when using semi-structured interviews, the participants talk about their own experience and/ or discuss the experience of others, with the purpose of enabling the researcher to collect data about perceptions and perspectives. For this type of research and in order to obtain the richness of data required for qualitative analysis, one needs at least 30 to 60 participants according to Morse (2000). As a matter of fact, then, I conducted 35 interviews and this was not purely because of practical issues, but because of the suggestion of Morse (2000) as well.

To be more specific, I intended to recruit people both from schools (organised by professionals) and from associations (organised by parents), thinking that different types of perceptions will be reflected in each of those settings, but also in order to underline through this choice the value of professionals and caregivers in educating a child with VI or with ASD. I looked at children with VI and with ASD, through the lens of their caregivers and professionals. I chose these students on the AS or with VI, because they present very common behaviours that are characterised by repetitiveness, under very specific circumstances that are described throughout the analysis. I chose to interview caregivers and professionals, since the former are the people most directly involved in a child’s upbringing, and the latter the first (generally based on the type of professional) who a caregiver would refer to when they first find out about their child’s diagnosis. Even if this is not the first practitioner to be approached by a family with a child with either VI or ASD, the process by which the child will be evaluated by an interdisciplinary team is common, whether it is a public or a private body that carries out the evaluation. In Greece, interdisciplinary teams always consist of a developmentalist, a psychiatrist or psychologist, a special educator, a speech and language therapist, an occupational therapist, a physiotherapist, a school nurse, a musician, a physical education teacher, a foreign language teacher in the case of children with VI, as well as an orientation and mobility instructor. In this case, I turned exclusively to educational institutions recognised by the state, to which the caregivers of a child are initially typically referred for her/ his special education in case of visual disability or that of autism.

Whether talking about VI or ASD, the selection of caregivers and professionals was also made because the approach and intervention strategies of both groups are considered very important and crucial for the psychological, behavioural and pedagogical impact they may have on their children and students (Boucher, 2017, Webster and Roe, 1998). Moreover, even if it seems challenging, collaboration between professionals and parents is an expectation (Morrow and Malin, 2004, Webster and Roe, 1998) that, when it becomes a reality, might impact positively even on governmental decisions regarding matters connected to VI and ASD (Morrow and Malin, 2004).

The inclusion of my research diary allowed me to take into account the notes I had from the daily interaction I had as a practitioner with the families of my students. These families could be foster families *(2/ 12/ 2017 - I so admire this family! Both parents with VI, they decide to adopt VP, also with VI. As for the RB that concerns me, the mother recently told me that from the moment the child permanently joined the household, they have almost disappeared.)*, so this was a reason I decided to refer to ‘parents’ as ‘caregivers’; because, according to my experience in Greek special education, it is not unusual to encounter adopted children or foster children in special schools/ associations. Regarding the group of the professionals, in terms of representation, I was aiming for the individuals taking part to be accredited practitioners from different professional areas that one could come across in a setting for children either with VI or with

ASD (e.g., special educators, psychologists, musicians, speech and language therapists, social workers). Finally, the individuals who were invited to participate were chosen according to the child who they were educating and their own availability. However, as can be seen from the demographics that follow, they came from various professional backgrounds.

I tried to recruit a certain number of caregivers and professionals targeting 40 persons (20+20) in total, by sending an equal number of email invitations ("Consent Forms" – *Appendix 1 & 2* and "Information Sheets" – *Appendix 3 & 4*) to the headteachers/ people in charge[12] of the Schools/ Association I had chosen. Every document attached to the email invitations (consent forms, information sheets, and post-interview form) was translated into Greek and transcribed by me into the Braille system for the benefit of the participants with VI. The headteachers/ people in charge then addressed these documents to the caregivers/ professionals whose child/ student fell into the age bands of 4-13 years of age, using class registers in alphabetical order. It should be clarified that in Greece students with disabilities have the right to attend special pre-primary and special primary school for two more years than children with no disability; namely from the age of 4 and until their 7th year and from the age of 6 (or 7), until their 11th (or 13th) year respectively. Practical reasons, therefore, lead me to focus on these groups of children. Another reason was that as a special educator and educational psychologist of primary and pre-primary education, it would be more interesting and familiar to me to be scientifically engaged with a field to which I had been devoted educationally and clinically for many years.

If any of them did want to take part in the research, then more consent forms/ information sheets had to be sent on my behalf. If a

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[12] AMIMONI's contact persons were the psychologist and the social worker of the Association.

caregiver declined to give me her/ his consent in order to approach a professional and have a chat about her/ his child, then I would not recruit that professional at all. If a professional did not want to participate in the research study, then I would use the data from the caregiver linked to the same child and vice versa. Their participation was voluntary and they were free to withdraw at any time within two months from the completion of all interviews without giving any reason. In cases of withdrawal, any related data provided by such participants would not be taken into consideration and would be destroyed. However, there was no such case of withdrawal to report.

Therefore, the type of sampling that was used was “purposeful” (Koerber and McMichael, 2008, p.464), since, as discussed, the sampling criteria were specific and had been developed in advance of the study (Giacomini et al., 2000). This is a type of sampling which researchers in Greece seldom have the chance of selecting in advance. My professional experience told me that some caregivers of the children with VI would also have VI themselves. Therefore, I considered this throughout my planning, reporting and accessibility process I followed. Professionals needed to have a specialised degree qualification in special education, yet caregivers and professionals would be interviewed regarding one specific child: their own child/ student.

More specifically, participants could be grouped into the following research groups:

1. Caregivers of young children with VI.
2. Caregivers of young children on the AS.
3. Professionals for young children with VI.
4. Professionals for young children with ASD.

The children with whom all of the participants were connected could be grouped into age bands (4 to 6, 7 to 10 and 11 to 13). Among the age bands, ‘extremes’ or ‘extreme points’ could be detected, in terms of the age range and of age bands, which I had to examine; in other words, I interviewed caregivers/ professionals of children who were 4 years old and 13 years old, 5 years old and 12 years old, 6 years old and 11 years old, etc. This was important from a methodological point of view, since analysis of continuous factors sometimes proceeds by selecting individuals on the basis of “extreme scores out of a sample distribution” (Preacher et al., 2005, p.178) and submitting only those extreme scores to further analysis. This is exactly what the Extreme Group Approach (EGA) suggests (Preacher et al., 2005), from which the use of my ‘extremes’ was inspired, without, however, being entirely based on. To be more precise, the EGA approach inspired me in the sense of selecting extreme ends of age in terms of the members of my research groups.

Professionals were recognised by the Schools and Association in Athens/ Greece that are listed above. They could come from any rehabilitation field (e.g., special education, speech and language therapy, psychology), provided, however, that they had some type of specialisation in special education (e.g., PhD, Postgraduate, Undergraduate, specialisation courses). All of the study’s participants lived in Greece, but some were originally from other countries. In the latter case, a translator for the participants’ native language was available outside the venue where the interview took place, in case translation was needed. In none of the cases did this prove necessary, so no ethical concerns were raised. The interviews took place outside school hours, either at the participants’ homes, or at the schools attended by the children. In the few cases (one caregiver and two professionals) where a meeting with a participant was difficult to arrange, online interviews (video calls that enabled sharing of the video/ toy elicitation tool) were attempted instead. In this way, the advantage for the researcher was that a distance was kept from the interviewees, allowing the latter to express themselves more comfortably

(Iacono et al., 2016). However, the same distance between the interviewer and the interviewee could be a limiting factor in terms of achieving familiarisation between the two (Adhabi and Anozie, 2017, Opdenakker, 2006). Rather than not include them at all in the interview process, I decided to conduct these three interviews, being aware of the risk of the two limitations mentioned above. At this point I would like to note that, in the cases of these three interviewees, the second adult who comprised the 'virtual' pair who spoke about the same child, did exist. That meant that it was feasible to compare data, as well as to draw themes that were as valid as possible.

The sample was accessible thanks to my professional network. I had worked for fifteen years as a special educator and an educational psychologist in the public and the private sector in Athens/ Greece and I had been headteacher of special schools for about six years. Thus, there was no expected difficulty in accessing the Institutions listed above by approaching the headteachers of the schools. It has to be mentioned, though, that for the last approximately four years I have been living in the United Kingdom, so I did not have any professional relationships with the families/ caregivers who were interviewed.

Overall, I tried to follow what Boyatzis (1998) and Langdridge (2007) suggest, namely to seek out different people with approximately common experience, who, however, varied on a variety of demographic characteristics, as seen in *Table 3* and briefly described below.

This is a table originally constructed using an Excel spreadsheet. I transferred all the information of the table onto a table made in a Word document, so as for it to be more easily readable for a screen reader. The table has three columns, split into more columns corresponding to the caregivers (17 columns plus one for the total number) or the professionals (18 plus one for the total number) taking part, and 35 rows. The columns correspond to each of the interviews that were conducted and specifically offer information as to the caregivers and professionals; in other words, the adults. The rows correspond to the disability, age of the child, level of the child's sight, level of the adult's sight, working experience in special education (in years), experience with VI, ASD, or other, working with the child in question (in years). The purpose is to present the demographics of those participating in the research, to understand their individual circumstances and how these may have influenced their perceptions.

The total number of participants was 35, 18 involved with VI disability and 17 with ASD disability. With regard to caregivers, 8 out of 17 people had a child with VI, while the remaining 9 out of 17 a child with ASD. Regarding the professionals, however, 10 out of 18 worked with students with VI and the other 8 with students on the AS. The participants' interviews concerned children whose ages ranged between 4 and 13 years. More specifically, there were 11 children of the ages of 4-5years, 13 children of 7-10 years and 11 children of 11-13years of age. All children with ASD were sighted, while individuals with either total vision loss (5) or with partial sight (13) were included in the children with VI group, as has also already been noted. I should clarify then, that according to their official diagnosis, none of the children on the AS that I am discussing had additional disabilities. The same applies to half the number of the children with VI. This classification corresponds to their official diagnosis; practically, though, and as all the professionals and the caregivers of the children with partial sight argued, their functional sight was so low that they consider them as blind. As for the adults' sight, all were sighted apart from 2 (both caregivers of children with VI) who were blind – still be considered as having VI too.

In *Table 3*, demographic details are also presented for the professionals (in both the disabilities in question). It was important to highlight the experience these people had had at the time of our interview, the years of their experience and the time working with the child whom we discussed in their interviews. In the first case, the professionals’ experience in special education was from 1 year to over 15 years. More precisely, 4 persons had already been working in special education for 1-4 years, two people for 5-9 years, 5 individuals for 10-14 years and 7 professionals for more than 15 years. There was, therefore considerable variety in the sample, in terms of their interaction both with children with VI (13) and children with ASD (17), or with both. Finally, concerning how long they had been acquainted with the student regarding whom they spoke, for most of them (10) it ranged from 1 to 4 years, while there were only 1 for whom it ranged between 5 and 9 years, 5 for whom it was less than 1 year and 2 who reported more than 10 years.

Table 3: Demographic information of the participants and the corresponding children

	CAREGIVERS																	Total	PROFESSIONALS																		Total	TOTAL ADULTS
DISABILITY																																						
VI	1			1	1	1	1	1	1	1								**8**		1	1	1	1	1	1	1	1	1						1			**10**	**18**
ASD		1	1								1	1	1	1	1	1	1	**9**	1									1	1	1	1	1		1	1	**8**	**17**
AGE OF CHILD																																						
4 to 6					1				1	1				1			1	**5**		1	1								1	1			1	1			**6**	**11**
7 to 10	1			1		1	1	1				1						**6**				1	1	1	1	1	1	1									**7**	**13**
11 to 13		1	1								1		1		1	1		**6**	1												1	1			1	1	**5**	**11**
LEVEL OF CHILD'S SIGHT																																						
sighted		1	1								1	1	1	1	1	1	1	**9**	1									1	1	1	1	1		1	1	**8**	**17**
partially sighted				1	1			1	1	1								**5**		1	1		1	1		1	1	1						1			**8**	**13**
blind	1					1	1											**3**				1			1												**2**	**5**
LEVEL OF ADULT'S SIGHT																																						
sighted	1	1	1	1	1	1		1	1		1	1	1	1	1	1	1	**15**	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	**18**	**33**
with VI							1			1								**2**																			**0**	**2**
WORKING IN SPECIAL EDUCATION (in years)																																						
1 to 4																					1		1					1						1			**4**	**4**
5 to 9																			1			1															**2**	**2**
10 to 14																				1						1			1	1			1				**5**	**5**
>15																								1	1		1				1	1			1	1	**7**	**7**
EXPERIENCE																																						
VI																			1	1	1	1	1	1	1	1	1	1						1	1	1	**13**	**13**
ASD																			1	1	1	1	1	1	1	1	1	1	1	1	1	1	1		1	1	**17**	**17**
other																			1	1	1	1	1	1	1	1	1	1	1	1	1	1	1		1	1	**17**	**17**
WORKING WITH THE CHILD (in years)																																						
<1																						1	1		1				1	1							**5**	**5**
1 to 4																			1	1	1			1		1	1	1				1	1	1			**10**	**10**
5 to 9																																				1	**1**	**1**
>10																															1				1		**2**	**2**

4.V.i Characteristics of the sample: When a child is officially diagnosed in Greece

The study focuses on VI and ASD, and therefore, part of the recruitment process was the condition that the official diagnosis of the children about whom the participants would be speaking was VI or ASD.

Hence, it is helpful to provide some contextual information about how VI and ASD conditions are identified in Greece, as that has an impact on what the participants think about RBs.

In order to attend a Greek special school, children with disabilities must be classified according to specific diagnostic tools by an official and state organisation. For children with VI, a special team has been created by the Greek Ministry of Education and Religious Affairs, which specialises in visual disability and which works for the Differential Diagnosis and Support for Special Educational Needs Centre (KEDDY)[13]. A developmental paediatrician or an ophthalmologist could also provide the family with a diagnosis and a referral for attending a specialised school; however, this is rare because few people have specialised in VI in Greece. Children are often classified according to the ICF (World Health Organisation, 2007) criteria. The Teller Cards Test and Lea Symbols are used by many specialists, since they were designed for the assessment of visual acuity and contrast sensitivity in children, including even newborns (Elgohary et al., 2017, Repka, 2002, Zimmermann et al., 2015). LogMar is also used for young children; it actually refers to the logarithm of the minimum angle of resolution and should not be confused with the Snellen scores used previously in some European countries, where a 6/60 Snellen value was equivalent to an acuity of 0.1 (Oluonye and Sargent, 2018). Doubtlessly, though, there is generally further difficulty in the classification of vision levels for children, which cannot be achieved for the very young ones (Oluonye and Sargent, 2018).

It is noteworthy to acknowledge that none of the children had an official CVI diagnosis but still, some of them in the sample may have undiagnosed CVI. This could be due to the fact that CVI is not officially

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[13] The service has since been renamed.

recognised in Greece. However, it is important to bear this in mind when reading the thesis.

As for children with ASD, the "Diagnostic and Statistical Manual of Mental Disorders, DSM-V" (American Psychiatric Association, 2013) is used by the scientific team of either a Differential Diagnosis and Support for Special Educational Needs Centre (KEDDY) or the psychiatrist or developmental paediatrician of a public Children's Medical-Educational Centre. It is important to mention that in Greece, a child with a disability is admitted to a public special school only if she/ he has been evaluated by one of the Organisations mentioned above.

Regardless of the official diagnostic process, it is important to clarify when it is that an individual either with VI or with ASD is considered to require the intervention of a specialist in Greece, due to her/ his disability. The concept of what constitutes VI in childhood has changed over the years, in the sense that total vision loss is observed more frequently as an accompanying characteristic in multiple disabilities (Hayton et al., 2019, Hayton et al., 2020, Hayton, 2017) and not as isolated VI (Flanagan et al., 2003). In Greece, what constitutes VI in childhood is defined both by Law and by the Ministry of Education and Religious Affairs and it is important that this is clarified, before any mention to research linking VI and RBs is made. According to Greek Law: "blind is any person entirely deprived of the perception of light or whose visual acuity is less than 1/20 of what is considered normal" (Law 958/ Gov. Gazette 191/ issue A/ 14-8-1979, article).

Nevertheless, as students exist who are legally considered to be blind, but are taught using the reading and writing systems for the people who are not, educators have adopted the following educational definitions, in order to have a reference point which will facilitate communication when VI-student-related educational issues occur:

i) Those individuals who, due to sight issues and following the best possible medical intervention need to be taught using the Braille system or auditory methods, are considered blind.

ii) Individuals who, following the best possible medical intervention can read texts in large fonts or with the aid of magnifying instruments and devices are considered partially-sighted.

With regard to the ASD, the process is much clearer, since the child should be assessed either in the public or the private sector by a (child) psychiatrist or a (child) psychologist. The practitioner should use the ICD-10 criteria or the DSM-V criteria for the diagnosis.

4.VI The pilot study

Before embarking on the interview process, I carried out pilot interviews with four adults, with the purpose of assessing the usefulness of a particular research tool, such as my interview schedule (Van Teijlingen and Hundley, 2001). I reached out to a caregiver of a child with ASD, and another one of a child with VI, as well as to two professionals who work or have in the past worked with children with VI and ASD. Conducting a pilot study does not guarantee success in the main study, yet it does increase the likelihood; this is the reason why pilot interviews are considered as a crucial element of a good study design (Janghorban et al., 2014, Kim, 2011, Malmqvist et al., 2019). In this case, I conducted four pilot interviews: one with a caregiver of a child with ASD and another with a caregiver of a child with VI using the pre-designed interview schedule. I also carried out two pilot interviews with two professionals, one of whom works with children on the AS and another who works with students with multiple disabilities. Based on the information I obtained, I could in theory answer my research questions, which confirmed the accuracy of the questions of the interview schedule. My pilot interviews provided valuable insights, in the sense that they confirmed the functionality of my questions, as well as that of the video/ toy as an elicitation tool. Three of the participants made use of a video, while one used the toy. The use of both seemed to be beneficial, in that it facilitated conversation. No need arose to carry out significant changes, other than in relation to my intention to discuss the video/ toy at length. During the interview process the participants automatically used the video as a means to think and discuss about the topic without needing prompting. Therefore, I finalised my research questions following the pilot interviews I undertook and after thoroughly studying the literature. In the first case, the interviewees' answers led me to the way in which I needed to express the research questions so as to receive adequate answers. In the second case, it was a matter of consistency towards the gap in the literature that I had detected.

4.VII Ethical considerations

The current study was approved through the University of Birmingham's Ethical Review Process. As Thomas (2011, p.543) argues, ethical issues are central throughout a research study, in the sense that they "move beyond institutional requirements of privacy, confidentiality and informed consent". Therefore, I had already taken provision so that the processes employed would protect participants, as well as myself, for the entire duration of the collection and analysis of the data. As a result, I personally had to hold both an English and a Greek Disclosure and Barring Service check, in accordance with the "Home Office, 2017" legislation.

Moreover, potential participants had been informed about the research study through the school they were connected with. They had been introduced to the study via an information sheet. Subsequently, a consent form was given to participants who were willing to take part in the study, to be signed prior to conducting the interview. After the completion of each interview, a "Post-Interview Form" *(Appendix 5)* was given to the interviewees as well. The post interview form was a follow-up letter given after an interview, whose aim was to thank the participants for their participation and to give them some final guidelines regarding the research (e.g., until when they could withdraw, how they could request to be informed about the final conclusions of the research)[14]. Upon completion of the research study, a copy of the summarised findings was made available and was provided to the participants, at their request. It had to be made clear that the report would summarise findings across all participants and there would be no specific mention of the participants' children/ students, while all personal data would be anonymised.

Further on the topic of accessibility that I raised in the introductory section (i.e., Accessibility) of the research study, I need to note that I provided all the enclosed forms in the Braille system and in the form of audio description for any participants with visual disabilities. Furthermore, following the submission of this thesis and my viva, I will personally carry out the necessary actions to ensure that it becomes available as a copy accessible to all (i.e., transcribed into Braille and in audio format).

Taking part in the study was voluntary. Each participant could choose not to take part or subsequently withdraw during the interview or at any time within two months after the completion of all the interviews and without providing a reason. Everyone was informed of her/ his right to withdraw from the project through the "Information Sheet", available to

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[14] All the documents mentioned above are available in the *Appendices*.

both caregivers and professionals. Caregivers were informed that this procedure would not have any effect on the work the school was doing with their children. For those participants who might like to withdraw from the study, there were no consequences. It should be noted that a possible withdrawal of a caregiver would affect the use of data provided by the professional (for the same child) but not vice versa. There was no such incident of withdrawal. However, there were two cases where a caregiver and a professional did not agree to talk about their child/ student respectively, while the other person in the pair did. In both cases the data of one participant was used, while in the case of the professional, the consent of the caregiver was first sought, in order to use the information.

The names of the participants were stored in the form of their initials, so that they could be contacted for the research. All data was stored on the University's secure data store server for 10 years. Only I, as lead investigator, and the supervisors had access to the files of the digital voice recorder. Specific quotes were used for research purposes under absolute anonymity. No details or descriptions of the subjects that would render it possible for the adult participants or the children to be identified were used or published. It will be worth mentioning that where names for the children are used (in Chapter 5), these are fictitious names or, in other words, pseudonyms and not the real names of the children in question. No paper copies of any documentation except the research diary (which does not mention individuals identifiably) were kept after a brief period. Therefore, all the documents were scanned and securely stored.

All interviews were organised within the school venue (after school hours), or alternatively at the participants' homes. In the latter case, I always ensured my personal safety by informing another professional about the venue and timing of the interview prior to every interview. A similar procedure was followed if the interview was taking place at the school, by informing the headteacher.

There was a possibility that caregivers would become very upset or emotional during or after the interview. In that case, I could address this situation by arranging a follow-up meeting with the school's psychologist/ social worker, myself and the participant, and ideally at the school. For the same reason, I had contacted the psychologists/ social workers of the schools (every Greek public special school has at least one psychologist and one social worker) beforehand, asking them to give their full agreement in advance that they are willing to support caregivers, if required. However, no such reason for concern occurred in practice.

In this study, the only person responsible for the data collection was me, the doctoral researcher. The data was collected via interviews and a personal research diary and was not shared with third parties (individuals or organisations). The records of this study have been kept strictly confidential.

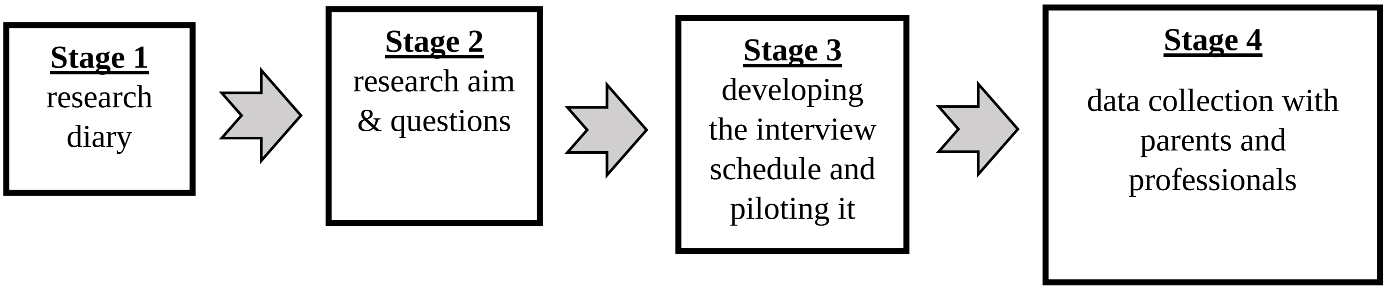
Aside from the Ethical Review Process in the United Kingdom, I was obliged to carry out a similar procedure in Greece, by contacting the appropriate department of the Ministry of Education and Religious Affairs. After submitting a detailed report regarding the purpose and procedure of my research in both Greek and English, the report was considered and a decision was issued concerning my permission to enter the aforementioned Schools, so as to recruit participants.

4.VIII Data gathering, tools used and procedure employed

As Yin (2017) states, to explore, describe or explain events, someone would have collected and used qualitative data and an ideal way to do so is by using a case study or a cross-case analysis as Schwandt

(2014) asserts, discussing the same methodology. Case studies are limited by time to the scene where a researcher collects information over a finite period of time (Creswell et al., 2003). It has been argued at the beginning of the chapter that comparative case studies (like any other form of case-study) gather data from multiple sources of information rich in context (such as interviews and diaries), as was exactly the case in the present study, concerning a social situation in different settings, about which it is appropriate that the researcher has inside information, so that they can make in-depth comparisons (Thomas, 2017b). Actually, to gather the information needed, a very specific methodological staging (as is shown in *Figure 4* below) was followed. The methodological staging is depicted via a sequence of four stages, where arrows lead from one stage to the other as follows. More specifically, two qualitative method tools were used and these were a research diary that finalised the aim of the research and structured the research questions and semi-structured interviews or the interview guide approach as described by Patton (2002), along with video-elicitation, as part of the interview process.

Figure 4: Methodological staging



The research diary is a primary method of gathering data (Braun and Clarke, 2013). It can be used as "contextual information" in the sense encountered in the work of Somekh and Lewin (2005) and as "memos" (records regarding gestures, facial expressions, style of talking and acting) like the ones in that of Strauss (1987). The use of research diary in this study was to record thoughts, feelings, actions, daily experiences and difficulties, as seen from the below extracts: *17 /11/2008 - Autism and blindness in a single diagnosis. Overdiagnosis or reality? The school counsellor said that based on his "main" disability the child must be enrolled in the corresponding school for children with VI or with ASD. OK. And how does one define "main disability"? He said it's the one that is the most impeding for the individual. I do not understand. 11/6/2016 - VH's mum left the parents' meeting crying. She stresses over the little one's stereotypies and how she will manage at Primary School. I think we need to schedule some extra visits to the school with the child, to make her acclimatisation smoother, but also to give warning to the new students and the school themselves. 29 /8/ 2005 - BD (diagnosis: pervasive developmental disorder) flapped his arms a lot today and suddenly banged his head against the wall. He had to have stitches and was given melatonin. The mother kept her calm and was supportive. I am thinking of creating some head-protection or we might start playing the keyboard again, which he likes. 7/ 1/ 2013 - YS (diagnosis: VI) smells everything before touching it or eating it or playing with it in the morning. I think he is afraid because of his experience with cancer and being hospitalised. In the evenings at the practice, I observe EY (diagnosis: autism) who also smells everything because she claims "she likes it". 2/ 2/ 2010 - Today was tough. So much violence in class. AG (diagnosis: autism) attacked all the other children, as well as me. Bites, pinches and kicks. I am genuinely upset and it makes me feel angry but also stubborn. I mean to ask for a team meeting. We need to commonly agree on a joint behaviour towards him. In such cases we are obliged to be firm and resolute.* These notes were about observations I had made in the classroom and during routines, and which I have been regularly keeping and using as a space for work, during all the years I have been working in special education, starting at the beginning of my first postgraduate degree. It has functioned as an effective formative experience that has changed my way of thinking, since it has enabled me to observe every aspect of my students’ actions and reactions throughout lessons. Given the fact that it is difficult for somebody to observe her/ his own self as an external observer, the research diary seems to be a really helpful tool. Using a diary and through the notes made, the writer can observe herself/ himself at a later time and reach conclusions as to the subject she/ he is looking into. Thus, in that manner and in the situation in question, I stopped myself from counting RBs and I started trying to interpret those types of behaviours in relation to the environment in which they occurred (e.g., other professionals, students).

For this study, the diary was a tool supporting my methodology and I used it because it provided me with a rationale as well as formal observations to help me reflect on my analysis. I consider this as an important point in my study, since it helped me to determine my role and position as a researcher and as part of a society. My written views, thoughts and emotions were part of my data analysis and assisted me in setting my limitations as a researcher. More precisely, I used the data gathered in the research diary so as to extract themes and categories for the analysis, in a similar way as with the data gathered from the interviews. In the same way, the information collected and memos made were data that basically helped me to design my research questions. This process was informative for me in the sense that it provided a reference point for when my thoughts changed and matured during the PhD research journey. It allowed me to trace the development of my research skills, as well as provided me with a space where I could reflect on my research. On a practical level, I decided to include part of the quotes I have used, in order to form categories, subcategories and by extension themes, in the context of the data analysis. As has already been mentioned, the aim was increasing credibility and trustworthiness through the transparency of the research methodology. The volume of quotes recorded via NVivo was substantial. For this reason, I tried to include around 10% of the quotes in each category; quotes that were selected at random as a sample (additional quotes from my research diary are provided in *Appendix 9)*.

Furthermore, in some cases (e.g., sensory stimuli) I referred to the data of my research diary, in order to give specific and more explicit answers to my research questions. Finally, my research diary had been used as a reference as well, in order to strengthen part of my justifications (e.g., caregivers' difficulty in discussing their educational progress of their child with a disability).

Apart from the research diary, interviews along with elicitation tools were chosen to be used. Interviewing is a particularly important method for collecting data in "present life" (Van Manen, 2016b, p.73). Maybe that is the reason why interviews are mainly described as the most efficient qualitative tool for understanding the meanings that participants attach to their own experiences. More precisely, semi-structured interviews offer the freedom to follow-up issues as necessary. They also provide the interviewer with the opportunity to engage with the participants individually, as she/ he is able to converse with them and ask them for clarifications (Scott and Usher, 2010). In the present case, the interview structure was provided through an "Interview Schedule" *(Appendix 6)*, namely a list of issues that needed to be covered (Thomas, 2011), in the form of questions connected to the research questions. When planning the interview schedule, each category of questions was linked with one of the research questions, so as to make it easier for me to analyse. There were three groups of questions. The first group was associated with the first research question and the general queries of 'what?' and 'when?': What are the RBs that caregivers and professionals observe in children with VI and children on the AS? What is the terminology they attach to them?

When exactly do they observe these behaviours? What is the adults' reaction when a child displays an RB? The second group of questions was linked to the second research question and the general query of 'why?': What explanations do caregivers and professionals attribute to RBs? How do they interpret them? What are the causes? As for the third group of questions, this concerned the third research question, the 'how' query: How might an RB impact on the child, the caregiver, the professional, the family? Are there any challenges? At this point, it has to be clear that these questions above relate to the kind of information I was trying to elicit and they were not the actual questions I asked the interviewees. Even though a semi-structured interview was used, I thought it necessary to have some "Interview Questions" *(Appendix 7)* as a core, at which I arrived after conducting four pilot interviews. In that way it could be confirmed whether or not the questions affect the content of the interviewees' answers, as well as whether I could extract information for the already designed research questions.

More specifically, the interview comprised four parts. Each time I started by outlining the interview plan. Then, the interviewee and I watched a video (no more than 10 minutes) revealing the RB of the child. In the case of face-to-face interviews, the video was watched on the participant's personal device (mobile phone, tablet, laptop). In the case of online interviews, the videos were watched via the interviewee's shared screen. In other words, it was a video that belonged to the participants, a video that was not sent to the researcher before the interview for ethical reasons. The reasons I ended up thinking and coming up with the use of a video (or a toy that will be mentioned later on) were multiple. Initially, the video was used as a useful introduction, an elicitation tool, prompting a discussion (Bugos et al., 2014) on the RB of the child and the reactions/ attitude of the caregiver/ professional. After all, as Barton (2015) advises, elicitation techniques are research tasks that use visual, verbal, or written stimuli, with the aim of encouraging the participants of a study to discuss their ideas. Especially when trying to explore topics that might be difficult/ sensitive to talk about, the use of elicitation tools would be useful. The actual cause, however, for which I chose to rely on an elicitation technique was that I wanted to be as sure as I could, concerning what the interviewees thought an RB is and how it is expressed. Their video choice could reflect their associated thoughts, beliefs and emotions (Henry and Fetters, 2012, Sandhu et al., 2013). It was not so much the content of the video, but what meaning they attached to the chosen video (Liebenberg et al., 2014).

This video would have been recorded by the caregiver /professional earlier. Specifically, participants had been asked beforehand: "Could you kindly bring to the interview a video of your child/ student displaying any kind of repetitive movements/ presenting an RB? This video may be recent or not". It has to be mentioned that in Greece, caregivers and professionals have the tendency to keep records of their children/ students via the use of video cameras for emotional/ academic reasons respectively. Alternatively, instead of bringing footage, all the participants could bring a toy, as they had been told: "It might help us to discuss concerning your child if you bring a toy that your child likes playing with, while demonstrating an RB". The toy can provide similar information to the video, and thus be used as an elicitation technique to determine the perspectives of the participants and tap into their own truth and reality (Johnson and Weller, 2002).

In the next part of the interview, I introduced an easily accessible and clear definition (a combination of definitions found in the bibliography) of the type of behaviours being researched, namely RBs. The aim was that the participants and I have a common starting point on which we would later base our discussion. The thinking behind this was that the definition encountered in the bibliography would exist as a common starting point, moving on from which the interviewees could agree, disagree or build their own approach and argument. Once I presented them with the definition, I worked with the next set of questions aiming to obtain a clear picture of what behaviours the child in question displays. Then, I asked them about the function of those behaviours, always making sure to refer to specific behaviours through the use of examples rather than by accepting a general answer. In the last part of the interview, I asked interviewees about the impact (they believe) those behaviours have on the child's everyday life and then about how those behaviours might have an impact on them (i.e., the interviewees), as well as on other people. All the interviews were recorded by me. Moreover, the interviews consisted of main questions and follow-up questions, and I was also prepared to use different types of probes, such as continuation, elaboration, attention, clarification, evidence, steering, slant and sequence ones (Rubin and Rubin, 2011). The language the interviews were conducted in was simple and everyday. This was important, because my intention was neither to impress the participants with my research study, nor to make them feel like I was trying to interrogate them. I tried to be more of a listener; to not guide them; to take notes, which were however succinct and codified so as to be able to maintain eye contact and for them to feel as if we are having an ordinary conversation. Interviewing served very specific purposes, such as the study of how people feel about the issue in question and of how people see themselves and others in a very specific situation. This is, actually, what Van Manen (2016b) also suggests.

4.IX The selection of a data analysis method

A prerequisite for the analysis of data collected via interview is the existence of transcripts. It is important that the process of transcription is done carefully, or the data analysis and results are likely to be affected (Oliver et al., 2005). For this reason, it was done manually, without the use of software.

Thematic analysis appeared as a "method" in the 1970s, first developed by Gerald Holton. It is considered "a way of seeing" and as Boyatzis (1998) points out:

> "Often, what one sees through thematic analysis does not appear to others, even if they are observing the same information, events or situations. To others, if they agree with the insight, the insight appears almost magical. If they are empowered by the insight, it appears visionary. If they disagree with the insight, it appears delusionary." (Boyatzis, 1998, 1)

Thematic analysis is an analysis of qualitative data through the use of extended phrases and/ or sentences rather than sorter codes (Boyatzis, 1998, Braun and Clarke, 2014, Riger and Sigurvinsdottir, 2016, Saldaña, 2016), that requires enough involvement on behalf of the researcher (Guest et al., 2012). It is classified under qualitative descriptive design and it uses sets of techniques to analyse textual data and elucidate themes. Systematic process of coding, examination of meaning and provision of a description are the key characteristics of the process (Vaismoradi et al., 2016). Thematic analysis takes the researcher through three phases of inquiry: Recognition of "an important moment" (seeing), encoding (seeing it as something) and interpretation of that moment (Boyatzis, 1998).

In practice, after I had transcribed the data verbatim, I transferred them electronically to a "Computer Assisted Qualitative Data Analysis" package called NVivo (12th edition). This is an example of a computer-assisted qualitative data analysis software, which, as a code, refers to, covers and manipulates text (Saldaña, 2016, Yin, 2017). I chose NVivo because it offered the potential to comprise data records (in this case, transcriptions or quotations), memos, variable-type information (e.g., demographics) and records of interrogative queries that I could manage in an organised way. NVivo is a management tool that provided me as a user with greater depth in analysis by managing a large quantity of transcribed data and providing a source of information concerning the research process and research implications (Bazeley and Zackson, 2013, Zamawe, 2015). I still had to define any relevant codes and interpret any observed patterns, and much post-computer thinking and analysis was required on my part. However, it took me time to feel familiar enough with every detail of that software (e.g., graphs, maps, codes, nodes) in order to make efficient use of it. There is also no Greek version of the software, so I considered it more sensible for me to translate the quotes I wanted to analyse English, so as to help my colleague throughout the "inter-rater reliability (IRR)" process (see below, section 4.IX.i) to extract her/ his conclusions regarding themes and categories. Time and the use of English were the main disadvantages I encountered and I could not omit to mention.

More specifically and as has already been mentioned above, "recognition of an important moment" took place each time information was detected in the transcripts, which provided answers to the research questions. Small phrases or entire sentences ("Selected Quotes" are mentioned in *Appendix 9,* with the aim of rendering the steps of the research methodology as clear as possible, in an effort to ensure credibility and trustworthiness via this form of transparency) that were used repeatedly by the participants pointed to the existence of patterns. "First cycle coding" summarised segments of data, while "second cycle coding" was a way of grouping those summarised segments into a smaller number of categories (Miles et al., 2014). I tried to think through all the “important moments” of my data imaginatively and creatively, developing codes from the texts, which “are prompts or triggers for deeper reflection on the data’s meaning” (Miles et al., 2014, p.73). This was a challenging process, since I had to think outside the box and without being affected by my own perceptions. What I decided would be important codes were the ideas which were likely to provide the answers to my research questions. I therefore re-read each one of the interview transcripts and using NVivo as a data repository, I transferred to it phrases that seemed to refer to a code, followed by a classification of codes into types of descriptive categories and cross-categories. Categories and cross-categories are ideas that repeatedly came up in the transcripts, to which I gave a more general title/ characterisation. According to Braun and Clarke (2013), coding is a pre-analytic process rather than part of the analysis. It is an organisation of data by way of contextually or thematically indexing them (Silver and Lewins, 2014). In this case, I used selective coding, meaning that I tried to identify anything of relevance to the answering of my research questions. Codes were frequently placed in more than one category or subcategory.

Needless to say, non-verbal data is still data, so I paid much attention to the notes I collected during the interview process, in which I found interesting information. An example of such data included the mood of an interviewee, who was crying during the interview.

As has been asserted by Rabiee (2004, p.657), “the process of qualitative analysis aims to bring meaning to a situation rather than the search for truth focused on by quantitative research”. Consequently, the coding of selected terms in transcripts was followed by descriptions of situations which were treated as meaningful themes in research and writing (Van Manen, 2016a), as opposed to uncovering perceived underlying truths. Therefore, after coding, I started searching for patterned responses in relation to the research questions, within the data set. These patterned responses may appear "as polar opposites of a characteristic or may merely seem to involve similar phenomena" as Boyatzis (1998, p.87) states. Then, I started developing themes, which Braun and Clarke (2013) define as promoted codes. Following that and based on the coded data, I created sub-themes and cross-themes, with the purpose of focusing on drawing comparisons among my case studies. The themes were a set of organised groups of repeating ideas, which enabled me to answer my research questions. I followed the same course of action regarding notes I had made during the interviews, in relation to data that emerged from what was not stated by the participants, or notes that did not fit the main thesis. According to Hamberg et al. (1994), this is "negative or nothing data", which could either strengthen the researcher's interpretations or cause her/ him to question her/ his coding. In that way I tried to enrich this project by adding elements that can prove of interest to the conclusions of the research study. I am referring to data that I expected to find but did not, such as disability issues which were not discussed by many caregivers, caregivers who did not accept the invitation to participate in the study although we had had an excellent collaboration in the past, the two schools for children with autism that refused to participate as well, when they were informed about the actual subject of the study.

Although thematic analysis has received considerable criticism (Braun and Clarke, 2006, Labuschagne, 2003), it can frequently go further than this criticism, and interpret various aspects of the research topic (Braun et al., 2018, Braun et al., 2019). According to Flick (2018), Braun and Clarke set specific limitations, noting that methodological suggestions about "thematic analysis" seek to provide practical examples regarding the analysis of interviews, even if they present the latter method as the basic one in qualitative data analysis. Despite these facts though, I consciously chose thematic analysis, as it seems to me the most valid way in which to access, understand and compare perceptions, views and opinions. It contains a theoretical freedom which provides the researcher with flexibility in terms of a rich and detailed, yet complex, account of data. Moreover, it seems a useful method for working within a paradigm and providing results accessible to the public. In contrast, analysis by grounded theory (where coding themes are a core feature as well) would be unsuitable in this case, since as Alhojailan (2012) advises, it is based on sampling that is determined during data collection and not beforehand as in thematic analysis. It is also not an appropriate data analysis method for the current research study, because all the analysis happened after the data was gathered, while in grounded theory the data collection and analysis process run in parallel. The most important reason why grounded theory is not appropriate for my study, is because it aims to generate a theory (Alhojailan, 2012), which was not my intention either.

Hence, a thematic analysis was done across multiple cases, what is called "a cross-case analysis" (Creswell and Poth, 2017). The categories and consequently the themes were identified in a "bottom-up" way, beginning with the specific and moving towards the general. This approach was based on what was found in the data and not on the attempt to explore specific theoretical ideas through the research study ("top-down" way). This was yet another reason why thematic analysis was selected as the ideal data analysis method. By using this method, I was aiming to employ a lower level of inference interpretation, rather than a more abstract interpretation. It seems to me a very insightful way of analysis when a researcher aims at illustrating the data in great detail, when seeking to discover using interpretation and when looking for relationships/ comparisons (Alhojailan, 2012). When using thematic analysis, the research questions and the research study in question can expand, contract, or even change altogether as it progresses (Braun et al., 2014).

Given that this was a comparative case study, the way I presented my thematic analysis was based on a comparative aspect. I decided not to analyse the cases of the study independently and then come to an overall conclusion, as usually happens according to Rose and Mackenzie (1991), but to analyse them in parallel to each other. I find that approach more vivid and appealing; the data are introduced comparatively one after another based on direct quotations from the interviews and referenced through relevant bibliography if needed. Undoubtedly, this process was followed by an overall discussion and the extraction of the conclusions.

4.X Credibility, trustworthiness and reliability: Methodological issues – Discussion of the methods used

An important consideration in qualitative research is the trustworthiness of the research process and the findings which emerge. Lincoln and Guba (1985 in McConville et al., 2016) and Whitmore (2001) assert that trustworthiness is composed of four different features: credibility, transferability, dependability, confirmability. In 1994, Guba and Lincoln added authenticity as a fifth criterion (Polit and Beck, 2012). Cope (2014), Lincoln and Guba (1985 in McConville et al., 2016), McConville et al. (2016) and Whitmore (2001) argue that on the one hand, in order to enhance credibility and dependability, methodological decisions should be clearly explained and justified; on the other, that the interviewees' perceptions should be reflected as closely as possible in the findings. As a matter of fact, an effort was made in the above sections to describe the rationale of the study, the research design, the methods and the participants chosen, as well as any ethical considerations that occurred, and the data analysis approach. Dependability can also be achieved when another researcher concurs with the decisions made during the research process (Koch, 1994). In the present case, through an IRR process which will be described in detail in the very next section (4.IX.i), an effort was made to ensure dependability. As for transferability, this may only be relevant if the intention of the research is to make generalisations about a subject, by applying findings to other settings (Cope, 2014); however, this does not apply to the current research study, which does not aim at generalisation. To address confirmability, an effort was made to indicate the participants' perceptions (Whitmore, 2001), without their analysis being affected by personal values and beliefs. It was also attempted to highlight this by indicating how findings derived from data and conclusions were established (Cope, 2014). The most secure way was by providing actual quotations from the participants that illustrate any emerging theme. By using the participants' direct quotations, readers can grasp something of the experience of the study and this indicates authenticity as described by Polit and Beck (2012).

Apart from credibility, transferability, dependability and confirmability, Whitmore (2001) advises that trustworthiness is linked to more criteria that are considered "secondary", because they are not always relevant to every research study, but which allow flexibility, investigation and application to different settings. These criteria include explicitness, vividness, creativity, thoroughness, and congruence. Explicitness refers to the records maintenance which followed, as has already been mentioned in 4.VII. Vividness encompasses language "of rich, thick descriptions that are vivid and artful" (Cope, 2014, p.90), something that I tried to achieve by making frequent mention of quotations and the description of the setting at the given time of the interview. Creativity challenges traditional ways of thinking and demonstrates novel methodologies that enhance findings, while remaining grounded in the scientific process. Thoroughness refers to choosing adequate sampling (a process that has been described in 4.V) and to data that result in a full exploration of the subject (which the use of a research diary attempted to achieve) (Cope, 2014). Finally, congruence refers to the sensible link between all the different parts of the study, such as research questions and the method, data collection and analysis, current study and previous literature, findings and implications of the study (Whitmore, 2001).

Much confusion and scepticism has been raised regarding the reliability, credibility and trustworthiness of qualitative work. As a matter of fact, though, what is proven is that there is a real need for research studies that focus on lived experiences and on the insight of human nature (Langdridge, 2007).

In the case at hand, all the transcriptions were accurate, recording the interviewees' words exactly as they had been said. In certain cases, actually, politically incorrect word(s)/ terminology was/ were used by the interviewees; however, I still transcribed and translated them as they had originally been said.

A challenging but interesting point in the methodology design and process was the fact that at times some of the caregivers said that they would rather not talk about a certain issue, especially in relation to the impact RBs have on their lives. This could impact on the reliability and credibility of the study, if I had never tested the interview questions through pilot interviews. It could be a sign that I had not used the most appropriate interview questions and elicitation tools, so as to create an environment of trust between me as an interviewer and the interviewees. Therefore, it could confirm whether or not the questions affect the content of the answers. On the contrary, and in relation to the above issue, relevant information was extracted through the participants' statements, which pertained to answers to other interview questions. At the same time, the caregivers' difficulty when it came to directly discussing that matter was acknowledged.

Moreover, upon examining the interviews, contradictions on behalf of the interviewees – and especially the caregivers – were observed; often an opinion was expressed, which was then refuted in the course of the same interview, by the caregiver saying something contradictory. This is a particularly interesting element, because perceptions and attitudes on the part of the participants are revealed, which betray the existence of ambivalence. This could potentially indicate a lack of reliability, credibility and trustworthiness, since the absolute reliability of the participants' statements cannot be somehow confirmed. However, I took advantage of this ambivalence and used it in data analysis to help me discern the perceptions of the participants.

Freud (1917 in Sandler 2018, p.64) referred to projection as an "internal perception of emotional and thought processes" that "can be projected outwards in the same way as sense perceptions". As a matter of fact, even though projection could be helpful in terms of people's interaction with others (Sandler, 2018), it might become an obstacle in thematic analysis, because it is possible for somebody – in the present case, myself – to recognise something that is their own characteristic, attitude, perception, emotion in another person. In order to minimise such an eventuality, Boyatzis (1998) suggests developing an explicit code, being reliable through consistent judgment and using more than one person to encode the information. Thus, I chose to follow the IRR process, as will be shown below.

4.X.i Inter-rater reliability process

Taking for granted that a researcher belongs to the human species and that every human being has her/ his own perspectives (Elliott et al., 1999), a researcher has to remain vigilant by reflecting on the role, the values and interests at play in the process of collecting and analysing data.

With the aim of reducing the threats of lack of credibility, untrustworthiness and unreliability, I checked the original purpose of the inquiry, using an external colleague specialising in the ASD field, as a “critical friend” (Yin, 2017). It was a matter of establishing trustworthiness by quantifying the degree of agreement between two or more researchers, which is achieved through the assessment of the IRR process.

According to this process, then, the researcher categorises all the answers in the interviews as mentioned above and then asks another researcher to categorise part of the data in the same way. The goal is to check the percentage of agreement between two different researchers, trying to minimise the subjectivity of the interviewer/ lead investigator. The IRR process’s function is to encourage better quality control in qualitative research through better self-monitoring (Elliott et al., 1999). Therefore, during the stage of data analysis, the external researcher I chose was originally from Greece and her background was ASD, the reasoning being that her own perceptions and knowledge would be as relevant as possible to those of mine and the participants in the research. In addition, she was a fellow PhD student and was familiar with the type of data analysis I used. That researcher, then, analysed approximately 10% of the whole amount of data, namely 4 out of 35 interviews, and comparison of our analyses produced 87% compatibility. As for the different categories and themes that emerged, I took all of them under consideration after having an extended discussion with my colleague and then proceeded to make changes or additions.

Summary

According to the methodology of research, it is important to consider the epistemological and ontological foundations of the study and organise its actual design. The design has to be situation-specific and each stage must inform and develop the next one smoothly. The process of defining the research’s purpose and the most appropriate sample, the manner of approaching the interviewees, accessibility issues and general ethical concerns, as well as the data analysis and issues of credibility, trustworthiness and reliability are some of the key points of focus in this chapter. These are the points on which the process of conducting this research was designed, organised and based. Let me now continue to the next chapter and the presentation of some initial thoughts regarding the data analysis process.

Chapter 5
RESULTS & INITIAL THOUGHTS

5.I Chapter Overview

The data in this section will be presented in the following way: It is introduced in the form of an overview, followed by eleven different sections for the various overarching categories and themes. Each section has a title that summarises the general idea extracted from the interviews, which in turn led to the gradual emergence of the categories and themes in question.

Initially, I recorded salient data and then negative data and organised it into groups, followed by a classification of codes into types of descriptive categories and cross-categories. I have used the term 'negative data', inspired by similar terms I came across, initially in (Stevenson, 2003, p.21)'s work, in the context of the discussion of the "negative case study" and how it depicts the opposite of what would be the most likely outcome of a situation. In addition, Robson and McCartan (2016, p.172) discuss "negative case analysis" as a means of countering researcher bias, which seems like a way of developing a more elaborate, honest and thorough version of one's theory. Further back, Emigh (1997, p.696) employed "negative cases" in comparative case studies in which some theoretically predicated outcome did not occur. Thus, "negative case methodology" examines a single case in light of a theoretical explanation that embodies knowledge of numerous cases. In other words, negative case methodology is a comparative research strategy that analyses cases in which an outcome that had been predicted by theory did not occur.

It seems like the aforementioned terms are basically used in quantitative studies with a more positivist point of view. However, I decided to use the term ‘negative data’ following a similar rationale, in the sense of highlighting data that was not given directly by the participants, but that was extracted by what was not provided by the interviewees of the study.

At that stage, I tried to organise groups of repeating ideas: themes, which will enable me to answer my study’s research questions (Bazeley, 2009, Vaismoradi et al., 2016). The main aim is to present the final results comparatively, as the discussion unravels. This chapter revolves around the research questions that had initially been set, as well as their deconstruction; in other words, it addresses some sub-questions that occurred during the interviews, as well as during the data analysis, which helped me as the researcher to arrive at the answers to the research questions.

5.II Interviewee identification method

At this point, a *Table 4* of the interviewee identification method will help the reader. To be precise, this is a list of pseudonyms used for the children about whom the participants spoke. For those cases when both a caregiver and a professional spoke about the same child, the pair is mentioned on the same row next to the child’s name, under the same number. The only thing that changes in the coding is the first half, which refers to the type of the disability (VI or AS), and the second half, which clarifies whether the participant is a caregiver or professional (CAR or PROF). Where there is a dash (–), this denotes that either the caregiver or the professional did not agree to an interview, but had – as has already been stressed – given their consent to the other party’s going ahead with the interview.

This is a table consisting of five columns. The first one concerns the number of cases that were discussed by the participants and the second one lists the names (pseudonyms) of the children discussed. The third column mentions the age of each child. The fourth and the fifth columns indicate whether the child in question was discussed by a caregiver, a professional, or both. Interviewees are identified not by their real names but via coding (a caregiver-professional pair discussing the same child share the same number).

Table 4: Interviewee identification method

	NAME	AGE	CAREGIVER	PROFESSIONAL
1.	Giannis	12	–	ASPROF1
2.	Alexia	9	VICAR2	VIPROF2
3.	Vicky	13	ASCAR3	–
4.	Konstantinos	13	ASCAR4	–
5.	Liza	8	VICAR5	–
6.	Nikos	5 ½	VICAR6	VIPROF6
7.	Kaiti	7	VICAR8	VIPROF8
8.	Maria	9	–	VIPROF11
9.	Irini	9	–	VIPROF12
10.	Panagiotis	7	VICAR13	–
11.	Fotis	8 ½	VICAR14	VIPROF14
12.	Dimitris	5	VICAR15	VIPROF15
13.	Christina	5	VICAR16	VIPROF16
14.	Sofia	7	–	VIPROF18
15.	Elpida	7	–	ASPROF20
16.	Orestis	13	ASCAR21	ASPROF21
17.	Thodoris	7	ASCAR22	ASPROF22
18.	Thomas	13	ASCAR23	ASPROF23

19.	Angelos	5 ½	ASCAR24	ASPROF24
20.	Petros	13	ASCAR27	ASPROF27
21.	Giorgos	13	ASCAR30	ASPROF30
22.	Anastasis	5	ASCAR31	ASPROF31

It would also be worth reminding the reader that especially throughout this chapter, where direct quotes from the participants' interviews are used, I have kept the vocabulary as close to my participants' words in Greek as possible. This is highlighted, because some of the words which my participants use (e.g., mental retardation), are not considered as acceptable in the United Kingdom. Notwithstanding, they are considered appropriate within a Greek context.

5.III Perceptions regarding the prevalence and causes of repetitive behaviours in children of both groups

The answer to the question above cannot be given in the form of a definite 'yes' or 'no'. It is more complicated, and this will be addressed gradually and in detail later on. Caregivers and professionals describe in their interviews different kinds of RB, regarding their children/ students either with VI or with ASD, referring to this behaviour in various terms: "stereotypical behaviour", "using stereotypies", "blindisms", "spastic movements", "repetitive movements".

In terms of both disabilities, the vast majority of caregivers state that their children present less RBs both in frequency and in intensity, as the children become older and more mature*: "I have observed changes for the better",* a father (ASCAR4) of a child on the AS states, as does the mother (VICAR15) of a child with VI: *"When he was younger, he used to present this behaviour more frequently"*. Similarly: *"Nothing like when he was a toddler. Now it's as if he tries to protect and not expose himself that much."* (ASCAR30) and *"Things were different when he was younger; more intense, less under control."* (VICAR2). Only one caregiver (VICAR6) has observed in his 6-year-old boy that this kind of behaviour becomes worse as the years go by: *"Generally, his behaviour is worse and varies, every time the environment changes"*. As is going to be discussed in section 5.V.iv concerning the feeling of blame that caregivers sometimes hold, caregivers seem to get used to the RBs of their child over time.

In contrast, professionals seem more conservative, regardless of the disability or the age of the child. They say either that RBs remain the same: *"From our first session, three years ago, up to this day, she has exactly the same behaviour."* (ASPROF20)/ *"I can't spot any differences in the repetitions she makes. At least not in the years I' ve been working with her."* (VIPROF2), or that they depend on various reasons that affect the child and her/ his tendency to indicate an RB: *"At other times and in a specific environment, she wanted to avoid the classroom environment; something irritated her somewhat and it was very intense*." (VIPROF8), *"His stereotypies change according to the person he is interacting with; I think he knows what each person can cope with and to what extent he can deal with them. He adjusts."* (ASPROF23). Actually, explanations like these could be the environment, the people who interact with the child, the child's psychological mood, the stimuli, the child's needs. Professionals, then, appear to be more meticulous observers of the RBs of the students. Given that they report lesson difficulties due to such behaviour, it seems logical that they would observe and report in the interviews any movement that may indicate RB. They may, however, also be influenced by their own perceptions, according to which a child on the AS 'must' present RBs, while in the case of VI, when a degree of repetitiveness is observed in a behaviour, they make insinuations as to the co-existence of autism and tend to wish to put an end to it.

At this point, I should clarify that according to their official diagnosis, none of the children on the AS that I am discussing had additional disabilities. The same applies to half the number of the children with VI. There are actually some professionals who attribute the RB of their students with only VI to a possible additional diagnosis: *"I think it's not just the blindness. He must have some other disability too. Maybe autism. There are many things he seems to be too immature to handle and process and first and foremost his stereotypical behaviour."* (VIPROF14), *"The child isn't only autistic. It only takes a few minutes with him to know. There is definitely mental retardation; that's why he has difficulty handling these movements."* (ASPROF21). Upon comparing the groups in question, then, what emerges is the perception of all the interviewees that RB is more likely to be linked to ASD or to any *"other additional disability",* than to VI. The caregivers provide a similar case as well, as they seem to attribute their children's RB partly also to "another disability*": "Oh, let's be honest with ourselves! The child stereotypes because he is autistic, but it would be better if he also had higher intelligence; there is certainly some retardation."* (ASCAR27), *"I read somewhere about autism. The child probably makes all these crazy movement because he has some of that too – it's not just sight that is the problem."* (VICAR6).

Overall, time seems to act and impact differently on caregivers and professionals. For the former, it plays a soothing and helpful role, as it enables them to get used to and accept such a behaviour in their child. The latter, however, affected by the educational goals that they 'are obliged' to achieve, continue to identify RBs with the same regularity. It seems that, for the caregivers, RBs decrease with the passage of time, whether they are ASD or VI-related, but for the professionals they do not.

Therefore, due to the interviewees' answers, the need arose to look more closely at the data to find out the answer to another set of questions, so that it is clear what they are talking about. The following is an example of such a question: "Which are the behaviours that are considered to be repetitive according to the caregivers and which according to the professionals?".

5.IV Perceptions regarding the nature of repetitive behaviour presented by the children

The RBs that caregivers and professionals observe in their children and their students respectively, seem to vary across situations but not in quality, namely in the way in which they are expressed *(Table 5).* To begin with, according to the participants, children with VI demonstrate RBs that involve body movement in general (e.g., *"spinning around, jumping",* VIPROF15) and in some cases leg movement (e.g.,*"constant forward and backward leg movements",* VIPROF18), hand movement (e.g., *"clapping and flapping",* VICAR2) or head movement as well (e.g., *"moving the head up and down",* VIPROF15). The same group of adults observe RBs linked to speech (e.g*., "vocalisations or expressions of verbosity"*, VICAR5), the olfactory sense (e.g*., "smelling everything and everyone around"*, VIPROF16) or sensory stimuli through sight (e.g., *"pressure on the eyes",* VICAR13). They also mention a persistence on specific habits and actions (e.g., *"At first when I said to her, 'Come, let's get dressed' she would say 'No! No! No! No!' and she could sit naked on the bed for two and a half hours after her bath. Every day.",* VICAR5). Moreover, they convey their concern about RB that is being expressed as self-harming (e.g., *"biting fingers and nails to the point of bleeding",* VIPROF14).

RBs manifested by children with ASD seem to have approximately the same expression as above. Namely, all the participants state that RBs are expressed in the form of body movements (e.g., *"moves his body like a pendulum",* ASCAR21), head movements (e.g*., "moves his head forward and backward fast",* ASCAR31), leg and hand movements (e.g., *"he puts his toes in front of his face and moves it and looks at it or links his hands in front of him, very close, as if clapping"*, ASPROF1*, "arm-flapping, like wings beating"*, ASPROF31*).* Also, they talk about RBs linked to speech (e.g., *"You might ask him a question and he'll answer with the same question",* ASPROF24), sensory sight-related stimuli (e.g., *"She might be doing that thing with her eyes. Opening and closing them with her fingers. Like she's playing with her sight. Especially when it's sunny, she sits in the sun and does it.",* ASCAR3) and hearing (e.g., *"Shuts his ears",* ASCAR23). The persistence in specific actions and habits, as a way to manage a stressful situation, could be interpreted as a ritual (Gillespie and Petersen, 2012): *"He might get up over twenty times to repeat the same process: go to the kitchen, drink a glass of water, and then go to the bathroom, thinking that he will in that way let out the water he has drunk and then five minutes later he will repeat the same thing. Four minutes later… until he gets tired and falls asleep."* (ASCAR4). Last but not least, self-harming behaviour is again a reality, according to those raising or working with children on the AS: *"He scratches his cheek to the point of drawing blood.",* (ASPROF27).

It is interesting to mention that both in the case of children with VI and that of ASD, challenging behaviour is differentiated from RB and is described by the interviewees as a persistent and severe behaviour, which is therefore of major concern to them: *"Because I told him two or three times where to write, he tore the paper, shouted, and started hitting his head repetitively… No! It's not an RB; it's just challenging.",* (ASPROF27), *"At night when he doesn't want to sleep, he tries to provoke me. He looks into my eyes intently and bangs his head on the table. That's challenging* *and not an RB at all!"* (ASCAR21), *"Every time I asked him to practise on the Braille machine, he had the same challenging reaction: he sang the same song and spat. But this is not an RB"* (VICAR5), *"It's her way of avoiding a hard exercise. She knocks things off the table. She knows it annoys me and I think she does it to provoke me; I don't see that as an RB, even if it happens often."* (VIPROF16).

According to Chung and Nolan (1998) and Waters (2016), the term "challenging behaviour" refers to a variety of causes , such as aggression, self-injury, property destruction, hyperactivity, withdrawal and RBs. What is more, McClintock et al. (2003) and Sharma et al. (2002) argue that challenging behaviours may disrupt family functioning, interfere with learning, inhibit social interaction with peers, and restrict participation in school and community settings. Emerson (2001), Emerson et al. (2013) and Korb et al. (2019) discuss undesirable behaviour that is of an intensity, frequency, or duration that threatens the physical safety of the person or others. Indeed, in the case studies in question, caregivers and professionals use the term "challenging behaviours" either to define behaviours which, as they themselves say, aim at the reaction and the effect of the adults themselves (in order for them to communicate a desire or an emotion): *"He wants chocolate. He knows how to tell me. But he doesn't. Instead, he prefers to shake his head left and right. I need to ask him to speak, he will shout, we will fight and then he will tell me."* (VICAR6), or because the children have adopted an aimless obsession: *"He only does it to me. Simply so I can say 'stop it'. To reset. It has become an obsession. It's not because something is bothering him. You always indulge him when this happens anyway..."* (ASCAR21), *"I think he enjoys this ritual, not stereotypy. He knows I will say no to his sleeping in class. He does ask, though, then pinches himself and after I say 'no', he stops and continues his lesson."* (VIPROF7). In any case though, they all make a distinction between an RB and a challenging behaviour, considering the latter much more intense, compared to the former.

Table 5 that follows is composed of three columns and 11 rows. It offers a list of ten possible natures of repetitive behaviours (first column) that could be observed in children, according to the participants, grouped together. Examples from the fields of VI and ASD are mentioned in the second and third column.

Table 5: The nature of repetitive behaviours in vision impairment and on the autism spectrum, according to the interviewees

NATURE OF RBs	EXAMPLES FOR VI	EXAMPLES FOR ASD
Body movement	spinning around, jumping (VIPROF6)	moving the body like a pendulum (ASCAR21)
Leg movement	constant forward and backward leg movements (VIPROF18)	putting the toes in front of the face and moving them and looking at them (ASCAR24)
Hand movement	clapping, flapping (VICAR2)	arm flapping, like wings beating (ASPROF31), linking the hands very close to the face as if clapping (ASPROF1)
Head movement	moving the head up and down (VIPROF15)	moving the head forward and backward fast (ASCAR31)

Speech	vocalisations, expression of verbosity (VICAR8)	repetition of phrases straight after hearing them (ASPROF30)
Hearing sense	–	shutting of the ears (ASPROF21)
Sensory sight-related stimuli	pressure on the eyes (VICAR13)	opening and closing the eyes with fingers, especially when it's sunny - sitting in the sun doing it (ASCAR3)
Olfaction	smelling everything and everyone around (VIPROF11)	–
Rituals	staying naked on the bed for at least 2 ½ hours after bath (VICAR5)	getting up over twenty times to repeat the same process: go to the kitchen, drink a glass of water, and then go to the bathroom, until tired and then fall asleep (ASCAR4)
Self-harming	biting fingers and nails to the point of bleeding (VIPROF14)	scratching the cheek to the point of drawing blood (ASPROF27)

After a first glance, then, at *Table 5*, it seems that these behaviours are expressed in the same way*.* There is no obvious differentiation between the two sides. All the adults describe RBs in a way that could be categorised into either of the categories above. This is not accidental. It is an interesting point which shows the impact this has had on all these people concerning the RB their child/ student might exhibit. It is obvious that RB is discussed as part of the diagnostic criteria of a disability and more specifically that of autism. Actually, the categories above do not differ significantly from those mentioned by researchers such as Traynor et al. (2018) when discussing heterogeneity among RBs on the one hand, and the Repetitive Behaviour Scale measuring RB score (Lord et al., 1994, Rutter et al., 2003) on the other. This happened accidentally and I did not use these categories as a basis for my coding. For example, mention is made of sensorimotor stereotypies, reaction to change stereotypies or restricted behaviours (Bourreau et al., 2009), which refer to groupings in *Table 5* such as "body/ leg/ hand/ leg movement", "sensory sight-related stimuli" or "rituals". RB refers to the behaviour of a child with ASD and this might have an impact on the way people perceive the possibility of a child being on the AS. However, the professionals on the one hand mention RBs that increase with time, while on the other hand the caregivers talk of them decreasing. This is something that needs to be clarified, as well as the nature of the impact of those kinds of behaviour on people.

Before answering these questions, it is worthwhile to present some exceptions that appear in this context: those are first of all the persons who can be distinguished by their denial of the existence of any RB in their children or students.

5.V Perceptions about the presence of repetitive behaviour in both groups

Focusing on the participants' statements, the answer to the question comes from the adults' perceptions, in the sense that they are sharing the experience of what they observe. More specifically, there are three caregivers who perceive their children's behaviour in a different way; they present a different kind of awareness of their children's RB, compared to the others. Although I understand that the effect of such a small sample may result in weakness in the sample as a whole in terms of its trustworthiness, I decided not to remove this outlier but handle it very carefully (Bakker and Wicherts, 2014). I recognise the importance of the outlier, and how much it helped me to see and draw the general picture of the study. The outlier is not related to "weaker evidence"; however, it may highlight "the importance of more transparent reporting" of data that sometimes cannot be said or admitted by the participants of a research study (Bakker and Wicherts, 2014, p.1), with "unusually large or small values" (Wilcox, 2017, p.32).

In the case of the caregiver of a child with VI, she describes behaviours which may contain repetitiveness to be the result of imitation; mimicking movements that occur as an expression of joy, or as a game, or simply as imitation of another person: *"I mean he's not like others, like other disabled children. Thank God, he's in a better state than other disabled children. (…) He doesn't present such RBs. He imitates other children. When a child is sitting with him and the child is calm, then my son is too. If some children aren't calm and start fighting or making noise, he does the same."* (VICAR13). Another interesting feature of the interview of the caregiver in question is that she does not include VI in the general category of disability. *"Sometimes he climbs on the fridge. So... a disabled person isn't like that, they can't climb on a fridge. My son is not disabled. We have the same vision pathology. I am not disabled either.*

Since we can walk, talk and think, we are not disabled.", VICAR13 says. The question arises, therefore, of who/ what is shaping these perceptions about disability and how has the depiction of VI or ASD been constructed. This could be a matter of culture (Argyropoulos and Gentle, 2019, Perepa, 2019), or a media construction (Samsel and Perepa, 2013). It could also be linked to the caregiver's expectations (Baden and Howe, 1992), or connected to the child's gender (Carpenter and Towers, 2008), to their individual characteristics (Lecavalier et al., 2006b) or to the type of the disability. I will attempt to provide some explanations in relation to the root of these perceptions at a later point below, because I believe that these answers will provide further information to my research questions.

This different attitude is shared by another female caregiver (VICAR16), according to whom the child shows no signs of RBs, but of reactions to the pain she experiences. She actually states that this RB is not linked to any kind of disability, and as a result her child cannot be considered disabled: *"When Christina is in pain, when her tummy aches, when she has a headache or when she has partial seizures, then yes, she will go into echolalia, and she will move her arms and legs and scratch us. But that's not RB. It isn't odd behaviour. It is normal because she's in pain. My daughter is blind, not disabled!"*.

Last but not least, here is another critical analysis regarding RBs indicated by a child with ASD. These are the views of ASCAR3, who believes that her daughter *"has recovered from autism",* claiming that *"recovery means independence and self-sufficiency. It means being able to compete in tasks with neurotypical peers. It means independently navigating relationships with neurotypical people whether in personal or impersonal life".* ASCAR3 notes that her 13-year-old daughter does not present any *"autistic symptoms"*, because of the diet that she has followed in the last few years; *"a diet based on studies conducted on flora and neural inflammation in the brain"*. She emphatically claims the following: *"Hippocrates said 'All diseases begin in the gut'. That's autism. It's something that starts in the gut and affects the entire body. (…) So, my daughter is under a strict diet. And when she is and she is well, everything is fine. She doesn't stereotype".* The caregiver finds support in that kind of approach, believing that the intensity and frequency of the RBs could be reduced or in some cases *"healing"* can be achieved, as she also mentions.

Summarising the points from the three caregivers above, it is noted that none of them is originally from Greece but from other countries from across Europe and Asia, and from the USA. Those three people were the only caregivers who stated that they do not consider their children *"disabled"*; that they do exhibit RB but this is because of reasons unrelated to any disability. Therefore, it seems that due to them not belonging to the Greek culture, they do share the same perceptions but possibly for different reasons. Only a limited number of research studies regarding perceptions and perspectives on disabilities exist in South-Eastern Europe and in Southern Asia. Concerning the former, Murillo (2014) states that the concept of disability is not well-understood and is a topic that is not typically discussed in families and communities. A possible reason may be the limited human and financial resources in such low and middle income countries such as the one in Southern Asia and the other in South-Eastern Europe that the caregivers in question hailed from, as Lachman et al. (2019) claim. This is a reason why awareness campaigns are desirable, as a way of increasing the understanding of disability issues. Another reason could be that these citizens have broader criteria of normality and do not consider someone an individual with a disability unless it impacts their cognitive ability or the ability to function on a day-to-day basis. To be more specific, VI is an obvious disability and its existence is not being denied by either of the caregivers above. Therefore, they perhaps have a more positive attitude towards disability than their Western counterparts.

Characteristically, however, Armstrong and Ager (2005) maintain that South Asian society distinguishes between traumatic and congenital disability, where disability awareness is much greater for persons with traumatic rather than with congenital disability. This probably suggests that Southern Asians are more aware of disability in people who have suffered an accident. In addition, there is a strong cultural responsibility (in South Asia), on the part of the adults, to care for children with a disability, rather than to intervene and encourage independence. Furthermore, Rahbar et al. (2011) identify knowledge deficits and a gap in the attitude and the practice in terms of disability matters in the South Asian area. Such a fact probably indicates that the way in which residents of that area perceive disability is also different, since professionals lack knowledge and, as a matter of fact, they may affect a family's perceptions about disability, as they are the persons who are predominantly in touch with a child's family, after they have been diagnosed with a disability.

American work on ASD, as well as Asian, focuses a lot on cure and the gut theory (Liang et al., 2018, Theoharides et al., 2013), which has already been mentioned and is really popular there. In fact, since the majority of the research studies on ASD and gut have been conducted by American Institutions (Abrahams and Geschwind, 2008, Hsiao et al., 2012, Mayer et al., 2014, Onore et al., 2012, Theoharides et al., 2011), this could be the reason behind the American parent's view. Moreover, there are plenty of research studies conducted in the USA trying to contribute to better understanding of disability, as well as to changing the perceptions and attitudes of professionals and families towards disability (Park et al., 2010). These changes have helped to promote better outcomes among children with disabilities and more inclusive approaches on the matter. "The way we imagine disability in America is changing. (…) Disability permeates our national culture and conversation" after the disability rights movement of the 20th century, Garland-Thomson (2005, p.522) argues. The way this relates to the parent's comments concerns how strong the perceptions of people seem, how these perceptions have been developed via society's own perceptions and how these perceptions could impact on the individuals' way of thinking, by guiding their behaviour towards their child or student with VI or ASD.

Interestingly, there is a research study conducted by Zaromatidis et al. (1999), comparing the attitudes of Greeks and Greek-Americans, toward persons with disabilities. According to their findings, the Greek-Americans' attitudes were more positive than those of the Greeks. Similarly, the impact of Greek culture was found to be negative in less recent studies, such as the one by Jaques et al. (1970) and another by Koutrelakos et al. (1978), when being compared to ethnicities like the Americans.

In a way, all three of the studies mentioned above are historical and may not represent the current situation in Greece. However, due to a lack of relevant studies that have taken place in Greece, as well as because I would like to highlight the impact society's perceptions have on individuals, I decided to include them in my data analysis process. Munyi (2012), actually argues that perceptions towards disability vary significantly from one community to another and that there are cross-cultural factors that influence adults' perceptions towards children with disabilities.

In Greece, research studies on disability matters are quite common and well-received, but they reveal different and contradicting attitudes that indicate mixed perceptions on the part of the Greek people. For instance, Avramidis and Kalyva (2007) reveal the positive attitudes of professionals towards disability, while there are variable views on the difficulty of accommodating different types of disabilities in mainstream schools. It seems that those who had been actively involved in teaching students with disabilities held significantly more positive attitudes than other professionals with little or no such experience. Their attitudes are also influenced by the nature and the severity of the disability of the child and by teacher and school variables. As for Greek parents, a research study conducted by Kalyva et al. (2007) indicates a positive attitude towards pupils with disabilities. However, Loukisas and Papoudi (2016) highlight that the mothers of children with ASD have mixed perceptions of disability, which they view through a developmental perspective.

The above views would be in line with Perepa (2019, p.12), who actually states that the conceptualisation of autism is based on Western norms and that for some individuals autism "can be disabling", but for others it is not. In terms of VI, after a comparative study of pupils with VI in Greece and in Serbia (Anđelković et al., 2017), I personally observed that the time of onset of vision loss and the coexistence of another disability (multiple disability) have significant impact on the caregivers' attitude towards VI and whether it is thought to be a disability for the child or not. It is obvious, therefore, that for some individuals (either caregivers or professionals), neither ASD nor VI comprise a disability, even when mention is made of other persons with the same characteristics and/ or the same diagnoses. For other individuals (mostly from a Western world background), however, it is easier to cite a disability as the reason behind certain characteristics or behaviours, or it may be that the Western discussions about what is considered as a disability influences them in what they see and how they perceive what they see.

Likewise, Teo and Lau (2018) in their own research study found that culture play a major part in the content of intervention chosen by parents of children with ASD and their attitudes towards involvement. In what concerns the diversity of cultural and social backgrounds and beliefs in terms of children with VI, Argyropoulos and Gentle (2019, p.118) have made ample reference. Thus, it appears that one of the underlying reasons that influences the caregivers of the current research study regarding their perceptions in terms of disability and more specifically the possibility of whether or not their children might have ASD, is also cultural. The parents of children with VI, though, do not deny the existence of VI. What they are saying is that VI is not a disability.

In an interesting way, similar observations were made by one of the professionals as well; a special educator, who lived and worked in Switzerland. She is not originally from that country but from Greece; however, she completed her studies there and worked in Switzerland with children with various disabilities for over ten years. As she herself stated, the impact of the educational system's culture, as well as that of the general mentality of the country's citizens played a pivotal role in the way in which the educator herself evolved as a professional in the long run. Her way of expressing her ideas and her perceptions greatly resembles that of the aforementioned three caregivers. She points out that RBs *"are normal"*, not just within the context of disability but also generally that of human nature. To be precise, she says that *"everyone presents RB; it's just that we are aware of our social environment (...) and perhaps for that reason they might not be too pronounced. And they are also in a sense socially acceptable."* This is an interesting point, as it underlines the presence of RBs even in children with no disability. What is more, according to Tregay et al. (2009) and Wolff et al. (2016), cognitive flexibility is associated with "just right" behaviours that involve RBs that include the repetition of actions, routine and play. Children with disabilities are not usually characterised by cognitive flexibility (Tregay et al., 2009), thus their RBs may be more common and not always socially acceptable. More precisely, for children with VI, no related research studies can be found. In terms of ASD though, it is Van Eylen et al. (2011) who state that individuals on the AS present deficiency in terms of cognitive flexibility, whereas mixed results with no consistent evidence and mainly unanswered questions are the main points of more studies in the field (Geurts et al., 2009, Leung and Zakzanis, 2014, Memari et al., 2013).

One more professional, a music-therapist, is the only one who stated to me that her students do exhibit RBs according to the literature

(*"I have come across plenty of research studies and papers describing RBs; between us now, they mean stereotypies"*) but according to her point of view, these are not repetitive but just behaviours that she has to cope with (VIPROF12 & VIPROF2): *"In music and in our interaction, she finds a motive, so she finds no reason to isolate herself; to withdraw within herself"*. However, even when the child does want to isolate and exhibit *"a typical RB, according to the bibliography"* as the professional said, the music-therapist validates it, by following the rhythm of her RB. This is her way of showing the child *"that I am with her and gradually she will eventually change it"*. Essentially, she mirrors the child's behaviour and through this mirroring the professional believes the child realises the existence of the behaviour she has. *"She becomes more conscious of it"* says the music-therapist, and *"when you realise, then you can later change it; you have control of it"*. In other words, the music-therapist is adapting her teaching on the basis of her students' behaviour. Even if the above approach concerns students with VI, it is reminiscent of the "Son-Rise Programme", according to which copying the RBs of a child on the AS provides improvement in terms of her/ his social-communicative behaviours (Houghton et al., 2013, Williams and Wishart, 2003). Similarly, it could be argued that the music-therapist's views can be emerging from the approach of "Intensive Interaction", which is offered to children of different disabilities, ages and needs. The aim of such an approach is to facilitate the development of the most fundamental social and communication abilities of the child, following identification of her/ his pre-verbal nature (Nadesan, 2013, Nind, 1996, Nind, 1999, Nind and Kellett, 2002).

The music-therapist's aim is to communicate with her students through music – using auditory information, as she does not recognise her students' behaviours as repetitive or challenging. As she points out, *"RB is a musical context of communication"*, inside which *"she is so absorbed in all of this that I don't focus on whether she does anything stereotypical at* *some point or not (…) she's in her own world doing her stereotypies. And I haven't found any of Irini's stereotypical movements challenging"*. According to the music-therapist's approach, *"RBs have a specific rhythm (…) that gives to the children a positive sense of relaxation. It is not a matter of disability; even people without any disability present RB consciously and unconsciously (…) so as to help themselves feel comfortable in a stressful situation"*. She believes that the problem stems from people's perceptions about RBs that are demonstrated by people with disabilities. RBs are frequently characterised as "undesirable, inappropriate and in need of reduction or elimination" as Nind and Kellett (2002, 265) argue. Thus, it is more likely for someone to notice a child's RB, because RB is not *"socially acceptable".* It has also been noticed that although the music-therapist generally states that her students do not exhibit RBs, in her statement above she mentions that RBs do have "a rhythm". She does mention both issues, but her words are contradictory; to these contradictions a further reference will be made in section 5.V.vii.

The interesting thing is that the other members of the interdisciplinary team of the setting in question find a use for this relationship that children have with music, so as to achieve the goals of their own programme. For instance, the music-therapist has a close collaboration with the speech and language therapist, who asked the former to contribute to the improvement of the child's posture by having the child toss her/ his head back. More specifically, the music therapist repeated the speech and language therapist's words to her for my benefit: *"If you can, lift the guitar a little higher, or whatever she does, so that her posture improves a little'. And I've done it, and I really see her trying to reach, so you know, she lifts her body up, her torso and the rest to get higher"*.

At this point, it would be interesting to highlight the results of a research study I conducted (Tavoulari and Filianou, 2020) on totally blind/ partially sighted children. In the context of the multisensory Orff-

Schulwerk musical approach[15], the aim was to connect cognitive objects of the pre-primary school’s curriculum. The important thing is that, like the music-therapist in this research, I and the musician who participated in this past research relied on the rhythm of the students. The rhythm often involved an RB that had already started before the musician played a musical theme. The rhythm of the RBs of the students is followed, in a way that combines the various cognitive goals of the Greek Curriculum for the pre-primary and primary education in an interdisciplinary fashion. In other words, students with VI are taught in an interdisciplinary way with the aid of music, while any RB that the students may exhibit is simultaneously incorporated into the learning process.

Returning, then, to the question posed at the beginning of this discussion – whether all the children in the study present RBs – what is recognised is that the answer is defined by the perceptions of the individual. Each participant, in other words, reports whether or not the child or student exhibits an RB, affected by her/ his perceptions regarding what defines disability as a term in general. What transpires is that, in the cases above, factors related to culture and professional training are what determines whether the adult will recognise a repetitive tendency in the child or student’s behaviour, and whether they will interpret it as stemming from the existence of a disability.

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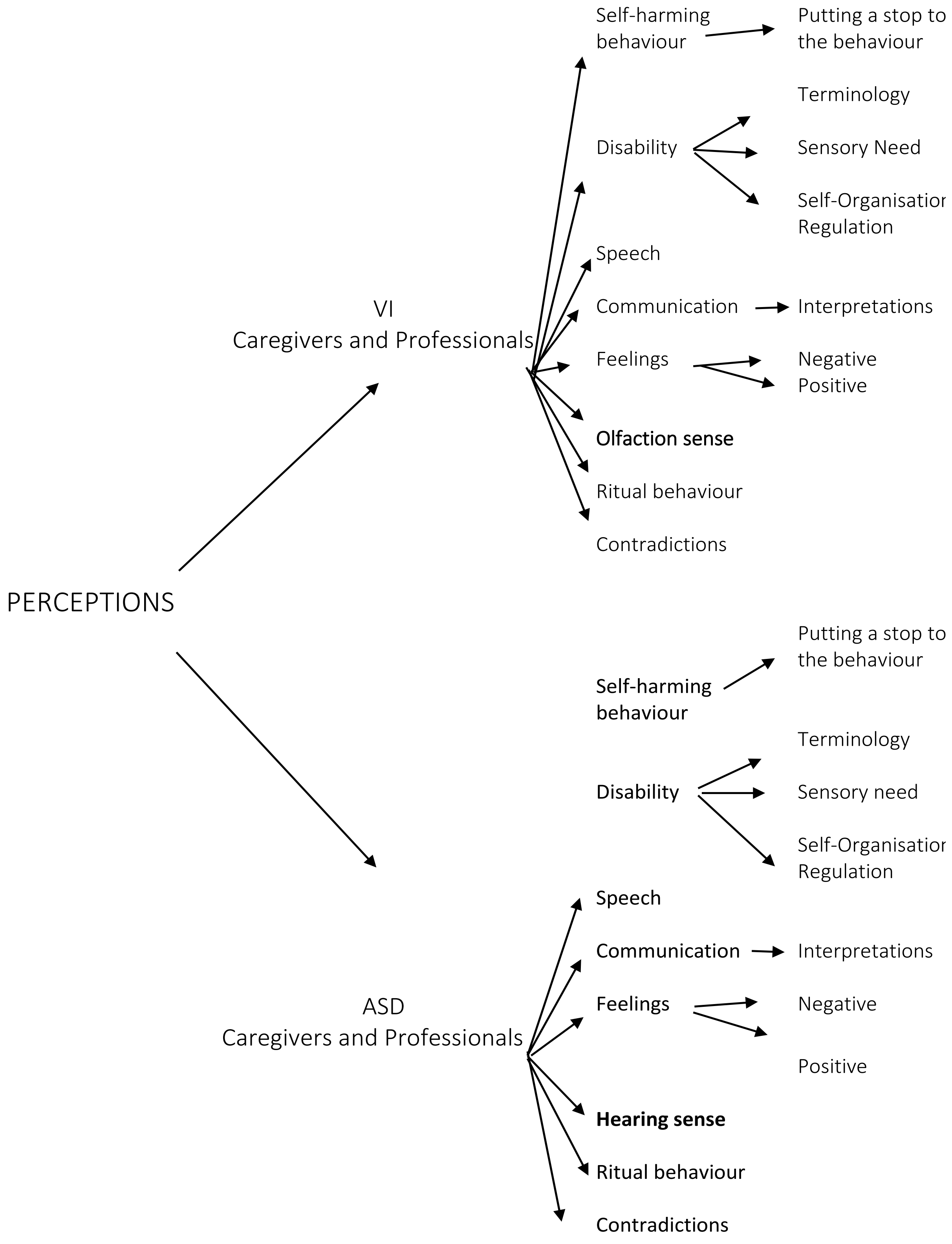
[15] The Orff-Schulwerk music approach aims at promoting arts education and generally an education that is concerned with the holistic development of a child’s personality. This approach contributes to the development of a child’s aesthetic standards, while simultaneously being recreational. The material used in this educational approach is for the most part derived from each country’s cultural wealth, and it’s especially selected and appropriate in terms of its aesthetic value. HASELBACH, B. 2003. Interpersonal and intrapersonal views at work with Orff-Schulwerk music approach [Διαπροσωπικές και ενδοπροσωπικές απόψεις στην εργασία με τη Μουσικοκινητική Αγωγή Orff]. *Ρυθμοί,* 65, 36-37.; ORFF, C. 2011. Orff Schulwerk: Past and future (1963). *Orff-Schulwerk in Canada: A collection of articles and lectures from the early years*, 134-159.

5.VI Characteristics of the perceptions regarding repetitive behaviours

Overall, the categories and subcategories that have occurred through the data analysis are the ones presented below in *Figure 5*.. Overall, the categories and subcategories that have occurred through the data analysis are presented as a thread, beginning with the general term of perceptions in the cases of the caregivers and professionals related to VI or ASD respectively. All the subcategories are the same, as well as the categories, with the exception of the olfaction sense in the case of VI and the hearing sense in the case of the ASD. These two different categories are highlighted in bold.

<u>Figure 5</u>: Categories and Subcategories that emerged via the data analysis



5.VI.i Self-harming behaviour and putting a stop to it

All caregivers and professionals talk about children's self-harming behaviour to varying degrees. It seems that they cannot ignore this kind of RB, as it often provokes strong emotional reactions, as Wilkinson (2015) points out, as well as the participants themselves: *"I feel so embarrassed when I look at the other children playing at the playground, while mine is banging his head with his hand because he is happy. He is happy, ok, but I am not!"* (ASCAR23), *"It is so disheartening to watch him scratch – tear at his cheeks with his nails. I have been a professional for years, as well as a mother, so I do care about him. It makes me sad."* (ASPROF23), *"I feel useless, like neither my training nor my intervention methods are effective enough to stop that behaviour. It ruins my programme!"* (VIPROF16), *"I can't stand seeing him banging his head on the wall* [the caregiver is crying]. *I feel emotionally devastated…"* (VICAR15). However, I could observe a difference in the way caregivers and professionals approach the issue. The former differentiate self-harming behaviour from other RBs. They say that self-harming behaviour does not comprise an RB, but is just a feature that characterises the disability: *"Self-harming behaviour is not an acceptable behaviour. It is not permitted during the lesson. It is not even part of the RBs according to my rationale"* (VICAR8).

On the other hand, professionals do consider it as a kind of RB, although they believe the disability, and not the child, to be responsible for that behaviour. VIPROF8 observes that *"Self-harm is slightly different from other simple forms of stereotypies such as visual or kinetic stereotypies. Such simple forms may be due to immense joy or due to a high level of stress. Self-harm is because of the visual deficit".* ASPROF1 says that *"self-harm is part of the disability. All my autistic students stereotype in one way or another and when they stereotype they injure themselves".*

Therefore, a perception could be observed, according to which some RBs are expressed by the children as part of their disability: either VI or ASD. In other words, professionals attribute the RB of children with VI and those with ASD to either one of the two disabilities, considering it impossible for the children to manage it. Thus, it could be argued that for both the caregivers and the professionals of the ASD group, RB is a diagnostic feature (Watt et al., 2008): *"After all, according to the DSM-V, a self-harming behaviour is, let's say, expected. It is part of the evaluation criteria"* (ASPROF23), while for the caregivers/ professionals of children with VI, RB is very common for the child to exhibit, due to the lack of vision that reduces an individual's social interaction as well as her/ his perception of the intentions of others (Dale and Salt, 2008): *"An unconscious kind of behaviour. It could be connected to the disability and the child's sensory deficit"* (VICAR14).

In addition, there is another difference in the ways in which the adults in question approach such a matter. Self-harming behaviour is supposed to be a behaviour that causes injuries to the child's body (e.g., *"hitting the head or biting nails until the fingers start bleeding",* ASCAR27). However, all interviewees who talk about the matter seem to differentiate self-harming behaviour which can cause harm to the person for the purposes of satisfaction, from self-harming behaviour that occurs in an attempt to communicate (e.g., *"expression of dislike"*, ASCAR30) or sensory purposes: *"I think that due to the fact that this takes place on the forehead, this reveals stubbornness or that something is not right, that she does not like something",* (VIPROF15).

Self-harming RB is a massively complex phenomenon, which occurs in many different settings, often causing fear, suspicion and misunderstanding (Rayner and Warner, 2003). From my perspective, this reflects a sense of the helplessness people feel towards the issue, maybe because it is not a well-understood type of behaviour: *"I don't know what to do to help him. I have given up my entire life for him. I should be* *stopping it from happening and now I don't know what to do."* (ASCAR27), *"She is trying to get my attention? She likes it? She's in pain? They tell me she is testing my limits. Do I stop it at once? Sometimes I don't understand but I try to ask so I can understand..."* (VICAR16). These statements also highlight that the parents feel morally responsible for their child's behaviour. Gal et al. (2009) hold it to be the most serious type of RB with a distinctive pattern, observed in children with intellectual disability but mostly with VI and on the AS. As far as individuals with VI are concerned, some researchers like Gal and Dyck (2009) write that the severity of self-harming behaviour is connected with the severity of the child's VI. If, for instance, the child is totally blind, then there is a higher possibility for her/ him to exhibit a self-harming RB than another person who is partially sighted, as echoed by a participant: *"I understand that sight loss adds to a person's sensory needs or the insecurity which may manifest in the form of a repetitive self-harming behaviour."* (VIPROF2).

A pattern regarding both caregivers and professionals can be observed, which seems to relate to a tendency to stop an RB. This stopping of the behaviour takes place *"when the RB is a self-harming one"*, say all the professionals who work with children with VI, but also with students on the AS. In other words, when the RB begins to become dangerous for the child's physical health, then the professionals choose to put an end to it *("Parents don't like seeing him getting injured, even in small places with his nails. Self-harm is unacceptable and prohibited in the setting."*, VIPROF15), regardless of what the child is trying to communicate through the RB *("When the situation got out of hand with self-harm, then I would stop anything we were doing at that time. Even if I knew that he was trying to communicate, for example, his dissatisfaction."*, ASPROF23). For the caregivers, however, this decision is usually made when they find themselves with their child in a public space*:* *"It's not nice. I often lower her hand a little bit, discreetly, give her something else to hold and occupy herself with"* (VICAR8), *"When my* *child was younger and we used to go see my sister who lives in the countryside, she and I both used to feel that everyone was watching us... it bothered her. I had to stop the behaviour immediately"* (ASCAR3). The effect, therefore, of the environment (public or private) on the decision-making of the adult, in relation to the acceptance or not of an RB, becomes obvious. It is an aspect that seems not to affect the professionals, but only the caregivers on the whole.

Similarly, regarding individuals with ASD, Richards et al. (2012) see a link between increased self-harming RB and children on the AS with additional disabilities (e.g., intellectual disability). Evidence for this has been found in some of the professionals' statements which reflect their own perceptions on the matter; that RB should be a criterion for multiple disability: *"I think he may also have an accompanying problem. It's not just the autism. His self-injuries are intense. (...) There may also be mental retardation. I don't know…"* (ASPROF1). What is also worthwhile mentioning is the observation of McDonnell et al. (2002), according to whom self-harming RB in a child with ASD becomes perceived in her/ his social environment as a greater social taboo and involves greater emotional involvement. In the current study, the self-harming behaviour of children with ASD is explained by participants as a 'symptom' of the disability that has to be eliminated for safety reasons (*"In autism we often encounter children who self-injure. And vice versa. When you see them hurting themselves, you know it's autism and you should try to change or eradicate it somehow. Otherwise, you will get in trouble."* ASPROF20), but for social reasons as well (*"Whenever he feels bored, he starts biting his hand until it bleeds… But it's so embarrassing when he does it in front of other people! It makes me look like a useless mother! This is a small community. Don't people understand? They only judge you."* ASCAR31). Caregivers seem to have adopted a perception according to which self-harm is not socially acceptable and at the same time it reflects the quality of the parental role, namely how efficient or not a parent is towards her/ his child on the AS.

Compared to the same behaviour in a child with VI, though, people's perceptions differ. Without any doubt, vision is an important factor in helping children connect with other people around them (Dale and Salt, 2008, Hobson, 2005). However, self-harm is considered as a stress result due to the lack of one of the senses (*"It's a justified reaction. Since the very important sense of sight is absent, it is natural and expected that something like this happens."* VICAR15) and is in no way thought to be taboo or an obstacle to communication (*"When she is angry, she'll want to go, she'll start shouting, start biting herself… This is her own means of communication. Everybody understands."* VIPROF11*, "It happens a lot during the day and a lot of the time we have to tell her to be careful so she doesn't injure her eyes. Our only concern is that she does not injure her eyes... Everybody adores her. Everybody understands that blindness is not an easy thing to have."* VICAR8). The question that emerges at this point is why this difference might exist. No further research studies related to what people think/ believe/ feel about self-harming behaviour individuals with VI might present, have been found. The only data found is related to recording and detecting RB in children and prompting adults to distract or stop that kind of behaviour, for safety reasons (Gal et al., 2009, Singer, 2009, Stone, 1997). Only Kingsley (1997) has referred to stopping an RB exhibited by a child with VI because it might stigmatise the individual. Very interestingly, Kingsley (1997) discusses body language and how it could be interpreted as inappropriate and as a recipient of negative comments. For example, she argues that RB is noticed after childhood when an RB is not expected to be exhibited by a child. More interestingly, the reason why an RB of an individual with VI could be considered negatively after childhood is "the impression" that the person has "severe learning difficulties rather than a visual impairment" (Kingsley, 1997, p.25). When referring to a severe learning difficulty, this does not refer to ASD; however a child on the AS might have a learning difficulty as well (Silva et al., 2017). This leads to the conclusion that, once again, the risk of stigmatisation probably starts from the perception that RB is equal to a learning difficulty diagnosis. At this point, it has to be highlighted that as far as VI is concerned, an RB does not comprise a diagnostic element. Therefore, from an EST perspective, it is the conceptulisation of a disability which impacts on individual perceptions about the behaviour. At this point I am referring to the exosystem, the ex-macrosystem as well as the macrosystem and their interaction; this is a point that will be discussed in more detail in the next chapter.

5.VI.ii The diagnosis behind the disability: terminology used, sensory need, self-organisation

More views connected to both disabilities could be identified in terms of the language and the terminology that all the adults use and the way they generally express themselves towards disability. For instance, some caregivers of children with VI argue that RB is very common for the child to manifest, maybe because they have been told so: *"According to the neurologist, RBs have a neurological base and they do affect my child's mobility."* (VICAR2) or because they believe that the cause of RBs is the person's sensory deficit*: "Since Christina can't see, she tries to sense her environment, through those movements. For instance, she senses the size of the space she finds herself in through the draft that her movement creates."* (VICAR16).

Similarly, all the caregivers and professionals from the AS group consider disability to be a reason for the children to indicate RB. Actually, two caregivers consider dysfunctions of organs such as the bowels or the central nervous system to be the main reasons for their children's *"challenging behaviour"*: *"Children on the AS have detoxification systems that do not function very well. (…) Therefore, the child exhibits RB"*.

Likewise, *"the neural inflammations in the brain have an impact on a child's behaviour, thus she/ he could demonstrate RB"*. In the first case, ASCAR3 believes that she can manage her daughter's gut, and thus over her behaviour as well. As for ASCAR22, she thinks that it is inevitable for the child to exhibit RB, because it is part of the child's disability.

Sensory need in either case is another important finding. In terms of ASD, it was only expressed by the professionals who believe that RBs are not related to the person but to the degree to which the child reduces the stimulation level: *"And he does it mostly during the break when it's sunny, when it's... and with all this noise with the children, and he has issues with his ears, he doesn't like hearing things, and he shuts his ears. And when it's sunny, he chooses to play with the light in this way. (…) Not play. He likes this in a sensory way"* (ASPROF1). People perceive that sometimes RBs can offer stress-relief and as a speech and language therapist (ASPROF20) points out about a student with ASD, *"Based on neuroscience, we can tell if it is a stereotypy through the parietal lobes, i.e., that she wants to hide a sensory stimulus because the molecules are softer and she receives a vestibular stimulus from that. Every time she is upset and she hits her head there, she finally calms herself down, as if she's taken a tranquiliser"*. This direction is different to the one originally pointed out in 1920 by Freud (2003), when discussing the way in which children are looking forward to feeling protected against a stimulus. Freud talks about the psychological basis of wanting to be protected, whereas this professional is trying to provide a more neurological or biological explanation. Similarly to ASPROF20 (speech and language therapist), ASPOF1, who is an occupational therapist, added that children on the AS exhibit RB, aiming to experience stimulation by throwing themselves on a hard surface. Speech and language therapists' and occupational therapists' perceptions are seen under the light of over – or under – responsiveness to sensory stimuli that may cause difficulties in terms of modulating sensory input (Baranek et al., 2006, Ben-Sasson et al., 2009, Grandin, 1996, Leekam et al., 2007, Robertson and Simmons, 2013, Williams, 2009). This is another way of approaching RBs that could be linked with the nature of the profession of the persons in question. In other words, these people are 'therapists' (e.g., speech and language therapists, occupational therapist, psychotherapists), a field that in Greece is mostly based on the individual's clinical picture and on the prevention, evaluation, diagnosis, cure and scientific research of the disorders in particular, as is stated both in the official task-book, defined by a ministerial decision of the Greek Ministry of Education and Religious Affairs[16] and in the "Study Guides"[17] of relevant University Department (e.g., psychology, speech and language therapy, physiotherapy) study programmes. To be precise, the professionals in question learn through their studies to focus on the clinical condition of a person and to make interpretations mostly based on a medical model. Sensory perception differences, therefore, are thought to be important when it comes to people with ASD. At this point, a link to the exosystem of EST and its impact on perceptions can be made. This link makes obvious how direct the influence and relationship between the curriculum aspect of the exosystem and society's perceptions are and how direct the influence towards children with VI or ASD and their families will be in turn, should these perceptions change. Because, if these perceptions change, then the content of the curriculum will be different and as a consequence, the professionals will rely on different principles when it comes to working with the child with VI or ASD and their family.

More specifically, however, there are many mentions of sensory sight-related stimuli, used as an explanation of RBs manifesting in

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[16] These are guidelines provided by the Greek Ministry of Education and Religious Affairs and are interpreted by associations according to their specialism. These are not curriculum, but they are based on it, in terms of the intervention method they choose.

[17] A "Study Guide" is the official informative handbook of any University Department of the country (Greece) regarding the general philosophy of the Department, the teaching process, the lessons, the staff, any finance obligations and the general aim of the Department.

children of both disabilities. To use an example, ASCAR27 says: *"For example, he does this (demonstrates movement while speaking: waves fingers in front of eyes) in front of his eyes. He might do this (demonstrates movement: moves pupils sideways and up and down) many times"*. Likewise, ASPROF31 notes: *"When it's sunny, he chooses to play with the light in this way. By blinking the eyes in the direction of the sun for hours on end if possible".* These RBs could be occurring as a reaction to the hyposensitivity that children on the AS have according to what Kaiser et al. (2010) assert. Their research has demonstrated that lack of accurate detection of people's movement due to reduced visual sensitivity might lead the child to "unsuccessful behaviour" (Kaiser et al., 2010, p.191), namely RB.

Similarly, children with VI could have the same reactions, due to their reduced visual sensitivity and low levels of sensory perception, because of their total blindness or partial sight. VICAR6 presents a similar image involving their child: *"He was pressing his eyes. They must have been causing some type of stimulus as he can't see well and so he pressed them".* Another caregiver (VICAR8) adds: *"The eyes, more frequently. Pressing the eyes is more frequent. Us too, if we press our eyes, we see sparks (…) Kaiti has her eyes on her knees and she is pressing them against them, er... she shows that she isn't available to speak with anyone".* In other words, eye-poking, can produce visual 'sparks', through applying pressure on the eye, for a child who has low levels of sensory perception: VICAR13, says: *"I mean I understand that when she is very happy, she does this (demonstrates movement: rubs eyes with fingers) or when she doesn't like something, she shuts everything out, like withdrawing, organising herself"*. Finally, VIPROF15 of a child with VI notes: *"If the teacher makes him (…) do something and he doesn't want to, he will either shut his eyes, which he often does too, or he will begin to do this and won't pay her any attention at all".*

At this point, consulting my notes in my research diary, I notice that professionals (including myself) had the tendency to use the term "sensory stimuli" very often, in order to describe a behaviour, explain it in the context of an interdisciplinary meeting and share it with parents/ caregivers. For example: *17/ 1/ 2008 - Today we had an interdisciplinary team meeting about KT and her RBs. The occupational therapist and the speech therapist insisted that they are the result of sensory stimuli and that the correct course of action is desensitisation. The psychiatrist and I did not agree with the approach.. He said this is a way for the child to communicate. She generally doesn't speak. If we stop that too? What then? I totally agree with the influence of the sensory stimuli, but not the desensitisation. But how to convince them?* The professionals showed an awareness concerning the matter, which I suppose was transferred to the families, every time they/ we had a conversation about a child. These conversations usually pertained to the self-harming behaviour of a child and were mostly aiming to explain the cause, while focusing on the hoped-for result: making the behaviour cease.

Nevertheless, the caregivers of the children with ASD make no mention of their children's sensory need, as they do not think it is necessary to justify a non-acceptable and dangerous self-harming behaviour in that way. On the contrary, though, caregivers of the children with VI seem more familiar with the sensory need of their child and this is really interesting considering that sensory perception differences are now part of ASD diagnosis (Robertson and Baron-Cohen, 2017). That might be because VI is a sensory disability and for the caregivers it might be easier to use this term to explain and accept their child's behaviour that might not seem so challenging: *"Or what I said before, pressing her eyes. I believe, as she can't see well, they triggered something and so she pressed them"* (VICAR8). Some of them, such as VICAR15, also believe that RBs offer the child *"a sense of doing something"* and it is quite acceptable, while people without VI have the same sense because their eyes are always ‘occupied’ with visual scenes. With respect to the professionals’ views on the ‘sensory needs’ matter, they are presented approximately in the same way as those of the professionals of the other group: *“I think it’s mostly simply that he enjoys the sensory aspect. I mean. Just as a baby wants to be rocked to calm down and you can immediately see it relax and calm down.”* (VIPROF12), *“All the stereotypies I have described to you, are a means of relaxation for Maria to cover the sensory needs she has; especially when she is in the same room with many persons.”* (VIPROF11)*.*

For the same reasons mentioned above, I consider the self-organisation/ regulation element as an important aspect of this research study. After observing similar reports by adults concerning the same child, it is clear that caregivers have been told about self-organisation/ regulation, which has made it part of their parenting: *“Sometimes it’s even soothing, I think, it makes him feel like that, I think... like, say, the way many of us have a cigarette or play with our phones.”,* ASCAR30 says about her child on the AS, while ASPROF30, who is referring to the same child, states: *“It’s soothing for the child. For that reason, I think he’s not so much trying to avoid, as to handle situations. He will remain here, he wants to do that or he knows that he must do it but tries to do it on his own terms. (...) Exactly like self-regulation! Like the way many of us have a cigarette or play with our phones”*. Similar confessions made by both caregivers and professionals of the VI group, have been recorded: *“I believe that she has that behaviour every time that she wants to regulate and organise herself; to reduce her stress levels.”* (VICAR2)*,* while VIPROF2, who is working with the child in question notes: *“…it depends on her mood, on how calm she is. Repetitive movements may have to do with the fact that she wants to regulate herself, to become organised, to help her levels, to reduce her stress…?”.* The influence of the professionals’ way of thinking on the caregivers’ opinions is apparent again, since caregivers appear to be using a similar manner of expression, in order to describe the same event; that is, the RB of the same child. Similar examples accompany all pairs of interviews relating to the same child, whether that is a child with VI, or with ASD. In other words, in the case of every caregiver who consented to the accompanying professional interview, or that of a professional who agreed to take part after the consent of a caregiver was given, one can observe the existence of a point that illustrates the effect of professionals on the perceptions of the caregivers. These relationships reflect that the caregivers' views and perceptions are not immune to what people around them perceive. An influence on the caregiver's attitudes from the messages the professionals send is apparent and this is something that points out how important the professionals' opinions and statements are for the caregivers. This could be because of the professionals' authority; because professionals are part of society, the voice of which the caregivers might feel that they represent. In any case, the EST is apparent again here and it shows the interconnection between the two systems: that of the professionals and that of the caregivers.

Generally, all the groups seem sensitive towards the existence of the self-organisation factor their actual opinions seeming not to vary much across the two disabilities. In VI, self-organisation seems a very important reason for the exhibition of RB, especially when the child does not like doing something such as being assessed or contained by a professional; it is like the child is meeting self-regulation needs: *"I believe all this jumping up and down isn't functional, it has no functional purpose. He only does it because it offers him something right there and then, some form of self-regulation, when I pressure him a lot.",* (VIPROF14)*.* Yet, regarding the ASD, caregivers insist more on the need of their children, every time they need to be focused or isolated from the environment around them: *"Due to several stimuli (e.g., acoustic, smells, anything) a level is reached where the child becomes overwhelmed. In other words, it is a state where the neurological system cannot take all this. There is a high probability for* *the child to manifest such behaviours more intensely, so as to allow her/ himself to self-regulate and to achieve self-organisation.",* (ASCAR30).

For the adults of all groups, RBs are often linked to the child's diagnosis of either disability. According to the ICD-10 (World Health Organisation, 1993) and the DSM-V (American Psychiatric Association, 2013), ASD could be diagnosed on the basis of the existence of RB, although it should not be considered a one-size-fits-all criterion; in other words RBs vary across those diagnosed with autism. In terms of VI though, no official diagnostic manual holds RBs to be an actual diagnostic feature. However, according to the caregivers' and professionals' perceptions, RB is attributed to the children's visual deficiency. In other words, it is apparent how diagnostic criteria might impact on people's perception.

5.VI.iii Speech and communication

Speech is another component mentioned by many adults from both groups. They link the children's RBs with speech, mostly referring to them by using the term "echolalia". In fact, echolalia is the repeating of words and/ or phrases that can be observed in young children (with or without any disability), serving the purpose of wordplay or rehearsal (Webster and Roe, 1998). In the current research study, the main idea is that for the professionals, echolalia is a kind of RB and it does have a purpose and function: *"His echolalia is surely meaningful (…) Its meaning isn't immediately obvious."* (ASPROF22), *"She uses echolalia to communicate. She repeats words or expressions that she likes and uses them persistently... As a stereotypy… When she does something well... well... When she achieves something learning-wise, and I say "Well done! That's perfect!", she repeats "Perfect!", "Perfect!"* (VIPROF8). For caregivers though, echolalia is not considered as an RB and does not involve a significant and clear purpose: *"He doesn't have RB. What he has is* *echolalia; meaningless echolalia. He does it without having had an acoustic stimulus. He just does it randomly."* (ASCAR21), *"That is called 'echolalia'; isn't it? He mumbles in the same way in order to eat. He doesn't repeat things he heard, though. Why would he? We could have avoided it."* (VICAR15). In the first case, echolalia is highlighted as a meaningful kind of speech for the child, yet in the second case it is not. There is a perception here on behalf of the caregivers that echolalia is *"annoying and purposeless (…) This has nothing to do with speech and has to be stopped otherwise it is ridiculous for everybody* (ASCAR23)*"* and *"It's shameful! I know! Only his nursery teacher can make him well. His echolalia is constant. When he wants to have his own way, he resorts to it and they can hear us two blocks away!"* (VICAR6). Professionals, however, consider the existence of echolalia as an opportunity for communication without usually aiming at making it stop but at taking advantage of it by developing it: *"Another stereotypical movement is her echolalia… For instance, you'll say 'Done' and I'll say 'Perfect'. She says I'll say 'Perfect'. And I say you'll say 'Done' and I'll say 'Perfect' if you do it right."* (ASPROF22), *"This is my way of communicating with Dimitris. I use echolalia to play and discuss with him. I know this is not pleasant for his parents, but it does make sense to me based on the progress he makes."* (VIPROF15).

However, from my point of view, in both cases the adults hold the goal to be the same: that of communication. Actually, in an old research study regarding children with VI and those on the ASD, Fay (1973, p.478) states that "echoic behaviour persists, reflecting the human drive to participate in communication by speech". The communicational function of the RB can be traced as a perception in the words of the participants. Caregivers and professionals try to understand the children's RB (*"Understanding the children's attempt to communicate by using stereotypies is a challenge that we have to confront."* VIPROF11, *"Decoding Angelos' RB is a great task that I owe to myself to undertake!"*

ASCAR24) by considering it to be a means of communication, thus attaching meaning to it (Chiang, 2008): *"When he has that behaviour, he always tries to involve an adult. It's a kind of interaction and communication with the other."* (ASPROF22), *"Whenever he wants to communicate something, he prefers not to ask for it but to start that RB."* (VICAR6). I also understand how important communication is for them, as it signifies a shared code of mutually understandable signals between the child and either the caregiver or the professional. It is as if they are trying to spot signs of communication between them, as well as to explain the RB: *"She would communicate it to me if something bothered her. But couldn't verbalise it. So, that could make me feel like, 'Ok, so now what? Are we going to spend all our time on this leg? And then I understood..."* (VIPROF16), *"I try to explain why he does it. Why he tears and throws the books. Why he wants to upset us. If I can't explain it to myself, then I can't offer any reassurance to his sister, who gets quite rightly annoyed."* (ASCAR11).

In certain cases, actually, some caregivers from both groups offer interpretations of different types of RBs. For instance, ASCAR24, states: *"Fatigue is the main reason for his ceaseless speaking. This fatigue may be the result of a challenging day at school or even of a pleasant day spent with friends. That constant behaviour is because of his mental fatigue".* Likewise, ASPROF31 confesses: *"He is so talkative every time he gets tired. He says the same thing repeatedly. For seconds... For minutes… For hours…".* Interestingly, Webster and Roe (1998) claim that there are plenty of explanations regarding speech and communication attempted for RBs that individuals with VI manifest. For example, self-stimulating activities in children who struggle in coping with an overwhelming environment and use RBs such as spinning, hand flapping, body rocking: *"Physical rocking is observed only in situations of extreme anxiety, e.g., before a medical examination he fears will hurt"* (VICAR15). Finally, when RBs occur, they might be a response to monotony, arousal or overwhelming social demands (Tröster et al., 1991a): *"This movement when he pulls his arm backwards is linked to strong emotions e.g., when he is angry or feels he's under pressure and he reacts"* (VIPROF15).

Specifically, as far as ASD is concerned, there are research studies that have focused on the difficulties professionals face in order to understand and initiate communication with children on the AS (Kroeger and Nelson III, 2006). Indeed, ASPROF23 argued about his student: *"He does it when he really wants to say what he wants. It took me time to understand…"*, when ASPROF20 stated: *"So, something that is Elpida's trademark... the RB she uses (…) can be linked mostly 'manipulatively' to communicating, (…) by banging her head she wants to show that she wants something, er... she has a need. I understood this by working with her over a long time".*

Interestingly, VIPROF2, mentioned that she tries to adjust her behaviour to her pupils' potential RB with the help of music: *"I make even their stereotypical movements meaningful… that is, I create, I play on the stereotypy's rhythm. Whatever that stereotypy might be…", "We can say that she is happy with music and expresses this by bouncing her body. With other activities that she doesn't like, she may hit her head. This is our code; a kind of communication for us"*. This is an attitude, the importance of which is highlighted by Kossyvaki et al. (2016), when they refer to "adjusting behaviour". They emphasise the adaptation of the adults' behaviour to that of the children's, with the aim of changing the behaviour of the latter. Yet again, therefore, it seems that a change in relation to an ecological circle (e.g., microsystem) could directly influence the behaviour of the child with VI or ASD, who is situated in the centre.

5.VI.iv Feelings

It was also found that all the caregivers and the professionals explain the children's RBs by pointing to their own – that is, the caregivers' and professionals' – feelings or the children's feelings as well. They attach more importance to what Fredrickson (2001) and Hammon-Jones (2014) call "negative emotions", namely feelings with unpleasant emotional nuances. For some adults, RBs are either an expression of dislike (e.g., *"With other activities that she doesn't like, she may hit her head.",* VIPROF18/ *"When he is not keen on something, then he starts biting his palm – not severely, but just like a reminder of his preferences."*, ASCAR31), or of disappointment (e.g., *"I think sometimes he also realises that… when he can't fulfil his wishes, he feels disappointed and sad.",* ASCAR4/ *"She is a sensitive child and easily feels rejected. She often uses RBs to express her disappointment."*, VIPROF8). In some other cases, RB is taken to denote lack of trust/ insecurity (e.g., *"It is a matter of insecurity. My child feels insecurity because of the sight loss and thus he exhibits RB. I remember his first day at school. It was catastrophic. He didn't even want to enter the room. (…) It took half a year until he started to feel comfortable, to enter the room and sit throughout the sessions without exhibiting any RB.",* VICAR14/ *"I think it makes sense that he would react with intense RB around strangers, or when a therapist in his programme changes; it takes him time to trust.",* ASPROF), or as an expression of stress/ anxiety (e.g*., "He couldn't sleep because he worries about something happening to him, and he doesn't know what that is.",* ASCAR4/ *"It is likely that they externalise their anxiety with these movements. We are talking lots of internalised anxiety. That's why I try to use music therapeutically. There is no reason for more pressure.*", VIPROF12).

Anger that the child might experience (e.g., *"When she gets mad, she scratches herself and the people around her! (…) It is like she wants to say: 'I don't want to! Leave me alone!'"* ASCAR31/ *"Of course she gets angry, as we all do. When that happens, she shakes her head vigorously and rolls her eyes around – I wonder how she manages!"*, VIPROF11) or insult (e.g*., "He is easily offended. I once showed him where to colour,* *and I said you are colouring outside the lines, he started shaking his head and flapping his arms repetitively.",* ASPROF22/ *"When he overhears people saying things about him that he doesn't like, he takes offense. And he's right. Then he starts running in circles around himself for a long time."*, VICAR13) might induce RB. Finally, fatigue (e.g., *"Speech-related RBs are mostly linked to fatigue. This fatigue is mostly mental, e.g., after intense studying for school, and social, e.g., after an event such as a party where he will need to interact with a lot of people. Afterwards, he feels the need to wind down and shut everything else out and this behaviour helps him.",* ASCAR30/ *"I have observed that RBs – echolalia in particular – become more intense towards the end of the day, when he is tired.",* VIPROF14) and boredom (e.g., *"I do think she does it when she is bored. And she jumps up and down and tries to release the feeling.",* VICAR8/ *"Can you blame him? He is bored in class and gets restless for minutes on end."*, ASPROF31) are also mentioned by the interviewees, as explanations that they attribute to the RBs. RBs occurred as a response to boredom, as is actually confirmed by Warren (1994) and Webster and Roe (1998).

On the other hand, "positive emotions" (Fredrickson, 2002) like joy (e.g., *"When we're out, say when we go to the theatre and he's happy, he does it even more.",* VICAR2/ ASPROF21) and satisfaction (e.g., *"We can say that she is happy with music and expresses this by bouncing her body.", "When our programme takes us out of class, he absolutely loves it. He knows that we might go to the supermarket and that he can buy chocolate, which is his favourite. What I am most interested in is that he expresses his joy in a decent way, so that he doesn't attract attention – which his parents dislike.",* VIPROF12) are mentioned by the interviewees only two times, as seen above, and by participants linked to the VI group, in order to explain the reasons why the children present RBs. It seems like the caregivers' and professionals' perceptions are connected more to negative feelings and negative incidents than to positive ones. RBs are the expression of a negative feeling inside a negative situation, as that is experienced by the participants. It seems easier for the individuals connected to children with VI to interpret an RB as having a positive intention, thus giving the impression that they accept that behaviour as occurring under the umbrella of VI.

Those cases reflect the understanding and expression of feelings, which is considered to be part of typical human development (Elfenbein, 2013). This expression of feelings is highlighted by Aviezer et al. (2012), as a core role of the human body, which is characterised by Williams (1998) as a sensory tool that welcomes every feeling. This is really important for people to understand, in terms of their own or their children's or students' mental and psychological health (Fredrickson, 2001, Hammon-Jones, 2014). Talking about children with ASD, Shalom et al. (2006) found that socio-emotional expression in ASD might be connected to difficulties in the expression of feelings. This could explain the means of expressing their feelings on the part of the children on the ASD in the current research; in other words, the fact that they desire and attempt to express their feelings, but in a way (i.e., RB) that is not socially acceptable. In terms of the children with VI though, who express their feelings in apparently the same ways as the children with ASD, there seem to be no related investigations into how they express their feelings and emotions through specific types of behaviour.

By critically examining the attitudes of the caregivers and professionals in both VI and ASD groups, one can observe that the participants talk with heartfelt passion about the issues that concern them. Whether it is about the way in which they intervene in their student's RB (e.g., via music), or the approach they use in relation to their child's everyday life (e.g., daily diet), whether it is about the way in which they experience their child's disability and the subsequent decisions they have made (e.g., website and a basketball club for children and teenagers on the ASD) or the way in which they handle the disability, by using the RBs constructively (e.g., music group of individuals with VI), or regarding a specific issue or the reasons that led them to adopt a child with disabilities and obvious RBs; in all of the aforementioned cases, it is obvious how strongly the individuals feel (regardless of whether they are caregivers or professionals) and how much passion they have about their parenting or their teaching.

The sense of blame emerged in both the caregivers' and in the professionals' statements, but in a totally different way for each. *"Where does the responsibility lie?",* VIPROF14 and VICAR5 rhetorically asked during their interview. For all the caregivers, the blame *"lies"* with themselves, especially when they have been dealing with any kind of RB for a few years. The younger the child is, the more difficult for the caregivers to cope with the idea of RBs that might be challenging both for the child and for the adult herself/ himself. In other words, the caregivers of the older children expressed fewer negative feelings (including blame) than those with younger children.

Caregivers might need time before they can feel comfortable with a new situation such as an RB and learn how to cope with it gradually throughout the years. It is like a "traumatic event" that has occurred, as Schulz and Decker (1985. p.1162) note, that caregivers have to face "successfully". In contrast to Neff and Faso (2015, p.938) who argue that "child symptom severity is often the strongest predictor of negative adjustment for parents", the caregivers of the current case study could cope with their children's very challenging RBs, but after having coped with those behaviours *"for enough time"* as they themselves say: *"The child is very young. It's still too early for us. We have a long way to go."* ASCAR24 said, whose child is 5 ½ years old*.* And they continue by saying, *"The stereotypies and obsessions are constant. It's something entirely new for the whole family. We haven't got used to it. I don't know if one can get used to it".* However, VICAR2 who has a 9-year-old child appears unruffled, saying: *"When I first saw her using stereotypies, I wanted to* *disappear from the face of the earth. Especially when we were in a public space. But now I have made my peace with it. I also discuss it with a therapist. It doesn't bother me that much. There's not much that can be done about it!".* In addition, there is one more interesting element regarding the feeling of blame. All the male caregivers of the research study, while talking about their children's RBs, put the blame on their children and how they cannot cope with their own disability whether it is VI or the ASD. However, the female caregivers claim to be feeling more responsible for their children's RB, showing a more self-critical attitude; something that Baden and Howe (1992) and Seymour et al. (2013) have also observed.

In terms of the professionals, though, the feeling of blame lies with the caregivers' attitude towards disability: *"With me he presents less stereotypies than when he is with his parents. He is afraid of me and he respects me. That's the reason. And I am honest towards them!",* VIPROF14 argues. While ASPROF1 states that *"Giannis's behaviour when at home differs from when he is here at school. That's to be expected, as with any other child of his age. The thing is his stereotypies and the reason why he demonstrates them more when he is with his family. What is he trying to say? This is a constant subject of conversation with the parents"*. Professionals express a high level of self-recognition, no matter how *"tired or exhausted"* they may feel, as VIPROF14 mentions. This attitude may be affected by various components such as the professional's confidence or the child's level of social skills (Nørgaard et al., 2012, Nota et al., 2007) and might also impact on the professionals' own management. That management could affect the caregivers' perceptions as well. In either case, those perceptions may influence the use of ineffective coping strategies and cause increased stress.

5.VI.v Senses

On the one hand, the group of adults relating to VI appear to be the only ones who consider the senses and more specifically the olfactory system to be important for the partially sighted or totally blind child. Indeed, as Fielder and Proulx (2019, p.21) argue, "blind individuals, given their loss of vision, have enhanced olfactory performance". The group of adults relating to VI, then, acknowledge the RBs as a perfectly justified need on behalf of the child to use smell in an attempt to activate the rest of the senses, since sight is lost (e.g., *"If I did say she presents stereotypies, it would be because of her strong sense of smell. This is because of her diagnosis. She smells everything and everyone around."*, VICAR16/ *"Olfaction is her second eyes - smell is a tool for her. It is absolutely normal. I don't worry at all. She is blind, so, as far as I have been told, this is normal."*, VIPROF16/ *"She bends down and smells… She does this RB more because she can't see well."*, VIPROF11). Because of the fact that the children with VI cannot see, the interviewees seem to consider it to be expected that the latter will express hypersensitivity in terms of their olfaction via RB. I have similarly observed that this behaviour is extremely helpful (Stylidi et al., 2015, Tavoulari et al., 2015), since smell can create memories and can imprint olfactory maps in people's minds (Ferdenzi et al., 2010, Koutsoklenis and Papadopoulos, 2011). So, if repetition occurs with a specific olfactory stimulus, this is an RB that becomes a pattern; a pattern which is not forgotten by the person (Weiss and Sobel, 2012). However, the interesting thing is that the use of the olfactory system in the context of an RB is not mentioned in relation to the children with ASD group, even though often enough in the literature it is referred to and described, for example under the term high smell sensitivity (Leekam et al., 2007) or hyposensitivity (Muratori et al., 2017).

On the other hand, caregivers and professionals who are related only to children on the AS mention RBs that relate to the sense of hearing.

For example, ASPROF22 states: *"When he shuts his ears I don't react much anymore, until he opens them, and I go and say, for instance, 'I want you to open your ears'".* Another one (ASPROF27) says the following: *"He also has an issue with noise made by other children, he doesn't want to hear things, and he shuts his ears".* Likewise, ASCAR24 states about her child that *"when she knows that the reason you are calling her is so that she will stop something she wants to do, she shuts her ears".* Actually, those statements could be linked to similar auditory behaviours that have been a matter of interest for several researchers (Danesh and Kaf, 2012, Egelhoff et al., 2005, Tharpe et al., 2006), due to hypersensitivity to sound or hyperacusis that children on the AS might have. In some cases, actually, some noises can be eliminated or avoided by children *"shutting their ears"* (ASCAR24) to decrease their stress levels (Gibbons, 2005). Thus, it could be suspected that this kind of RB is a matter of communication for children who are startled by moderately loud sounds. This is something that was not reflected in the VI group's statements. It is perhaps because adults see children's behaviour as functional; they expect children to do things with their hearing, because of the fact that they cannot see. Notwithstanding, there is another aspect of that interesting observation, namely the fact that children with VI do not present hearing-related behaviours. This potentially shows that children with VI do not let these RBs interfere with their vital information gathering capacity.

5.VI.vi Rituals

Another finding is that people link RBs with time and the child's needs. Their reports are related to the children's desires plus the children's association of time and their needs or desires being met: *"One has got to do with his desires. Meaning, whether he has associated a particular time of the day with something he particularly wants."*

(ASCAR4). This child seems to know which person (mostly the father) will satisfy his desire and as a result he acts in a very specific way. This seems associated with the “ritual behaviour” system of Turner (1999), according to which RB could be divided into low-level behaviours (repetitive motor actions) and high-level behaviours (rigid routines, circumscribed interests, and resistance to change), as in the example above. Ritual behaviour of individuals on the AS can be regarded as not purposeful or problematic, while often considered functional (Eisele and Howard, 2012, Hsu and Ho, 2009): *“It is as if he has some built-in clock. Everything must be done as scheduled. Otherwise, he starts using stereotypies. I try to keep him informed about any changes and to listen to his wishes.”* (ASPROF24).

A similar attitude is also observed in some of the participants linked to the group of children with VI, who describe behaviours that refer to everyday routines in their interviews, *“After eating, when he sits in his chair and looks at his little hands and places them near his eyes. (…) In the morning, the afternoon, the evening. (…) It’s because he wants pudding and to be left alone.”* (VICAR15), *“As soon as the session is over, she puts five clothespins on a box or around one, does it on her own and tells me she’s finished. Every single time lately.”* (VIPROF16). RBs like these have been recorded by Webster and Roe (1998, p.75) as ”systematicity” of children with VI, in the form of routines and repetition of a narrow range of actions (with elements of touch, sound or movement) on objects, so as to impose and generate everyday rules.

Recognition of rituals is a key theme that I personally identified based on its characteristics as mentioned above. Rituals were not highlighted by the participants as being, for example, distinct from the RBs category. What I recognised in rituals was a type of “formality” (Michaels, 2019, p.19), as if, in some way, their daily presence in the child’s behaviour is sanctioned.

5.VI.vii Contradictions in the data

Upon examining the interviews, contradictions on behalf of the interviewees, and especially the caregivers, can be observed; often an opinion is expressed, which they refute in the course of the same interview, by saying something contradictory. This is such an interesting element, because perceptions and attitudes on the part of the participants are revealed, which betray the existence of ambivalence. It could be a matter of coping responses that influence the stressors and vice versa (Pottie and Ingram, 2008), a process which is not stable and may also have an impact on the individuals' mood and, as a result, their reactions. It could also be a matter of guilt or low parental self-efficacy beliefs (Meirsschaut et al., 2010) that place caregivers in an uncomfortable position of judging themselves. For instance, when ASCAR23, a caregiver of a child on the AS is being asked about her child's RBs, she says that they do not affect her at all; while earlier she has already mentioned how embarrassed she feels every time her child manifests RBs in front of other people. Some adults often speak contradictorily when referring to the existence or not of RBs in their child: *"No! No! Nothing at all! The only thing is that he puts his toys in lines. Rather than play with a car, he could be looking at its wheels or putting them in a line repetitively."* (ASCAR31)*.* Others present contradiction, when discussing the reason behind their children's RBs. On the one hand, they do not believe there is a reason for RB, but on the other they themselves offer a possible explanation for it. For instance, VICAR6, says that there is no reason for his son to indicate RB: *"I always tell him that there is no reason for him to exhibit a stereotypy. My lovely Nikos, please do not do this. Don't run. Don't jump. There is no reason!".* He has already stated though that boredom is what impels his son to have that RB. Moreover, and according to VIPROF8, there is no reason for the student to present an RB. However, the same professional states at a point that the student does so because of communication reasons: *"She wants to communicate with me but she can't find other ways than saying: Perfect! Perfect!".* In the same way, ASCAR22 described RBs that the child exhibits *"without a particular reason*", when at the same time the caregivers insisted that the child *"doesn't do it to congratulate or to show someone something, he does it for his own satisfaction".*

Regarding the type of RB, contradictions in the participants' statements can again be observed: *"There are repetitive motifs of movements, the clapping, the rocking of the body, the rotation of objects…yes."*, VICAR8 states, while shortly after she says: *"Hmmm… she does not rotate objects, she wants to put them in order though, or to place them around her".*

The issue of impact appears to provoke contradicting behaviour on behalf of the caregivers, like VICAR16, who emphatically denies the impact of her daughter's RB on herself: *"To me? No. To me personally, no. Of course, not"*, after she has stated how affected she feels because of being exposed to bullying, every time her daughter exhibits an RB. Likewise, VICAR14, argues: *"Bullying is inevitable. I don't mind though! I have got used to it! However, I can't go anywhere with him, without feeling other people's gaze on me – on him – on us. It's a…silent bullying, because of him using stereotypies".* When ASCAR3 was asked about her daughter's RBs, she said that they do not affect her at all; while earlier she had already mentioned how embarrassed she feels every time her daughter exhibits RBs in front of other people. Although ASCAR4 mentions that there is no specific challenge posed by his son's RB, he has already stated above how exasperated he and his family feel, because of the same issue. In the same context, on the one hand, a caregiver states that she/he has clinical depression and the signs become more intense, every time the child displays an RB; Warren (1994) actually spoke of a link between depression in mothers and the increased RBs a child has. On the other hand, the caregiver in question says that there is no impact on her caused by the RB of her child.

Few examples of ambivalence from the part of professionals who work with students with VI are noticed. For instance, although VIPROF12 generally states that her students do not exhibit RBs (*"She doesn't manifest stereotypical movements (…) She is very focused (…) Her motive is music, she actively participates, she plays the guitar, she sings."*) in her statements she makes mention of the RBs children present during the lessons, and which the professional uses as a tool during the teaching process (*"I always follow the rhythm of their behaviour as a teaching tool, along with my guitar."*). Likewise, talking about another student, the same professional VIPROF2 states: *"Whatever she does with her hands, her fingers and so on, of course I give meaning to this and hence we have this communication as well."* in contrast to the fact that *"I don't pay attention to what she does. She may also present stereotypies. She may not. Probably not. I don't care. Sometimes she manipulates me and sometimes I do the same".*

Contemplating the evidence provided above, I focus on the fact that all the participants had been informed in advance of the interviews, concerning the theme of our discussion and the general topic of the research study. That was the way in which they were given the opportunity to participate. Since they agreed to participate, it means that they recognised (as observers) in their child or student a kind of RB. At that point it did not matter how they defined this RB or what name they gave it, but that they identified it in their children's behaviour. Something similar that highlights this contradiction that I observed concerns the fact that the participants did come prepared with videos and the toys, in order to share examples in that part of the interview. If, therefore, during the interview they questioned the existence of an RB, this was interpreted as a contradiction. According to the findings, though, this contradictory attitude on behalf of the participants could be interpreted as anticipated behaviour. Very often, the experiences shared by the interviewees contradict their story. This might be because an emotional relationship often develops between the interviewer and the interviewee. The interviewee now reacts less as an observer of herself/ himself but comes closer to her/ his perceptions and attitudes, as she/ he enters into more detailed descriptions (Roulston and Choi, 2018). This is something I did notice with my participants, who acknowledged the behaviours later in the interview. For example, VICAR6 mentions *"I thought it would be a straightforward process – just talking about my child stereotyping. Now I realise that I am trying to find solutions through our conversation; solutions regarding my child's unjustifiable behaviour"*.

One last point of contradiction in the participants' attitudes towards the presence of RB that I would like to indicate is regarding the videos and toys usage. In some cases, the content of the videos (e.g., a child moving her body right and left as a pendulum in front of an audience) or the examples of the toys (e.g., staring at a doll and then shaking her hands constantly in front of the eyes) and associated behaviour which was discussed (e.g., in both cases mentioned above, the interviewees said that the child *"fortunately does not present any kind or RB"),* highlight the ambivalent sense of reality interviewees have. A sensible enquiry that reinforces the aforementioned ambivalence, is why did they bring the video and the toy imitating an RB, if there is no repetitivenss observed in their children's behaviour? And in fact, why did they volunteer to take part in a study on RB, if they thought their child/ student did not have any RBs?

5.VII The biggest challenge in trying to manage a repetitive behaviour

Interestingly, only a few of the adults from both groups spoke about the greatest challenge that they are facing in relation to the RBs of their children or students, while the rest of them avoided answering the question. To be precise, for some caregivers of children with VI, there is no challenge *"There is no challenge at all* (VICAR6)", while for all of the rest a challenge does exist, relating to factors like the ones below: *"It grieves me to say that since the moment Fotis was born and we discovered what was going on, that's when the challenge started. When he stereotypes in public, it makes things a lot worse."* (VICAR14).

On the one hand, caregivers from both groups did not give a clear answer, or they appeared to contradict themselves by saying first that there is no specific challenge in trying to manage an RB and then describing a really challenging behaviour with them trying to cope with their feelings and their reactions/ intervention methods. For example, the same caregiver as above, VICAR14 of a child with VI states that there is no challenge posed by his son's RBs, while later in his interview he said: *"Because there will be bullying. Let's say we go to a coffee shop for a coffee, and he will drink his juice, and I my coffee etc, and when he starts doing that, I try to stop him because I know heads will turn. That bothers me. Not that it makes me feel bad, God, of course not. He's my child".*

On the other hand, professionals want to deliver their services as well as can be expected in either the case of VI or the ASD. However, they have the perception that once the RB occurs, it will be impossible for them to redirect the child's attention and continue their intervention programme as scheduled: *"The fact that he won't let me work is a challenge."* (VIPROF15), *"What I find the most challenging when he does it is that he won't pay attention to me. So, I can't... I direct his movement somewhere but I would like him to look at me at some point and pay attention so that* *he'll understand what we're doing."* (VIPROF16), *"The teachers' responsibility is a challenge."* (ASPROF30), *"The biggest challenge is... it's either to explain it or to stop it. One or the other. And I'm not for stopping it. If it's not harmful to the child and those around him. If it's not harmful then just leave it and control it somehow. So that it occurs when... for shorter times."* (ASPROF23).

As far as both disabilities are concerned, a difference is observed between the quality of the challenges linked to the RB of children with VI and those with ASD. It seems that caregivers of children with ASD try to cope mostly with their own anxiety, caused by their children's behaviour and with the fact that a child's RB might not be socially acceptable: *"Ensuring he is independent before you pass away is a challenge. Knowing that he could take control of himself, every time he manifests an RB in front of other people."* (ASCAR21), *"Social integration is a challenge. You think he's made it, and all of a sudden, he might start using stereotypies again in front of other people."* (ASCAR22). Caregivers of children with ASD believe that their child's social image is affected by the RB they might have, which is not socially acceptable.

Caregivers of children with VI though, agonise over how the children themselves experience their own RB, which might disturb them emotionally: *"I find it challenging. What's difficult is maintaining a balance which will prevent her from doing that without tiring her, without making her angry, or offending her in front of other people."* (VICAR8*), "The biggest issue is when she wants something and she shows it in a repetitive way and I try to understand and can't and she gets angry. That's our biggest problem, this anger."* (VICAR16).

Last but not least, in the case of professionals working with children on the AS, they seem to have cultivated a sense of responsibility with regard to decision making and problem solving, concerning behaviours that are potentially harmful for the child (i.e., self-harming RB): *"Finding* *the real solution is a challenge, for him not to be self-harming."* (ASPROF21), *"During our sessions, I am responsible both towards the child and the family. If anything, I need to make sure the child does not leave the session with an injury."* (ASPROF20).

All of these differences could be related to the professionals' expectations; the expectation, for instance, of the soothing or the disorganisation that their intervention in an RB will result in. It appears that the professionals' expectations might be related to the way in which they manage RB exhibited by their students and as a matter of fact the collaboration they have on that matter with the caregivers: *"When he starts doing his thing, I don't expect much of him. He is completely absorbed. And it's an issue when his mother is present. I think she gets annoyed with me. Whatever we've achieved in the one hour of the session, she doesn't see it."*, (VIPROF15). Other related evidence is seen in ASPROF27, as well as in VIPROF18 accordingly: *"I don't always tell his mother about the stereotypies he uses. (…) It's not that she doesn't trust me, but she tells him off and I don't want her to. She may be right, though; when I see him like that, I know there's no lesson happening."*, *"I explain to the family how the brain works during such repetitions in behaviour, and they understand and stop them at home as well. They say that they explain what happens to other parents as well to help."*. The caregivers connected to the above professionals present a similar attitude towards a potential RB in terms of the way in which they discussed the same child with me: *"Whoever cannot contain his stereotypies can therefore not control his behaviour or him himself."* (VICAR15), *"I have the tendency to reprimand him every time he presents a stereotyped behaviour and I expect the same attitude from the people working with him."* (ASCAR27), *"They have explained to us how the brain works when an RB is happening. We have also been told how to react and terminate such a behaviour."* (VICAR18). Ultimately, an effect on the perceptions of caregivers caused by the professionals could be observed and vice versa, namely an effect caused by caregiver expectations on the professionals' perceptions.

5.VIII The impact of repetitive behaviour on the child

It seems that all the adults made mention of the impact RB might have on their children's/ students' lives. However, it emerges that this impact is expressed differently by caregivers and professionals. Only VIPROF11 talks about the difficulty of the child in communicating with other children clearly, because of her RB: *"Certain acoustic stimuli don't … while she likes songs, loud voices and hubbub throw her into a lot of confusion. She wants to avoid it; she doesn't like it and thus, she avoids other children."* The rest of the professionals as a whole are focused on the aspect of health, which is affected especially when the child resorts to self-harm: *"It definitely affects her health first of all. I mean head injuries."* (ASPROF20)/ *"Her RBs affect her health and I am not only talking about head injuries, but also about potential headaches or emotional agitation that she may feel."* (VIPROF18)*,* as well as that of education, in the sense that the professional's work, and as a result the child's learning, are obstructed, when the RB appears: *"When this (self-harm) took place, the programme would 'fall behind'. We could not proceed… the main concern was for the child not to hurt herself and not following the programme."* (VIPROF8)/ *"How can I not think of his performance at school? He is a good student, but when he engages in RBs he loses it entirely. And then I have to face mostly his mother, to whom – cooperative though she is – I must explain things that should be taken for granted."* (ASPROF30).

In terms of the caregivers, there is no difference that could be specified between the two groups of disabilities, but only three types of similarities. Firstly, they focus on the social aspect of their children and mostly on their relationship with peers: *"Her stereotypies throw her into a lot of confusion. She wants to avoid it, she doesn't like it and thus she avoids other children."* (VICAR2), *"Usually when he does it in front of other children, they look at him funny or they get scared and go away*." (ASCAR24*)*. Their perception is that RBs are not accepted by children without any disability, and this could be a barrier to interaction. RB could be a barrier to learning as well, according to the caregivers' perceptions. They are also worried about their children's learning progress, since their intervention programme could be frequently affected by the latter's RB and the fact that they prevent their educators from delivering their lesson: *"I am sure that if he starts stereotyping and obsessing, the teacher won't be able to teach him. He creates hassle all around!"* (ASCAR21),*"So what? I should pay when he can't have a lesson? I can't afford that. He might stereotype the entire time during his session in order to avoid having it."* (VICAR6). Finally, they argue that RB might have an impact on the child's psychological health by causing disappointment, stress and annoyance: *"I tried to approach him... explain to him, sit with him, anyway to help him feel better, communicate and not stereotype."* (VICAR6), *"Now as for himself, I think sometimes he also realises that… when he can't fulfil his wishes, he feels disappointed and sad, therefore he demonstrates RBs."* (ASCAR4). The aforementioned situations are examples of how the child can impact on the caregivers' and professionals' ecological system. These are typical cases of the inside out effect that the ecological systems might present, and not necessarily an effect with an outside to inside direction.

5.IX The impact of repetitive behaviour on the professionals and the school environment

RBs might actually comprise a major impact on the professionals and the school environment, either for a child with VI or for a child with ASD. The school environment is an integral system, which plays an essential, central and important role, based on the professional's statements: *"We are part of the same school environment. We are part of the same performance. We need to be provided with the right tools, the most talented actors and the best directors."* (ASPROF22), *"I have managed to create a sensory room, to have sufficient staff, to have tactile and 3D materials. I wish I could also get a permit for the pool. It would be really helpful."* (VIPROF14). By the term "environment", therefore, is meant the general environment of the school and the classroom space, including the teachers' intervention tools, the professionals themselves and of course the students (Goehlich, 2003, Ravenscroft, 2009, Strong-Wilson and Ellis, 2009).

The professionals, related both to VI and ASD, adapt this environment on the basis of their students' behaviour: *"You will see that in the classroom we have placed … a small curtain behind which she can isolate. Also, this box is for Sofia."* (VIPROF18), *"I have adjusted the classroom's corners to match the needs not only of Anastasis, but also all of my other students with ASD. I have bolsters for Anastasis, so he can go sit when he is stressed and starts using stereotypies."* (ASPROF31), *"When he starts using stereotypies, he keeps getting off and, on his chair, he moves his hands and presents echolalia. Then I know that he will only calm down if we do a puzzle, and we have agreed that we take him to an isolated table in the classroom for puzzles."* (ASCAR27). Therefore, just like any other "living organism" (Strong-Wilson and Ellis, 2009) in the context of which there is communication between the members that comprise it, behaviour can affect the environment and the environment can affect an RB. According to Warren (1994), actually, RBs are influenced by environmental causes and can be affected by them, not only regarding individuals with total vision loss, but also children with no VI that might display a repetitive or challenging behaviour.

On top of that, what has been noticeable throughout the data analysis concerning the length of the experience the participants have, was the fact that the longer the experience of a professional was, the more positive attitudes towards disability (either VI or ASD) they held. This might be a result of the high teaching experience which impacts the professional development of practitioners. Increase in professional development might occur either due to the potentially high number of seminars/ training programmes the person has attended, or because of the more positive attitude practitioners hold towards disability and inclusive education in Greece (Avramidis and Kalyva, 2007).

5.X The impact of repetitive behaviours on the caregivers

On the one hand, some caregivers admit that they feel stressed, tired, even exhausted: *"What makes me exhausted and upset is when we go out and walk around and I can see other children walking and not behaving like that (…) I'm dying inside."* (VICAR16), *"Mainly the family (…) we become a little exasperated that he can't understand that he doesn't need to be repeating this."* (ASCAR22). On the other hand, though, other caregivers consider themselves and their families totally unaffected by their children's RBs*: "No! I don't consider myself affected by my child's mannerisms. My other child frequently does the same."* (VICAR13), *"No. This behaviour doesn't bother me. I have so much else to handle, that this doesn't even register."* (ASCAR30). Caregivers mainly argue that RBs have an impact on them and the family as a whole. Yet it is worth examining whether the adults' perceptions are linked to the children's negative feelings. In the cases where children could communicate their feelings, the caregivers would know whether they felt negative or not. If the opposite was true, though, that is, in cases where the children are struggling to express their feelings, then the caregivers would just make assumptions about their psychological mood. If the caregivers, though, react in a negative way to their children's RB, tis could affect the children's emotions negatively, in the form of emotional arousal. My perspective is in agreement with a proposal of Eisenberg et al. (1996), according to which the parents' perceptions concerning their child's negative emotionality are linked to their reported emotion-related reactions.

Considering the impact that level of VI has on parenting stress, no related research studies exist. However, there is a powerful statement from one of the participants (VICAR5), talking about her daughter with VI who is adopted: *"There is no guilt, shame or remorse to battle, because my daughter and her disability along with the RBs were all my choice. I didn't have to deal with it after giving birth. It is considered as a social stigma!".* Wolfe et al. (2014, p.189) do indeed speak about the possibility that the RBs, in combination with the lack of variability that usually characterises them, can result in "social stigma and limited access to reinforcement", whether we are referring to children with ASD or not. VICAR5 also adds: *"You know? Parents carry guilt, from what I've seen. Biological parents... I am privileged in that I'm not the biological parent, and perhaps that makes me feel guiltless. They blame themselves. (…) I carry no guilt that I did something wrong and this child... Maybe that's what it is actually. (…) And that makes me stronger perhaps. They are fighting themselves too. Battling their guilt.".*

After all, as far as the ASD is concerned, caregiver stress and anxiety have been recorded in the research of Abbeduto et al. (2004), Baker-Ericzén et al. (2005), Hamlyn-Wright et al. (2007), Singer et al.

(2007) and Bolton et al. (1998). Referring to the same group of parents, Kuusikko-Gauffin et al. (2013) and Mazefsky et al. (2008), speak of adults who are vulnerable to anxiety. Such anxiety might actually be linked either to both parents (Lecavalier et al., 2006b, Uljarević et al., 2016) or to the mothers, coping with their children's RB, which is characterised as "an ASD symptom" by the American Psychiatric Association (2013), Beck et al. (2004) and Bishop et al. (2007).

5.X.i Difference between the responses of female and male caregivers

At this point, it is worth mentioning that in the current research there is a higher number of female statements: 5 out of 17 caregivers are male, 3 of whom attended the interview together with their wife. This may have happened because the female caregivers were more accessible to the headteachers of the settings during the recruitment phase, as far as I was informed in retrospect.

Female caregivers believe that their children are not responsible for their RB (Chavira et al., 2000). All of them claim to be feeling more overwhelmed than male caregivers, maybe because they spend more time in the day with their children as the "primary caregivers" (Simmerman et al., 2001, West and Honey, 2016). For example, they characteristically say: *"I retired early so I could always be by him! His father couldn't handle it and he still can't."* (ASCAR27), *"My husband works all day. I am raising all three children."* (VICAR16)*, "There is no father. I adopted her and am raising her on my own."* (VICAR5). Another reason for which female caregivers do not believe that their children are responsible for their RB, is maybe because it is more likely for them to judge their own parenting as ineffective, as they might hold "cognitive stances of blame and helplessness" (Baden and Howe, 1992, p.467) that may contribute to their withdrawal from their parenting role: *"I am saddened by my child's* *general state and it makes me feel angry and frustrated, but on the other hand I try to battle my negative emotions."* (ASCAR23). This sounds like "the effect of a lost dream", as Bloch and Weinstein (2009, 26) note.

On the contrary, male caregivers focus on comments that relate mostly to the overall picture of the child, which subsequently is commented upon by the people who constitute the child's social environment. The men also seem to be trapped inside "the myth of manhood" and a set of expectations regarding their role as providers (Carpenter and Towers, 2008): *"There are some things that worry me. And say he starts doing these... some spastic movement of his hands like that. It's something I don't know if I can help Fotis with so that he gets to a point where he can control it and that worries me."* (VICAR14), or on the AS: *"My husband often makes comments on our child's behaviour, when using stereotypies."* (ASCAR22). The men seem to be emotionally more distant from their children's RB. The fathers believe that the child is responsible for an RB and their role is to support the children and their mothers, in terms of that difficulty. Especially based on the male participants' statements (both in terms of children on the AS and those with VI), they express their worries concerning their partners. Actually, they worry about the way in which the mothers of their children try to help, as far as potential RBs of their children are concerned, so that they can offer them practical and emotional relief: *"He is growing and becoming strong now. How can my wife cope when he constantly stereotypes? I try to be at home more."* (VICAR6), *"When my husband sees him behaving that way, he takes charge. He doesn't like to see me struggle. He handles his stereotypies and obsessions better."* (ASCAR21). Male caregivers seem involved, even if sometimes they choose to *"postpone their own reactions, in order to support their wives"* as ASCAR4 says. Sometimes they experience the situation as an insurmountable difficulty, given how they feel powerless to offer a solution to a family difficulty, as a *"pater familias"* ought, VICAR14 states.

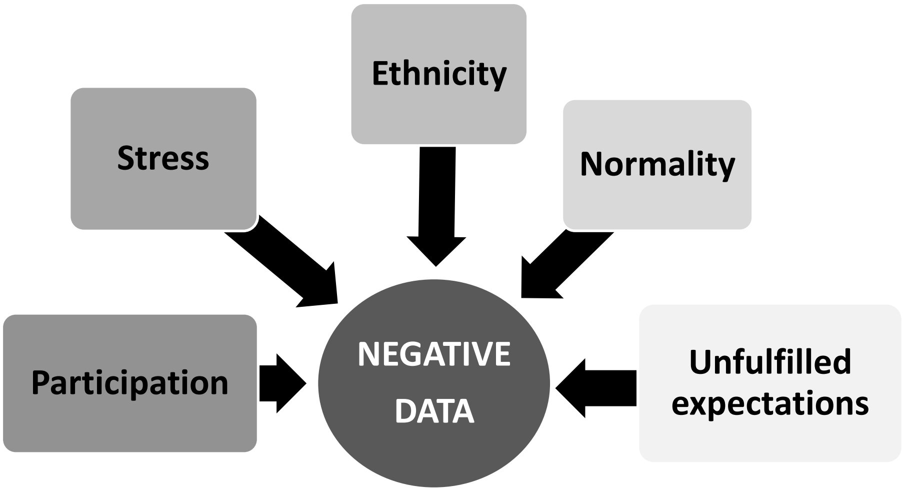
In terms of Greek society and the parental attitudes towards VI or ASD, no related references have been found. However, different cultural expectations between fathers and mothers can be observed in the collected data. These are data that are reminiscent of the results of the recent research by Mitrogiorgou (2020), which focuses on children with disorders who experience the lowest levels of maternal and paternal affection and the highest levels of maternal and paternal indifference and hostility/ rejection, compared to other children without a disability. The fathers in the current study are the ones responsible for the wellbeing of the family; they are the supporters of the challenges the VI or ASD disabilities might pose either to their children or to their wives. The mothers seem to consider themselves responsible for the upbringing of their children, a fact that makes them more emotional towards their children, while on the other hand though, they appear to be strict and controlling when it comes to the children's education (Mitrogiorgou, 2020). Doubtlessly, these expectations may have influenced the comments of my participants, like, for example, the professionals working with these families, who in turn express themselves in terms such as the following: *"The dad finds the child's general state stressful. He thinks that's what we should fix."* (VIPROF24), *"The mother, essentially on her own, tries to handle the stereotypies at home – the dad works long hours and I think he also avoids the situation too."* (ASPROF22), *"The dad appears to be the protector and the mum the executive. He can't bear to watch the child stereotype and... gives his wife instructions on what to do."* (VIPROF14*), "The mother is very assertive, but also guilt prone. She is the one running everything and blames mostly herself for Petros's autism. The father is more discreet – I think this works fine for him, he can't stand the whole thing."* (ASPROF27).

Although Davys et al. (2017) highlight the lack of information related to fathers of individuals with disabilities, recent studies have reported a transformation in fathers' expectations in terms of their children with disabilities (Schippers et al., 2020, Shave and Lashewicz, 2016), which agrees with the case of the fathers in this study. Nevertheless, remembering always that the sample size is limited, there is a possibility that the male participants are not very representative of the wider group.

5.XI Negative data found

In addition to this explicit data, more data was analysed from what was not said or mentioned by participants. This is 'negative or nothing data' and as has already been discussed, it enriched this project by adding elements that can prove of interest to the outcome of the research *(Figure 6)*.

Figure 6: *Negative data*



The figure had the shape of a converging radial of six pieces: negative data in the centre and the five categories around. Below, though, a list of these five categories is provided and they are the following:

- Participation

- Stress
- Normality
- Unfulfilled expectations
- Ethnicity

To be more specific, even though I had not expected such a thing to happen, there was higher professional participation than caregiver, even though a larger and equal number of participants had been invited. This is similar to the experiences I had with some of the families I had worked with in the past, experiences I have recorded in my personal diary. No matter how good the relationship that I had with them was, caregivers found it very difficult to respond to an invite to discuss their children; after all, they are caring for children with disabilities.

The intersectionality of culture and VI or ASD has been analysed and discussed in 5.V, while considering the participants from outside Greece, who all agreed on the absence of RB in their children/ students. The same participants were the only ones to question the existence of disability in the children of whom they spoke. This was an element, then, that was not considered from the beginning or hypothesised, while it also does confirm that the results of the research diverge in terms of ethnicity, even though they refer to a Greek setting.

Also, it is worth mentioning the case of a caregiver, who was struggling a lot to talk about her child at the beginning and during the interview. To be precise, in order to answer my interview questions, the caregiver asked the child’s special educator (who happened to be present) to answer the questions on her behalf. Similarly, certain questions I posed to parents received no answer, and I was asked to refer to their child’s special educator or headteacher. This is another indication of how stressful they found it to discuss their own children, something I had not thought would have occurred.

Furthermore, I discerned a tendency by some caregivers and professionals (from both groups of disabilities) towards an implied comparison between their child’s or student’s RB and other children or students without disabilities: *“It’s bold and tricky to use but I think that everyone uses movements like those, maybe not with the same intensity or frequency, in the same way disabled children do.”* (VIPROF12), *“This continuous thing is seen in other children too, and it offers great relaxation and relief from tension and feelings. I mean it’s this continuous back and forth, left and right. These movements surely offer a positive feeling of relief from tension and relaxation.”* (ASPROF24), *“I also observe my other children or the ones in the playground. They all have these repetitions in their movements. It’s natural both for them and my Panagiotis*.” (VICAR13)*.* The above statements present a potential RB as “normal” behaviour (*“Depending on our feelings: rage, hate, grief, fear. We have specific movements, sometimes. When we’re waiting in line, maybe we have... yes. They help us focus somehow, be calm...”,* ASCAR24) which is perceived as challenging, when a child with ASD or VI presents it. It seems as if there is a kind of fear about repetitiveness underlying the behaviour of a child with disability, since the same behaviour presented by another child without a disability is not perceived as non-acceptable. That happens either because its characteristics are more pronounced, due to the fact that the disability often hinders the child from adhering to social norms and rules, or because the adult herself/ himself is biased due to the child’s disability: *“And they might not be as pronounced because we are aware of our social surroundings. And they are, say, literally and metaphorically socially acceptable. Like, shaking your leg doesn’t mean anything. If I start banging my head on something in a coffee shop, of course that will make people suspicious.”* (ASPROF20), *“We definitely use some movements that have this, say, stereotypical rhythm to self-regulate. Like, sometimes someone who’s annoyed might do that thing with their leg, it offers relief. Again, with a certain rhythm. Or they might fidget with their thumbs. A person who isn’t disabled. Normal, like us.”* (VICAR5).

Last but not least, in my attempt to achieve the highest degree of reliability possible in this research study, I tried not to project my own perceptions and attitudes onto the participants' statements. However, due to the use of a personal research diary, I had become predisposed to certain expectations regarding the data that would emerge. For that reason, I expected to hear the participants saying more about how disruptive RBs are (in general and not only with regards to any self-harming behaviour that has already been mentioned) and that they try to stop them somehow. On the contrary they did not; some assumptions for this can be that they do not really believe in the disruptive nature of RB, that they would rather not talk about it, or tat they think stopping them is wrong.

While looking at the data, even if the sense of social stigma when a child is presenting an RB was apparent, I did not find any examples of the participant saying that the children should stop that RB somehow. This leads me to think that the underlying issue is personal 'unfulfilled expectations'; my personal unfulfilled expectations that have been built on the perceptions I have constructed during my years as a professional in different positions and which I can detect in the notes in my research diary. While working in the public sector and especially when I held the position of headteacher, I felt more flexible regarding the RB of my students with VI or ASD. I tried to decode such potential behaviour and to create a personalised programme based on each student's needs, even if those were related to RBs they may have had. As a matter of fact, I always informed my colleagues in interdisciplinary teams of the perspective from which I regard RBs and of the manner in which I use them as a tool in the context of my teaching. However, I can recall feeling stressed when, during a nativity play at the school a student with VI started exhibiting an RB and his mother, full of shame, impulsively removed him from the stage. I can also recall feeling anxious while working in the private sector as a practitioner of ASD or as the owner of my own practice, each time either my manager or respectively the parent of a child realised that the child presented RB during the lesson. It was as if I was trying to justify my teaching methods; and that is because I know that within the Greek society in which I was raised, not only is the existence of an RB not accepted, but often it is seen as proof for the responsibility or the efficiency of a professional specialising in VI or ASD, or lack thereof.

Summary

This chapter analysed the data of this study and discussed its findings. Taking into consideration the demographic characteristics seen in Chapter 4, there appears to be a link between participants' perceptions and aspects such as the professionals' professions and experience, the caregivers' gender, the children's age. The participants' perceptions and disabilities (VI, ASD) appear to be another point where an interrelationship can be observed, while perceptions about RBs seem to correlate with the professionals' professions. This could occur, since speech and language therapists and occupational therapists organise their intervention based on the child's disability, while there is also the case of the musician who incorporates RB into the learning process. What is interesting at this point is that the rest of her colleagues acknowledge the effectiveness of this approach without imitating it, but by asking her to achieve goals that relate to their own subject through her teaching. The professionals' experience is linked to perceptions that they have formed in relation to the RBs of their students. The longer the experience, the more positive attitudes towards disability (either VI or ASD) they hold. Something similar applies to the issue of the children's age and their caregivers. The older a child is, the more positive the caregivers' approach towards the RB of their child and the disability. Caregiver's gender seems to affect their perceptions as well. In the case of men, they seem to hold that RB is a matter of disability and they view it as social stigma. In the case of women, however, their perceptions and attitudes appear to be determined by their own expectations as parents. Finally, in relation to the type of disability, perceptions regarding RBs indicate a conceptualisation of VI and ASD according to cultural norms: cultural norms which in the case of the caregivers affect the perception or lack thereof of the existence of RB in their child, while when it comes to the professionals, the manner of their intervention is affected.

The overall difference between the two disabilities is that ASD is considered as a more challenging disability than VI; ASD is perceived as a disability with challenging characteristics such as RB. RB stems from social stigmatisation and taboo, in contrast to VI where the existence of RB is perceived as a consequence of a sensory loss. Yet ASD seems to be perceived in a negative and stressful way, whilst VI is seen with a more empathetic, compassionate and understanding attitude.

One more point of lack of convergence is the fact that their culture seems to determine the participants' perceptions concerning RBs and disability matters in general. This is another perception which indirectly occurs in professionals, since caregivers testify that the latter inform and guide them accordingly.

As has already been mentioned, a reason why I conducted this research study was in order to understand the connection I had noticed (through analysing the data from my research diary) between VI and ASD. Yet, what seems broadly the same is the expectations that all the adults have from themselves. Their perceptions have an effect on their expectations and their expectations affect the content of the conversations they have with caregivers or professionals respectively. Another main similarity is that RBs are expressed in the same way in both disabilities according to all the participants, as well as that the participants experience the situation in a way that is often intense and contradictory.

Ultimately, there are implications that are completely different and those lead to the following conclusions: on the one hand that the way in which caregivers and professionals perceive a behaviour might impact on how they respond to it, and on the other, that caregivers and professionals could learn from each other by altering their perceptions, and thus improve the lives of their children/ students. This could be achieved by motivating and empowering society. These key points will be summarised in the next two and final chapters.

Chapter 6
THEORETICAL DISCUSSION

6.I Chapter overview

Using reflection, I will try to provide the reasons behind the methods and methodology chosen, as well as the key subjects of the study, while trying to answer my core research questions. I will also try to clarify the link between my results and the Ecological Systems Theory, in order to prepare the reader for the implications suggested in Chapter 7.

6.II Further information and reasons behind the methods and methodology chosen

Further enquiries concerning issues of method and methodology are going to be summarised briefly in this section. This, then, will clarify to a greater extent the reason for which I chose to focus on people's perceptions and why a change in these perceptions is necessary. I am going to highlight one more time how important it was to undertake a comparative case study and to focus more on caregivers and professionals, rather on the children.

Thought and knowledge are constructions of the perceptions that people have in terms of different aspects of the world surrounding them. Perceptions are seen as a subjective experience (Solms and Turnbull, 2010); a completely personal, instant and often passive (Hopp, 2011) process that depends upon the sensory information received from the various sensory organs and processed in the various parts of the brain. All people rely on their senses so as to experience reality; yet they interpret and make sense of the world around them in different ways. To some extent, though, the information might be overwhelming and it is then that the brain selects the most relevant aspects of information to fit any current set of beliefs. In the same way, the individual who presents RBs engages in them for a uniquely personal reason. Likewise, people interacting with that individual perceive her/ his RB in a manner determined by another uniquely personal reason, which determines the interaction with or the intervention on that person. This is what the present study tried to explore and represent. Perceptions help us interpret the various aspects of the world around us, and without their help, our thoughts are simply empty (Hopp, 2011, Van Mazijk, 2015). As mentioned before, the way people perceive a behaviour might impact on how they respond to it and the manner in which people construct a perception is based on past experience or in other words on empirical information (Purves et al., 2015). This means that, whatever change in perceptions is thought necessary to take place will usually be a hard process, since people's pasts and experiences do not change. Simultaneously, though, a change in perception – particularly in this case, where little attention has been given to the perceptions of people regarding VI and ASD, and yet even less to RBs displayed by children with either of the two disabilities – is necessary, because, should it be achieved, this will entail liberation from society's long-standing stereotypes that have been proven (McDougall, 2006, p.305) to hinder and create barriers in the daily lives of children, families and professionals.

Change in perception can be sought by empowering individuals' families and practitioners by investigating their attitudes, views and perceptions, as well as the impact RB might have on them or on their children's/ students' life. Thus, this process seems very attractive and also challenging to me, as understanding it could alter people's perceptions and finally help children with VI and those on the AS. I chose to focus on caregivers and professionals, since they are the persons most directly involved in a child’s upbringing and education, and the ones from whom the child receives direction in her/ his first attempts to enhance cognitive, motor, behavioural and social development (Chavkin, 2017, Fuertes et al., 2018).

An imperative need occurs, therefore, for further investigation concerning how RB is perceived by people, on a comparative basis. This is important for two reasons. Initially because comparative research in education usually tries to clarify “whether certain behaviour patterns are characteristic for a certain group or a certain culture” (Antonio and Yariv-Mashal, 2003, p.425) or whether these behaviours are significant for society. Secondly, because comparative research is basically inspired by a need to create “comparative indicators to measure the ‘efficiency’ and the ‘quality’ of education” (Antonio and Yariv-Mashal, 2003, p.425). As a matter of fact, this comparative study managed to reveal considerable similarities in the behaviour of the children of the above groups, as well as the corresponding adults. As for case studies, I believe that one of their greatest strengths is the opportunity they give to a researcher to achieve high levels of validity regarding societal phenomena and more specifically societal perceptions (Bennett, 2004). The choice of a case study, therefore, helped me to meet the initial aims of the study and led me to highlight the importance of empowering individuals who have or who work with children with VI or with ASD, by seeking their views.

These factors highlight the need for the present research, which tries to shed more light on VI and ASD, through the RBs that children with these disabilities present and the perceptions that the adults hold, concerning such behaviours. By understanding how caregivers and professionals perceive RBs, answers could be given to the question regarding the manner in which such perceptions could be altered in the context of EST to benefit the children. As a consequence, discovering this kind of perceptions was a great challenge. Especially when referring to the case of Greece, where never before has such a research undertaken, a challenge of this kind seems even greater to me.

6.III Answering the research questions

As the end of the thesis approaches, it seems worthwhile to provide clear and direct, individual summarised answers, to the research questions that were introduced in the beginning of the thesis. As has already been mentioned, further responses were given also to questions that occurred as this research was being conducted, as well as during the literature review. This issue will be discussed in the next section, 6.IV.

6.III.i What are the repetitive behaviours that caregivers and professionals observe in children with vision impairment and children on the autism spectrum? How do these behaviours vary across situations?

One of the gaps that emerged from the literature review was the need to describe the interpretation of RBs occurring in children with VI or ASD by the people in their environment. This gap can be observed on a global level; however, the current research study is focused on the Greek culture and this is the answer it offers to the first research question.

Comparing the way caregivers and professionals of both disability groups (VI, ASD) observe RBs, this is expressed and experienced in the same way. In other words, all the participants recognise RBs and attach to them specific interpretations, no matter whether they are discussing VI or ASD, whether they are caregivers or professionals. Therefore, RBs were categorised under one of the groups that follow: body movements, leg movements, hand movements, head movements, speech, sensory sight-related stimuli, rituals and self-harming behaviour. The only difference lies in the fact that in the case of VI there is talk of RBs that relate to the sense of olfaction, while in that of ASD some RBs are linked to the sense of hearing. Overall, though, there is no obvious differentiation between the two sides of disabilities, and the caregivers and professionals recognise RBs in their children/ students with VI or with ASD, in the same way.

Taking into consideration factors such as the age of the child, the experience of the professional, the gender of the participant and cultural norms, it could be said that the results also show RBs that vary across these situations. More specifically, caregivers who are more engaged with the RB their child might exhibit and are more positive towards her/ his disability tend to have older children. Similarly, the longer the experience professionals hold of VI and ASD, the more positive the attitudes they have towards children with these conditions. Apparently, the older the child in question, the more accustomed the participants are to speaking about them and their RBs. The caregiver's gender seems to be another factor according to which perceptions differ; women's perceptions and attitudes seem to be determined by their own expectations as parents, while RB appears to be a social stigma that accompanies a disability, when it comes to men. Finally, cultural norms seem to affect perceptions regarding RBs in relation to both VI and ASD. In the case of the caregivers, cultural norms affect the perception or lack thereof of the existence of RB in the child, while the manner of the intervention is affected in the case of the professionals.

6.III.ii What explanations do caregivers and professionals link to repetitive behaviours?

The answer to the second research question is another gap that a review of the literature revealed (both in an international and a Greek context). To uncover how the adults interpreted RBs, it was necessary to discover the background of the perception that is hidden behind the interpretation caregivers and professionals give to the RBs children (with VI or ASD) may manifest.

The overall difference between the two disabilities lies in the severity that participants attribute to ASD, in contrast to VI. ASD is perceived by the participants as a disability with challenging characteristics, such as RB. RB is perceived as social stigma and taboo, in contrast to VI, where the existence of RB is perceived as a consequence of sensory loss. Yet, ASD seems to be perceived in a negative way and in a way that causes stress to the caregivers, whilst VI is met with a more empathetic, compassionate and understanding attitude. The explanations the adults give concerning the children's behaviour are linked to the environment, the people who interact with the child, the child's psychological mood, the stimuli, the child's needs and the age of the child. Therefore, it appears that it is the conceptualisation of a disability which impacts on individual perceptions about the behaviour and not the behaviour itself.

6.III.iii How do repetitive behaviours impact on the child, on the caregiver or the professional, and on others?

The way in which children with VI or ASD are affected by the RBs that they themselves may exhibit, cannot by seen through the results of the present research. What can, however, be mentioned is the manner in which the participants believe it affects the children, and if this perception affects them and their behaviour in turn. In other words, an interesting point would be whether the adults' perceptions are linked to what they themselves consider to be negative feelings on behalf of the children, in the way that the assumption that the children may be having negative feelings in itself could shape perceptions and the way the adults interact with children.

The literature review disclosed a tendency on the part of the professionals to advise putting an end to an RB and an inclination on behalf of the caregivers to reinforce the stopping of the behaviour too, with the aim of avoiding any personal impact. This perceived impact is linked to the way in which caregivers and professionals consider disability. In other words, they pathologise disability depending on whether it is VI or ASD, along with any kind of behaviour (e.g., RB) that might accompany each disability. Even though the emotions experienced by caregivers and professionals are mainly negative (containing the fear of social exclusion or social stigma), there seems to exist some leniency as far as children with VI are concerned. As a matter of fact, then, the social seclusion and social stigma experienced by the caregivers are linked to the personal impact of both caregivers and professionals essentially of children on the AS. When it comes to VI, once again I need to point out that many children with CVI present RB for many reasons (Zihl and Dutton, 2016) but this is something that has not been covered, because none of the children discussed by the participants of this study had been diagnosed with CVI. The caregivers and professionals discuss the presence of RBs as a by-product of the children's visual deficit, a fact that is not considered as a taboo. Therefore, then, perceptions about RB could differ based on the diagnostic label, and this diagnostic label is determined by the society that influences the diagnostic criteria. A very striking example is the use of interviews (through which ideas, attitudes and beliefs are expressed) as part of the diagnostic process, as has also been discussed. What is for certain is the fact that caregiver perceptions appear to be shaped by the negative feelings the caregivers may have concerning the children's disability and the professionals' perceptions as well. This is doubtlessly linked to the concept of ableism in the sense that RB does not comprise a well digested and embedded notion in Greek society, because it is not considered as "normal" or fitting with the general norm.

Simultaneously, the professionals are affected in another way too. They are prevented from completing their programme, which has been planned and timed in advance. In broader terms, professionals are concerned with achieving stability in their intervention programme, while they believe that caregivers see them as less professional, should they allow RBs to occur. What seems broadly the same, is the expectations that all the adults have from themselves. Their perceptions have an effect on their expectations and their expectations affect the content of the conversations they have with the people of the other group (either caregivers or professionals).

In terms of the effect of the professionals on the caregivers' perceptions, this has also been observed. The importance of the professionals' opinions and statements for the caregivers was a salient point, and the caregivers' views and perceptions were not immune to what the professionals perceive. As a matter of fact, then, professionals play a double part. On the one hand, they are the experts; they are the specialised practitioners who focus on offering the child (and her/ his family) support, so caregivers and generally families do need their help. On the other hand, though, professionals are a part of society/ part of the system and the system's attitude towards people with disabilities is often based on discrimination and labelling (Buljevac et al., 2012). Thus, caregivers feel uneasy, because of the negative feelings they may have due to their perceptions about disability. In other words, caregivers live with the idea of their children being different, and people with disabilities are often considered “different, less fortunate, unsuccessful or less valuable as a partner, parent, friend or employee” (Buljevac et al., 2012, p.726). This is a social construction that leads to social stigma. Social stigma influences the caregivers’ views towards their children and their behaviour towards their own RB.

Considering the impact that the level of VI has on parenting stress, no related research studies exist. It appears, then, that children with VI possibly exhibit RB that might either evade detection or, even if detected, might not be viewed as concerning for the adults/ the child, since a child’s loss of sight does not constitute a social taboo. The child’s RB, however, is perceived in a way that might entail social exclusion, only when considered harmful, taking into consideration the participants’ statements that have been cited in the previous chapter. Although it has been recorded that stigmatisation is more likely to be observed in minorities (and people with VI form a small minority group in Greek society), still the research indicated that there is no link to VI. Participants agreed that RB presented by children with VI does not constitute a challenging behaviour, unless it is harmful. They believe that this is part of the nature of VI and that it has to be respected.

It is interesting to say that according to Buljevac et al. (2012), one of the factors of disability stigma is the decisions professionals make concerning the education of children with disabilities, something that is apparent in Greek special education. Schools for children with sensory disabilities (e.g., VI) follow the official curriculum of the Ministry of Education and Religious Affairs. To put it simply, the pupils are taught the same subjects as those of mainstream schools, but adapted, in large print or in Braille. However, the educators have the right to make changes to their programme and goal setting, if the child has also been diagnosed with ASD, or they themselves detect ‘autistic elements’ in the student, which hinder her/ him from following the same course as any other student. In fact, when it comes to schools for children with ASD, there is a different curriculum that has to be followed as scheduled, compared to that of mainstream schools. I believe that the Ministry views this as a reasonable adjustment, rather as a stigma. This is another example of ablism, where the government has decided who is able to engage with the curriculum and who is not. This adjustment can imply that children with ASD are less capable, which can then lead to social stigma. In other words, this attitude is partly the outcome of the disability stigma that society encourages and whose recipients are first the caregivers and then the professionals. Children with VI are offered an equal education to children without any disability and they are expected to make friendships, create relationships, live independently, study and participate in the workplace. Thus, they are brought up as socially included and the possibility of displaying an RB is easily managed by caregivers and professionals. However, students with ASD live their life stigmatised by members of their community, who mainly focus on the disability’s diagnostic criteria. They (i.e., the caregivers and professionals) schedule their intervention and base their behaviour on that aspect, by taking for granted the fact that the characteristics associated with the diagnostic criteria (e.g., RBs) have to be eliminated.

6.III.iv Additional enquiries that emerged and were answered during the research process

I need to clarify again that the research study was carried out in Athens, Greece and that all the participants were situated in that country. The fact that, however, part of the sample I used was composed randomly of people originally coming from other countries or having spent a considerable part of their life abroad, offered very valuable data to the study. This multiculturalism issue had not been considered or hypothesized from the beginning. But this is a qualitative study's value and charm; that suddenly new data might emerge and redirect the aim and focus of the researcher. The presence of multiculturalism confirms that the results of the research diverge in terms of ethnicity, even though they refer to an exclusively Greek setting. This implies that an RB as a disability issue is conceptualised differently by individuals, a fact which leads to variation in terms of the degree to which it impacts each participant.

Moreover, perceptions regarding RBs indicate a conceptualisation of VI and ASD according to cultural norms, which in the case of the caregivers affect the perception of the existence or lack thereof of RB in the child, while in the case of professionals though, the manner of their intervention is affected.

6.III.v Summary points of convergence and divergence based on the Ecological Systems Theory

Comparing the caregivers' and professionals' perceptions with regards to the RBs their children or students with VI or on the AS manifest, what occurs is for the biggest part similarities. Examining the RBs presented by children with VI and children with ASD, as previously mentioned, one can see that RBs are linked to the senses of olfaction (VI) or hearing (ASD), and that the RBs apply to children of both groups in the same way (i.e., movement, speech/ echolalia, routines/ rituals); even though for the professionals they increase with time or stay the same, for the caregivers they decrease or do not even exist. It transpired, then, that the nature of the impact of RBs on people is different, something that also determines the way in which they perceive their presence in the children's daily lives.

Microsystem lens

Within the ecolology of RB, the microsystem is conceptualised as being situated directly around the child and contains her/ his family and more specifically the caregivers. The caregivers are persons with already developed perceptions, according to which they react to the RBs of their children. Caregivers seem to reflect society’s values and perceptions on the one hand, while on the other hand, as has been shown, they affect the decision-making of the professionals.

There is something really important here concerning the pathologising of RBs. These behaviours are generally seen and perceived differently by the caregivers. It seems difficult for the caregivers to acknowledge a behaviour that might be repetitive in their child, given that the existence of RB usually (according to diagnostic criteria) also signifies the existence of a disability.

Overall, caregivers consider it unnecessary to justify a non-acceptable RB, even when it concerns their own child. There seems to be variation in the perceptions (and as a result, the reactions and responses of caregivers), depending on the environment in which a child's RB is exhibited each time (e.g., public space, school, home) and whether the caregivers feel uncomfortable due to an intense or frequent behaviour. In any case, caregivers make mention of RB curbing techniques, when the behaviour is intense and frequent – namely, when it is considered harmful.

As a matter of fact, the challenges faced by the two different groups of caregivers presented in the research are not the same. To be precise, one can identify a link between anxiety and intensity. Caregivers of children with ASD try to cope mostly with their anxiety caused by their children’s frequent RB and by the fact that their child’s RB might not be socially acceptable, because of its intensity. The difference with caregivers of children with VI is that they cope with the intensity of an RB. In that case, an RB does not cause the caregiver any additional anxiety, unless it is harmful. That happens when the behaviours seem harmful and ominous for the child’s health. In other words, the manner in which an RB is perceived is socially constructed, and is relative to the behaviour’s frequency and intensity. Frequency and intensity seem to signify the existence of a criterion, and a diagnostic one at that. It is obvious, then, that people have different perceptions, because RBs are construed in a different way.

According to the respondents of the study, an RB should be stopped even in the case of VI, when the behaviour is severe, namely when it is self-harming. In other words, severity is an element that is defined by the possibility that the individual incurs an injury. Even when referring to a child with VI, though, the same harmful behaviour is neither pathologised nor considered as socially unacceptable, even if the children are stopped from engaging in it. The reason presented by the caregivers is that an RB manifested by a child with VI is a necessary means to either communication or the satisfaction of a sensory need, owing to the visual deficit. In the case of ASD, therefore, an RB is part of the diagnosis, and thus a sign of pathology which should not be present.

Mesosystem lens

This mesosystem is made up of the interrelationships between the family and the professionals and as Anderson et al. (2014) report, these relationships and interactions within the mesosystem are not static but are changing and evolving continuously and they always influence the child/ learner in the centre.

The previous section presented the viewpoint of the caregivers. Here, professionals working with the children and school environment are a secondary “factor in which the learner directly experiences both formal and informal learning” (McLinden and McCracken, 2016, p.482), with the distinctive role, though, of the impact they have on children and caregivers. In contrast to the caregivers, for the professionals it is emotionally easier to cope with an RB, and hence to observe one in their students. As in the case of caregivers, so in the case of professionals, they consider it unnecessary to justify a non-acceptable RB, even when it concerns their own student. However, unlike the caregivers, they try to adapt their teaching on the basis of their students’ behaviour. In addition, there is a potential influence of professionals (regardless of the disability) on caregivers, through the way in which the latter consult the former, and the way in which the former refers to the diagnostic manuals and the intervention methods they observe. All of that is based on the perceptions that they have already formed regarding VI or ASD. At this point, it should be stressed that, even though tracing the interaction between the mesosystem and the microsystem has been the focus of my study, data emerged in its course that concerned the basis of a diagnosis in cases of VI and ASD and the manner in which those are interpreted in the context of each of these disabilities. This study, therefore, indicates that the professionals seem to play a vital role in that type of relationship, since they can influence both the child and the caregiver directly with their attitude.

Exosystem lens

This system includes special education policy and curriculum. The results showed that diagnostic criteria of the ASD and VI could change, as has, after all, already come to pass with time - three times for the DSM (DSM-V is the current revision in use and autism did not appear as a criterion until DSM-III) and two for the ICD (ICD-11 the current one in use and autism did not appear as a criterion until ICD-10). With reasonable adjustments therefore and reconstruction of educational policy and as a matter of fact of educational programmes and curriculums that reflect society's culture, people's perceptions could shift.

Macrosystem lens

In relation to an ecology of RB, the macrosystem encompasses the perceptions and attitudes that a society holds regarding VI and ASD as disabilities and as a matter of fact about RB presented by children with either of these two disabilities. Whilst the macrosystem is placed outside the child at the centre of the ecological systems, the results of the research process might be implemented via the nested systems and thus impact on future intervention methods for children on the AS or with VI, or on the way professionals are trained to advise the caregivers accordingly.

Ex-macrosystem

Since European Union policies set up the framework for diagnostic criteria or national curricula, they may gradually affect the child at the centre. To be precise, a change in the macrosystem can cause the ex-macrosystem to change as well, which in turn may affect the child with VI or ASD via the intervening ecological systems. Moreover, it can be argued that the potential of mobility that EU provides, leads to more multicultural societies and also international work experiences which impact the professionals' views.

Chronosystem

Overall, the results showed that the way society and culture perceive RBs, could be altered and this is something that will gradually influence the child either with ASD or with VI. In any case, the chronosystem seems important for this kind of change, since it provides the timeframe for everyone to adapt to this system in a new reality (Anderson et al., 2014) and at the same time "a passage of time in relation to the child's development" (Pound, 2011). More specifically, the results show that caregivers and professionals struggle more in terms of the children's RBs, in the child's younger years. This does highlight that while perceptions may be determined by environmental aspects , the contribution of a child's development should not be ignored. There are cases, however, when this influence is not exclusively positive but also negative too. For this reason and aiming for positive influence in the context of the chronosystem, if adequate training or counselling is offered to the caregivers and the professionals starting from the time of the child's official diagnosis, then the perceptions could be altered and gradually also affect policies, curriculums and finally the child herself/ himself.

To be more specific and as a summary of the above, by applying an EST knowledge can be gained from the most complex characteristics of the individual all the way out to the broadest cultural, political and historical factors. In other words, it offers a holistic framework for professionals and caregivers in their role as "potential agents of change" (McLinden et al., 2017, p.570) for the children either on the AS or with VI. Moreover, the existence of an EST framework interrelation among the different systems is unquestionable; the question is how this can be defined and how it can be used to address further implications. The answer to that question has been outlined in *Figure 7*. RB, then, is situated around the child and depends on the interaction between caregivers (microsystem) and professionals (mesosystem). The key point is the pathologising of the RB in case of VI or in case of ASD and the way caregivers and professionals perceive it. RB is an official diagnostic criterion for ASD, something which automatically causes this behaviour to be pathologised, since the presence of RB in a child’s behaviour is an indication of autism for the professional. This entails that the professional follows an intervention based on ASD, while simultaneously holding relevant conversations with the child’s parents. In the case of VI things are different, since RB does not comprise an official diagnostic criterion, therefore not signifying the existence of a disability in the child with VI.

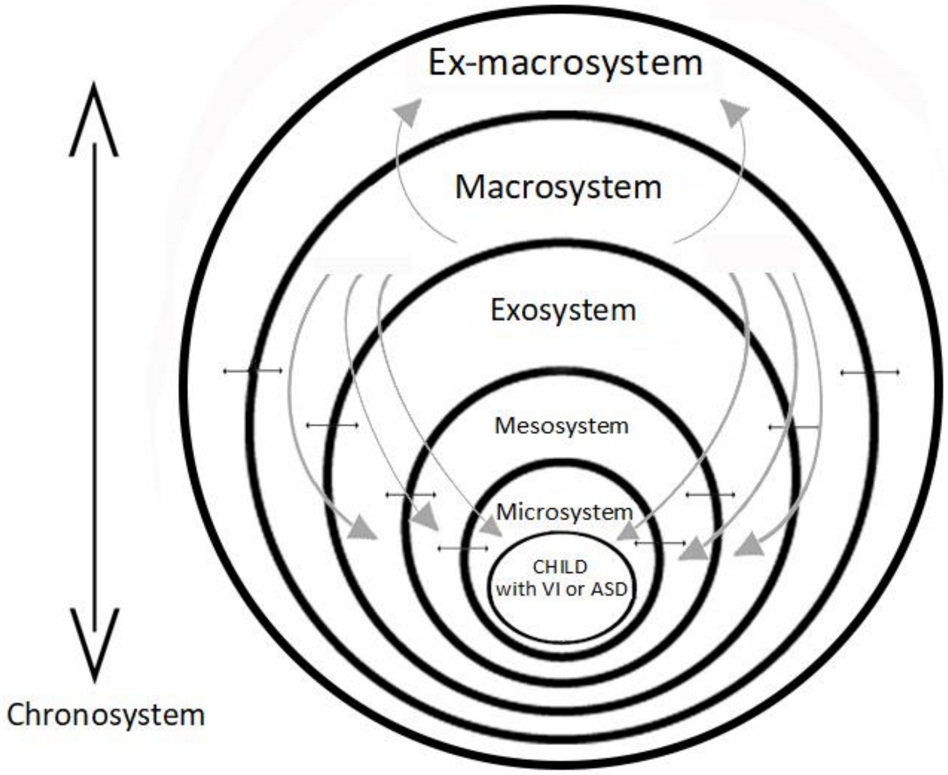
The professional seems to play the part of an “intermediary” between the exosystem, the microsystem and the child; part of the influence seems to stem from her/ him, in combination with the perceptions which they themselves, as well as the caregiver, have developed socially (macrosystem), and which are reflected in European and international diagnostic manuals (ex-macrosystem) or in national curricula. It transpires, then, that the shaping and consolidation of perceptions is a process that develops in the course of time (chronosystem), and therefore time is also required for it to change through the sensitisation of the society (macrosystem), in the hope of improving the development of a child with VI or with ASD.

In conclusion, then, the current study suggested that the macrosystem (society’s attitudes) has the power to affect the ex-macrosystem (DSM, ICD) and the exosystem (diagnostic policy); caregivers seem to reflect society’s values and perceptions on the one hand, while on the other they affect the decision-making of the professionals. The professionals, then, influence caregiver attitudes (mesosystem). Thus, what has to be done is to try and change society’s perceptions and attitudes towards RBs.

Even though Bronfenbrenner supports a bidirectional relationship or otherwise a mutually influential relation (Tudge et al., 2016) between individuals and “contexts that define the basic processes of human development” (Lerner, 2015, p.166), based on my findings I would like to argue that this is not always the case. I believe in the power of the macrosystem and the direct impact it has towards the ex-macrosystem, exosystem, mesosystem and microsystem as well. The bidirectional relation between the ecological systems does exist; however, my results shown that perceptions affect children's development via the surrounding environment (i.e., caregivers, professionals, policy, diagnostic tools, society) and this has to be approached in a holistic manner, as is going to be discussed further on in Chapter 7.

The difference lies in the addition, in this case, of four curved arrows. Two start from the exosystem pointing towards the microsystem, while the other two begin at the mesosystem and also end up at the microsystem. These additional arrows represent the ecological systems which appear to influence the child's microsystem in the present research study. In other words, this is my personal addition/ suggestion as an overall outcome of the work done so far, which is represented in *Figure 7*.

Figure 7: The EST tailored to the findings of the study



Summary

In this chapter, which is now drawing to a close, I tried to summarise the answers to my research questions, as well as to the enquiries which emerged during the course of the study. Additionally, I attempted to present the results of the study through the lens of an ecological model, which essentially informs the manner in which my suggestions and implications, which will be presented in the next chapter, are approached. In Chapter 6, moreover, I have clarified the reason why and the manner in which the change in perceptions regarding RB in VI and ASD comparatively was linked to the methods and methodology chosen to be used.

Chapter 7

CONCLUSION, REFLECTION & IMPLICATIONS

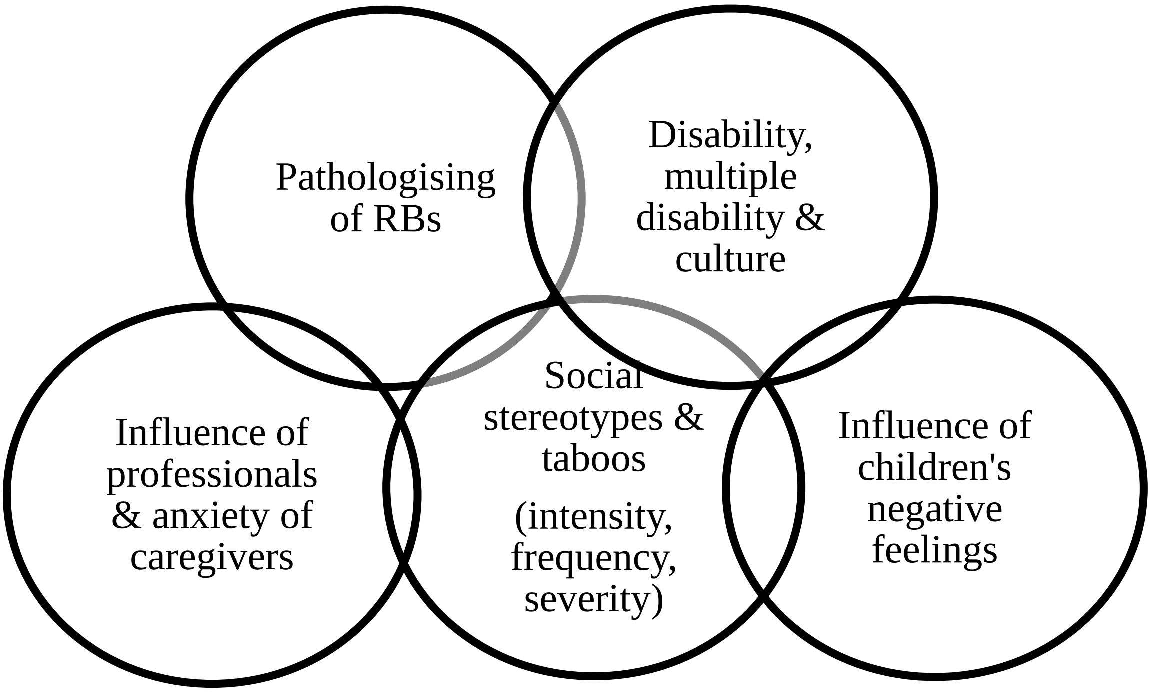
7.I Chapter overview

Chapter 6 concludes with *Figure 7* as an overall conclusion and contribution of my research study, based on a slightly different approach of the EST to the one originally designed by Bronfenbrenner and as has also been done by later researchers. The presentation of EST comprises a transition into Chapter 7, more extensive discussion of the contribution will take place in this current and final chapter. The macrosystem seems to be the main focus of attention which, as the arrows of the figure show, affects the ecological systems around it and ultimately the child with VI or ASD. Based on that finding and the additional themes that emerged, in Chapter 7 I will try to highlight the suggested originality of the study, the strong points of its contribution to the field, as well as its weaknesses and limitations too. Driven by my results, I will conclude this chapter by providing implications for policy and proposing suggestions for future research.

7.II Originality and strengths of the study, through the emerging themes

Thinking through and across categories, I focused on topics that occurred sometimes directly and at other times indirectly, and which relate to the themes that are described in *Figure 8.* Any conclusions that emerged, which have already been mentioned above and will be further discussed below, were based on these themes.

Figure 8: Emerging themes about perceptions



The *Figure 8* consists of five interweaving bubbles. Each of the bubbles represents each one of the themes, as listed below:

- Pathologising of RBs
- Disability, multiple disability and culture
- Influence of professionals and anxiety of caregivers
- Social stereotypes and taboos (intensity, frequency, severity)
- Influence of children's negative feelings

Over the years, researchers have conducted extensive research on the perceptions and attitudes of various groups towards people with any type of disability. What was already known, is the tendency to further explore the relationship between VI and ASD; likewise the description, definition, cause of an RB and the impact it is likely to have. To the best of my knowledge though, this study's findings comprise the first ever instance of research in Greece, where the voices of both caregivers and professionals related to children with VI and children on the AS have been heard comparatively and with an accessible way for all. The simultaneous use of different groups is a factor that adds to the significance of this research study, since it contributes to the presentation of a comparative look at the perspectives of groups that are rarely easy to access (i.e., those linked with VI). In addition, the study has significance for anyone seeking a theoretical and conceptual framework for comparing people's perceptions across disabilities.

Of course, another element of important originality is the participation of individuals related to children with total vision loss, since, as is often mentioned in the academic literature (Flanagan et al., 2003, Hobson and Lee, 2010), as the years go by there are fewer births of children with the sole characteristic of blindness, something which renders the number of relevant research studies limited. In addition, people with VI are usually viewed by psychologists as an extreme case (because of their VI), in order for psychologists to discover information concerning the sighted (Brambring, 2007, Cornoldi et al., 1991, Millar, 1994, Morrongiello et al., 1995). Consequently, it is important that in this case attention is paid to the behaviours of individuals with VI, as well as to the opinions of those around them.

Another strength of the present study is that it is the result not only of methodical research, but also of extensive experience born out of many years of work with students and their families. This was recorded in my research diary, out of which the hypothesis that VI compares so much to ASD arose *(30/ 9/ 2019 - After several years of keeping records and several notebooks filled with even more thoughts, I will stop updating this diary towards the end of the year. There is one thing I can infer and I hope the results of my study will contribute to this: that the behaviours of my students with autism or with VI present many similarities. However, the behaviours of the persons in their immediate environment present* *both similarities and differences. What is it, then, that we should "curb"? Is it the children or the adults?)*. Data analysis has indicated the existence of a link between VI and ASD, which concerns the manner in which potential RBs that accompany the disabilities are perceived. This perception is socially and culturally constructed, and more specifically, it is people's perceptions that reinforce social stigma and social rejection concerning RB and VI or ASD as disabilities. In other words, a behaviour is considered as repetitive if it is related to a perceived disability. Ableism is embedded deeply within culture and very much linked to pathologisation of disability. In addition to this, it could be said that in the way that ableism devalues disability and highlights normality (Ho, 2008), ableism devalues RB and highlight normality in this study. It has to be mentioned, though, that the participants referred to the self-harm aspect too; the self-harm aspect was perceived as a stress result in the case of VI, but as a diagnostic feature in the case of ASD. In both cases, self-harm is an RB that should be stopped, according to both the caregivers and the professionals of the aforementioned disabilities.

Perceptions are also different because RBs are not always exhibited with the same frequency or intensity. What makes RBs noticeable by caregivers and professionals is the frequency and/ or intensity they might have. In this respect, caregiver and professional development could make room for critical thinking and discussion regarding any type of RB exhibited by children and the way in which they should be supported in order to ensure best practice with the children and best interaction/ collaboration between caregivers and professionals. Another reason why perceptions about RB are not always the same is diversity of cultural and social backgrounds and beliefs, a fact that according to Argyropoulos and Gentle (2019, p.118) highlights new values and new orientations in education, while also redefining the "ontology of disability". If the ontology of disability was reconsidered in this way, then VI and ASD populations and the people surrounding them would be better understood and more efficiently supported, which would in turn greatly benefit the field. This result highlights not only cultural differences but also international perspectives. Actually, it transpired that ASD and VI are socially constructed disabilities, in the sense that disability is perceived differently among different cultures or civilisations. VI is an observable physical disability and therefore less likely to be subjective - although how impaired an individual is considered could be subjective. ASD is more of a diagnosis based on perception (socially constructed), while VI – as it is used in this study and excluding CVI from the discussion as has been already clarified in Chapter 2 – is a much more objective diagnosis (clinically based).

Concerning the methods I used, I can say that the personal research diary and the video/ toy used as an elicitation tool were of great importance for the development of my interviews. These tools have not only assisted me in better organising my aims and interview questions (in terms of the research diary), but also helped me to approach interviewees in a more discreet way (in terms of the video or the toy used) (Johnson and Weller, 2002). That way, the ultimate goal of a research study, that is, "knowledge acquisition", according to Cooke (1994), could be achieved. The use of a personal research diary was the only way to link the past, the present and the future of my life as a practitioner and a researcher, as seen in the following extract: *1/ 3/ 2016 - Today marks a year since the beginning of my PhD and I decided to read at random some of the pages of my diaries concerning my students. My thoughts have been repeating themselves without variation for years. Yet, in the last one, it feels as if it is someone else who is doing the writing. I have changed, as a person, a professional, a researcher; so much, that I am still in search of the subject of my thesis*. In other words, it was my main tool as a researcher for structuring my research question. The elicitation tools used, as I have said, were the best ice-breakers I could think to choose, for the benefit of the interview process. Applying the video/ toy in the context of interviews may be very helpful for elicitation purposes, doubtlessly for any future research that I may conduct and for the general context of research that makes use of interviews. It opened up participants' interpretations of questions, and allowed for a creative way of interviewing that is responsive to the participants' own meanings and associations (Bagnoli, 2009). What the participants of the study achieved was on the one hand to address their potential uncomfortable feelings (such as embarrassment, shyness, timidity) towards me and on the other hand to reproduce (thanks to the toy used) or watch again (via the video) an RB that occurred in the video, which had originally been recorded for other purposes. The use of an elicitation tool was priceless and without it, the data collection process, as well as the results, would not have been the same.

7.III Reflection and implications

7.III.i Reflection on the limitations

Although there were very strong views from both the caregivers and the professionals of children with VI and children on the AS, several relevant issues emerged that I had to take into account and thus, I had to develop my perspective accordingly. As with any small-scale research, this study has some limitations in terms of its credibility and trustworthiness, as well as the reliability of its themes. Doubtlessly, any type of limitation can generally be overcome by thorough and careful research, a sceptical approach, planning and interpretation (Hall and Rosenthal, 1995, Shelby and Vaske, 2008).

First of all, the data from the interviews is based on what people say rather than what people do. For that reason, I tried to collect data from two individuals for each child. That, however, was not always possible since caregivers and professionals were not always willing to participate in the research study. Nevertheless, I think that this has not led to negative impact on the data, since it was only a small minority of comparable data that is missing.

As has already been discussed, out of the data emerged statements on behalf of the interviewees and especially the caregivers that are not consistent. More precisely, in the context of the same interview, there are those caregivers who discuss their child's RBs in a contradictory manner. That kind of ambivalence could potentially highlight the complexity of trying to understand someone else's perception. However, I used those conflicting statements to my advantage, since they helped me discern the perceptions of the participants.

Notwithstanding the uncertainties, as well as the different interpretations and areas for improvement in the work I have presented above, I think that I have adequately illustrated the theoretical and methodological path I followed, with the aim of presenting the demands of my data. The core of the study is humans as research participants in relation to their environment and a researcher who is trying to understand the world as it is from the subjective experiences of individuals. Thus, the interpretative paradigm was the only one I considered for discovering the experiences and perceptions I sought.

Alternatively, an ethnographical approach (Gericke, 2020) instead of a case study could have been structured, aiming to address some of the limitations in my study. My thinking was that as a professional I already belonged to the situation I wanted to study. I was already part of the situation from within. I was already "an instrument" (Thomas, 2017b, p.157) of the investigation I wanted to undertake. I just had to structure it in a different way. The difficulty lay in the fact that I would have had to disengage entirely from my personal interpretations of the phenomenon I wanted to explore, and to try only to understand the significance it had for others. This is usually “a long immersion” (Thomas, 2017b, p.157) in the culture being studied that requires time and funds that were not sufficient in the present case. What would have also become clear through an ethnographical research would have been my spontaneous participation, without holding myself back by trying to avoid affecting the research results.

Apart from the semi-structured interviews, though, I would have additionally liked to use questionnaires composed both from open-ended and closed questions. In such a case, the aim would be to reinforce and strengthen what has been termed “method triangulation” (Carter et al., 2014, p.545), or in other words triangulation through multiple methods or data sources, which in the case at hand has already been employed through semi-structured interviews, video-elicitation and a research diary, as well as the IRR process. The interviewees, though, may try to second guess what the answer is that the researcher is expecting to hear, and try to respond accordingly, either in the case of an interview or a questionnaire. That is the main reason why I needed freedom as an interviewer to ask my participants any clarifying questions if appropriate. On the other hand, although closed questions, due to their limitations, do not offer participants the choice to truly voice their opinions, they are more likely to be answered when concerning sensitive topics (Tourangeau and Smith, 1996). I decided not to use a questionnaire, though, believing that due to the fact that it requires further commitment on behalf of the participant towards a researcher they are probably not familiar with (having to complete the questionnaire and spend time alone with the researcher for the interview), it could also prove to deter potential participants from joining the research (or having joined, they might not come back with the questionnaires completed).

Last but not least, since the EST focuses on the interactions among the environments, what matters the most in this study is the impact these interactions have on the child's development. This is another limitation, a detailed mention of which has been made in Chapter 3 (3.V).

7.III.ii Reflection on myself as a researcher and practitioner

Apart from the above, I personally had to be very careful in terms of my unfulfilled expectations, which were formed based on multiple years of professional experience in the field of disability, special education and inclusion. In the course of my career, and through the different positions which I have occupied (special educator, vision impairment practitioner, educational psychologist, Headteacher of a Special School and owner/ Director of a personal practice for children and adolescents with disabilities and their families), I have adopted my own personal attitudes. In addition, and in terms of the RBs exhibited by children (with either VI or ASD) and the way my colleagues and I as practitioners interact with them and their families in relation to that matter, I have gradually constructed my own personal perceptions as a professional. I believe that it might be impossible to entirely remove myself from a research study, but this is part of the research adventure; a research study which has been conducted by a specific person, with specific beliefs, within a specific period of time. Nevertheless, as I am currently writing as a researcher, I am obliged to be faithful and consistent accordingly in the way in which I approach my research questions, participants and data. For this reason, I have followed a very detailed ethical procedure.

Consideration of language and accessibility issues is extremely important for me; that is the reason why I tried to make these matters clear to the reader, from the very beginning of this study. Both subjects have been discussed in detail. The only thing I would like to pinpoint here, in case I will be undertaking another research study in the future, is the person first/ identity first language used. I still consider it very important – when talking about children – to consider person-first language; however, I do recognise the need for some disability communities for identity-first language, something that seems sensible to me as well. In a future research attempt, then, I would use both ways of writing, randomly, so as to express my flexibility, as well as my appreciation and respect for the matter.

Moreover, I have employed the IRR process for the greater part of the data and of course for negative data, by enlisting the help of another researcher, with the aim of achieving the highest percentage of reliability in the themes possible. This process was appealing to me for two reasons; the initial reason was because it guarantees a significant degree of reliability in terms of themes, which is one of the requirements of a qualitative study. In this way it offered me greater security and confidence when it came to locating the themes and the extent to which those were also recognisable to other researchers. Moreover, it offers a very good opportunity to discuss and rethink the themes of the research study at a relatively early stage of the data analysis, with a person other than the supervisors of the study. This person can offer a fresh and spontaneous look at the subject and might offer the researcher more or different angles in relation to the subject in question. As always, the way in which that person will go through the IRR process cannot be immune to her/ his own perceptions and attitudes and this is a sensitive stage of the interpretative paradigm.

Part of the process of my research study was not only the search for answers to the research questions that have already been posed, but also a series of realisations pertaining to my personal and professional habits and perceptions. First and foremost, I reconsidered perceptions I had regarding the correct terminology used in the field of disability, inclusion and special needs. Terminology seemed to be very important for people: ‘using stereotypies’, ‘challenging behaviour’, ‘ritualistic behaviour’ all refer to a specific behaviour, yet the interpretation of each word is different for each individual. I have also experimented with different aspects of conducting a qualitative research study (e.g., by using negative data, or not using statistical data at all).

Moreover, as part of my personal research and scientific development, I now know that I would prefer to continue conducting interviews in person, as I believe that the easiest way of detecting people’s perceptions is through observing their conversation, reactions, body language and comments. Furthermore, I gained more appreciation for the value and importance of the recruitment process; even if as a researcher I had connections with potential participants, it was never easy to approach people and ask them to express themselves concerning their child with disability. I have also learned that disability might not be seen objectively across cultures. People from different parts of the world perceive VI or ASD in different ways and this was something that had to be understood by me. As a VI and ASD practitioner, I used to view the RB of children with VI as an important and difficult factor of their education. I realised how demanding I sometimes was towards them, every time they were exhibiting an RB; and this was not due to my own beliefs, but because I was feeling uncomfortable either towards the children’s parents or towards my colleagues. It was like I was trying to make myself compatible with their own beliefs regarding the elimination of an RB.

Furthermore, during the course of my PhD, I have started observing the behaviours of people around me more and I have realised that RBs are common; the more I observe people, the more I change my point of view and realise it. For example, putting objects in lines compulsively is a type of RB and it is not necessarily negative. However, people usually get annoyed or uncomfortable when an RB becomes intense and frequent; so, their behaviour towards an RB depends on the feeling they themselves have while noticing it. Thus, what matters is how these RBs are perceived by people. It is undoubtedly difficult to measure and transform or change a person’s attitude or perception. This is not an easy process, but trying to change their viewpoint might help people to react better to an RB. Starting to gradually change these attitudes by initially focusing on the awareness of the society and to monitor children’s/ students’ reactions to that change would be an interesting and worthwhile task.

Such an approach can be linked to the EST, according to which a strong interaction is observed to exist among the different ecological systems of the framework. What, initially, the study was focused on was actually the interaction between the mesosystem and the microsystem with regard to the RB presented by children either with VI or with ASD. In the course of the research, however, the focus was transferred to the exosystem and the ex-macrosystem and the manner in which they influence/ are influenced by the perceptions of the macrosystem. Ever aiming at child development, any change can be brought about, provided any of the systems change and thus begin to influence the rest of the systems external and internal to them and finally the child who occupies the centre. The present research has shown that, for the time being, the perceived disability of the child reflects the wider social attitudes, or in other words that the social attitudes impact on caregiver and practitioner views. As will be discussed in the next section on “Practical Implications”, what is mainly suggested, then, is that an attempt be made to do more around raising public awareness.

From my point of view, the most important lesson I learnt as an outcome of this methodological process is that my current model of methodological and theoretical thinking, following the completion of the study, is very different from the one with which I started off. I have realised that a methodological process is not static; there is no right or wrong way unless a researcher cannot justify a decision. The multiple changes that the research questions underwent, from the moment the preparation of the present study began, until even after the pilot questions had been tested, bear witness to this fact. The reason for these changes is that the needs of the research are connected to those of the researcher and to the ones that arise through the influence of the participants. I personally view research as a living organism, whose needs may transform at any point, which is why Chopra (2015) urges each researcher to be agile, adaptable and ready for problem solving. I assume that this is what is called "learning" (Williams et al., 2011), which I believe to be the ultimate point of completing a PhD.

7.III.iii Practical implications

The transformation of people's perceptions in relation to the social stigma of disability may be a useful means of affecting people's response to children with disabilities; however, it does not sound like a smooth process because deeply rooted perceptions cannot be easily changed, especially "about things we have always taken for granted (…) because of our culture" (Coleridge, 2014, p.40). Nevertheless, "changing perceptions is the key to altering behaviour", (Coleridge, 2014, p.40). Thus, there is a need for dialogue between parents and professionals, so that it can be professionally determined whether an intervention method is needed or not in the first place. In order, however, for this constructive dialogue and interaction between professionals and caregivers to occur, adequate training on the characteristics of RB for professionals is required. The aim of that training would be for the professionals to work more efficiently with families and caregivers. It could also be beneficial, if an attempt is made at creating training or intervention programmes focusing on the children's or the adults' observed reactions, when they find themselves present around an RB. Alternatively, the use of RBs in the context of the educational process would be another suggestion, as is seen from the example of the music-therapist in this research study. As has already been pinpointed, the general aim is for society to enhance its awareness. If public awareness is raised, then the wider social attitudes will be altered and as a consequence, caregiver and practitioner views would be changed. I am referring to the impact that the school/ home/ family/ professionals/ policy has on the child with VI or with ASD, as well as the interactions between these systems. Bi-directionality seems to have been lost completely and social perception is seen as the driving force; or in other words, the macrosystem seems to drive the relationships between the ecological systems. A practical implication, then, would be the need for caregivers and professionals to work together more, without judging each other or feel being judged.

7.III.iv Implications for policy

The implications for policy should ideally be based on the results of the study. For that reason, I would try to pinpoint again some important points of the present research study, so as to justify the implications for policy that will follow.

An important outcome of this research study that appears to be a link between diagnostic criteria and peoples' perceptions. Perceptions about RB differ based on the diagnostic label, which is determined by the society that influences the diagnostic criteria. This is perhaps related to limited knowledge and low awareness in relation to VI and ASD. What is suggested, then, is the reinforcement of social awareness and the knowledge concerning these disabilties. As has already been mentioned in Chapter 2, disability is considered under the umbrella of minority prejudice or in other words “inherently negative” (Campbell, 2009, p.17) and it is “shaped and formed by the politics of ableism” (Campbell, 2009, p.17). In that sense, in the current study, the politics of ableism are the diagnostic tools that needs to be seen, developed and used through a different perspective.

More specifically, I believe in the reconstruction of diagnostic policy and, as a matter of fact, of educational programmes and curriculums that reflect society’s culture. To be more precise, as was also mentioned earlier, my motivation in choosing such a topic for my thesis was first and foremost my own teaching and research pursuits, which have emerged throughout my career as a practitioner in disability, special education and inclusion. Thus, it is hoped that this study will be applicable in contexts like the home, school, public spaces and in clinical practice, in the context of someone having to interact with a child with VI or with ASD presenting an RB, and having to make decisions about that interaction. In other words, my intention was not just to describe the characteristics of the two different groups. As a supporter of the EST, I discovered the importance of altering perceptions and attitudes that members of society hold (macrosystem), or in other words of curbing the social stigma towards children who, according to their diagnosis, might present an RB (e.g., ASD). This could gradually affect the curriculums focusing on VI, ASD or disability in general (exosystem) and the interaction between caregivers and professionals (mesosystem), which will then affect the microsystem (caregivers, families), and ultimately the children with VI and children with ASD. This work can provide a starting point on which to base future research and diagnostic policy transitions, which could concern issues such as the community's (i.e., caregivers and professionals) voice and the integration of a psychosocial element into discharge interventions.

This case study is based in Greece. It took place in Special Schools and an Association for children with VI and children with ASD in Athens. The results reflected the caregivers' difficulty in dealing with an RB, which stems from their perceptions about the RBs that children demonstrate. The same difficulty is faced by the professionals, who frequently characterise RBs as undesirable, inappropriate and in need of reduction or elimination, according to their own perceptions. Yet, it would be beneficial for the discussion to make clear which is the party that influences and which the one that is influenced. It seems like multiculturalism is reflected in the terminology used, the intervention programmes scheduled and the legislation followed. The special education settings in question, therefore, view children as having a certain disability and, more specifically, as exhibiting the disability's diagnostic criteria. In the case of ASD, RB is a criterion established by both the American DSM and international ICD; in the case of VI, though, RB is not part of the diagnostic criteria, so it is not perceived by people as a disability. As a result, it does not give rise to challenging feelings linked to social stigmatisation. Thus, the diagnostic criteria seem to affect the caregivers' perceptions. However, some kind of understanding regarding VI is apparent, because it is less likely for someone to perceive and recognise the behaviour of a child with VI as repetitive, maybe because it is not included in its diagnostic criteria. In that case, then, RB is more socially acceptable.

As a matter of fact then, this research suggests that in order for the perceptions that will be shown to affect children's development to shift, the matter must be approached in a holistic manner in order to further raise public awareness. One very specific suggestion on the matter is the inclusion of individuals with disabilities in policy making. The presence of individuals with disabilities in such responsible positions can cause knowledge about VI, ASD and RB to be rendered clearer, as it stems from the individuals with disabilities own knowledge of her/ his life. Apart from that, knowledge and awareness could be raised, if the practitioners' training ceased to be based on the diagnostic criteria of each disability, as is traditionally done in Greece. I can distinctively remember myself in 2013, having been appointed by the Greek Ministry of Education and Religious Affairs as an adult trainer in the programme "inclusion of children with disabilities" (funded by the European Union via the National Strategic Reference Framework) for two years. More specifically, I was a tutor for the areas of VI and ASD. The exact content of the digital presentations that were used in class was subjective. However, according to the guidelines, I was advised to teach my students – who were newly appointed teachers and pre-primary school teachers – the DSM and ICD diagnostic criteria, to help them identify the characteristics of a/ the disability and use them as a reference for their teaching programme. RB (in any disability) was undoubtedly a non-desired behaviour that had to be stopped or minimised. If, however, for ICD or/ and DSM, RB did not carry diagnostic significance, then I doubt if I would have had to teach it to the practitioners I was in charge of. These practitioners would potentially advise and/ or guide the families of their students, according to the training they had received from 'the experts', regardless of their perceptions. Consequently, in order for the policy to change, individuals trained in a direction less diagnosis-oriented should participate in its formation.

7.III.v Implications for future research

I personally argue that the present study provides meaningful findings, which will narrow the gap between theory and practice. Its aim was to answer any unanswered questions that were set from the beginning, but as the process progressed, new enquiries emerged. More specifically, this research study can motivate future researchers to continue exploring the role of RBs in the lives of both children and adults, with the aim of providing better support to both the latter and the former, as well as improving intervention methods (Leekam et al., 2011, Luecht et al., 1990).

For instance, I think discovering the children's own perceptions of their RBs was the area most distinctly missing (Williams, 2009), in terms of perceptions. This could shed light on the reasons and the motives on the children, due to which their RBs originate. It could also be helpful to find out if there are any negative feelings based on RBs and if the children become recipients of the social stigma which their parents often feel due to their behaviour. In a case like this, there could be multiple challenges in gathering the views of children, and it would be interesting to find out if they are similar to those of the parents who participated in my study. The voice of children with VI or ASD has to be heard, as carrying the same importance as that of the caregivers and professionals. As has already been mentioned above, there are no related findings in literature, but it might be interesting to find out if there is a difference in the presence of RBs in children who acquire VI at a later age (e.g., 3,5,9 years) and what role the context or setting plays in this. This might lead to a clearer picture in relation to the motives behind an RB and the feelings that arise in the individual due to it. Another suggested point for future research could be the examination of the impact that RBs of children with VI or with ASD have on their siblings, so as to access the children's perceptions and points of view and compare them with those of the caregivers and professionals. This will probably lead to a more comprehensive view in relation to RBs and the attitudes within a family setting.

Similarly, I have mentioned the lack of focus on child development and its influence on perceptions a few times in this research study. I believe that this is worthy of the attention of future research too, provided it focuses on the child and thus, in this way, contributes to the existing knowledge concerning the child's microsystem.

It would also be interesting if similar research was conducted on an international population; in other words, on populations from continents other than Europe (e.g., Africa or Australia), so as to examine whether similar outcomes (mostly related to cultural perceptions) will emerge again, or not.

Last but not least, focusing on the RBs children with other types of disabilities (e.g., deafblindness, multiple disabilities) exhibit and the way these RBs affect caregivers and professionals (and/ or vice versa) might be another recommendation for further research that could contribute to the RB field in relation to children with VI and children with ASD, and the way education and intervention programmes are constructed around them.

The above was a summary of the overall conclusions, which emerged from examining the themes and emphasising the general points of the study. What follows is a summary of the overall impression I have regarding the work that I conducted and the results that emerged.

Summary

This is the end of my research study. After almost six years of thinking, writing, editing and reflecting, I managed to weave together the various strands of the research project and the thesis. To conclude, I tried to review my findings along with the implications and any limitations which have emerged so far. The undertaking was challenging; however, I feel satisfied with the result when considering my initial aim: To discover the deepest connection between VI and ASD; to examine RBs in children with VI and with ASD, and their caregivers and the professionals who work with them. The results highlighted the connection between the two aforementioned disabilities, and the way caregivers and professionals perceive them via the RB exhibited by children. In parallel, though, any points of divergence have been highlighted, mainly those pertaining to RBs in terms of the social construction of perceptions concerning the ASD, as well as the VI disability. What follows is an epilogue, including a review of the series of decisions and developments in my thinking which I have gone through in the last few years.

EPILOGUE

This is probably the longest document I have ever written, to be read by the smallest of readerships (Williams et al., 2011). The impact it has had on me, however, is remarkable. “Learning” was the ultimate point of completing this PhD (Williams et al., 2011, p.21) and I think it has been accomplished at a communicational, cognitive and attitudinal level, as well as an entrepreneurial and organisational one. I am not sure, therefore, if I have now become a better researcher or a better human being; what I do know, though, is that I have become a different type of researcher and human being.

Osanloo and Grant (2016, p.12), in a very striking manner, liken the course of a research aiming at the acquisition of a doctorate to the effort of building a home:

> “the dissertation is a labor of love requiring much work, sweat, and tears, as well as organisation skills and extensive resources from others who are involved with the process. The final product is a document that one can recognize as a once-in-a-lifetime achievement. We liken this experience to the task of building your own home”.

This reminds me of the opening lines of the Odyssey, written by the poet Homer, potentially in the 8th century BC, which talk of the long journey of the Greek hero Odysseus’ (Ulysses) return back home, after fighting in the Trojan War. Although Odysseus lost his men, his ships, his supplies and at times his direction, faith and love bring him home. Thus, having opened this work with an excerpt from the first book that I read in English as a child, I will now conclude it with one from the first Greek book, Homer’s Odyssey, which I read in an English translation by Fagles (1996, p.77):

“Sing to me of the man, Muse, the man of twists and turns
driven time and again off course, once he had plundered
the hallowed heights of Troy.
Many cities of men he saw and learned their minds,
many pains he suffered, heartsick on the open sea,
fighting to save his life and bring his comrades home.”

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APPENDICES:

Appendix 1 & 2

Consent Forms

UNIVERSITY OF BIRMINGHAM

School of Education,
Disability, Inclusion & Special Needs Department

Consent for Caregivers to Participate in a Research Study

Title of Study: "Disability, attitudes and stigma in Greek society": Exploring the perceptions of caregivers and professionals regarding the repetitive behaviour of children with vision impairment and children on the autism spectrum (a comparative study).

Lead Investigator	Lead Supervisor	Second Supervisor
Ms Katerina Tavoulari[20]	Dr Liz Hodges	Dr Kerstin Wittemeyer

Please read the information given in the attached "Information Sheet" available both to caregivers and professionals. Caregivers who agree to participate, will be asked to decide whether the person participating in the study is the mother or the father.

Each participant in the research study will have the right to obtain a brief summary report of the study's results, upon request. The results may be published at either a research conference or in a scientific publication. All personal data of caregivers, professionals and children

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[20] Contact information such as email addresses and telephone numbers were provided.

will be completely anonymised in all study-related reports, publications, presentations etc.

If you have any questions or concerns, please do not hesitate to contact either myself (lead investigator) or the study's supervisors.

Please tick the applicable boxes:

☐ I confirm that I have read and understood the information provided in the "Information Sheet". I have had the opportunity to consider the information, ask questions just before the interview and have had these answered satisfactorily.

☐ I understand that my participation is voluntary and that I am free to withdraw at any time up to 2 months after the completion of all interviews (i.e., until the middle of March 2019), without giving any reason.

☐ I understand that the information I give will be completely anonymised and no identifiable information will be shared.

☐ I give my permission to the lead investigator to use brief video recordings of my child for the purpose of the study. The videos will be recorded by myself and given to the researcher for a limited period of time. After completion of my interview, the videos will be returned to me by the researcher. The videos will be used with my consent by the researcher, in order to help define the interview questions.

☐

☐ I give my permission to the lead investigator to ask qualified professionals who work with my child to show her a video recording (up to 10' long) from either an event or an activity that my child participates in and that the School already holds.

I give my permission to the lead investigator to have a conversation with a qualified professional who is working with my child about the child’s behaviour.

Please sign and return the form in hard-copy

Participant's Name: ______________________________

Participant's Signature: ______________________________ Date: ________________

Lead Investigator’s Signature: ______________________________ Date: ________________

School of Education,
Disability, Inclusion & Special Needs Department

Consent for Professionals to Participate in a Research Study

Title of Study: "Disability , attitudes and stigma in Greek society": Exploring the perceptions of caregivers and professionals regarding the repetitive behaviour of children with vision impairment and children on the autism spectrum (a comparative study).

Lead Investigator	Lead Supervisor	Second Supervisor
Ms Katerina Tavoulari[21]	**Dr Liz Hodges**	**Dr Kerstin Wittemeyer**

Please read the information given in the attached "Information Sheet" available both to caregivers and professionals.

Each participant in the research study will have the right to obtain a brief summary report of the study's results, upon request. The results may be published at either a research conference or in a scientific publication. All personal data of caregivers, professionals and children will be completely anonymised in all study-related reports, publications, presentations etc.

If you have any questions or concerns, please do not hesitate to contact either myself (lead investigator) or the study's supervisors.

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[21] Contact information such as email addresses and telephone numbers were provided.

Please tick the applicable boxes:

☐ I confirm that I have read and understood the information provided in the "Information Sheet". I have had the opportunity to consider the information, ask questions just before the interview and have had these answered satisfactorily.

☐ I understand that my participation is voluntary and that I am free to withdraw at any time up to 2 months after the completion of all interviews (i.e., until the middle of March 2019), without giving any reason.

☐ I understand that the information I give will be completely anonymised and no identifiable information will be shared.

Please sign and return the form in hard-copy

Participant's Name: ______________________

Participant's Signature: ______________________ Date: ____________

Lead Investigator's Signature: ______________________ Date: ____________

Appendix 3 & 4:
Information Sheets

UNIVERSITY OF BIRMINGHAM

School of Education,
Disability, Inclusion & Special Needs Department

PARTICIPATION INFORMATION SHEET FOR CAREGIVERS

Research project title:

“Disability, attitudes and stigma in Greek society”: Exploring the perceptions of caregivers and professionals regarding the repetitive behaviour of children with vision impairment and children on the autism spectrum (a comparative study).

Lead Invesigator: Ms Tavoulari Katerina, Ph.D. Researcher

Lead Supervisor: Dr Liz Hodges, Senior Lecturer in Deafblindness and Multisensory Impairments

Second Supervisor: Dr Kerstin Wittemeyer, Lecturer in Autism

Associated funding body:

“A. G. Leventis Foundation” (Zurich Secretarial Office: Tüdistrasse 44, P. O. Box 1527, CH-8027 Zürich / Switzerland) and the “Bakalas Foundation” (20 Panepistimiou Street, P.C. 10672, Athens)

Dear Madam/ Sir,

You are being invited to take part in a research study that is being conducted as part of my PhD at the University of Birmingham. Before you decide whether to take part, it is important for you to understand who I am, why the research is being conducted and what it entails.

My name is Katerina Tavoulari and I am a qualified special educator. I have been teaching children on the autism spectrum and children with vision impairment and multiple disabilities for the past seventeen years.

The purpose of the study is to investigate how people (caregivers and professionals) perceive the repetitive behaviours of children with vision impairment and children with autism spectrum disorder.

Repetitive behaviours refer to patterns of movements and activities of children with autism and children with vision impairment, such as hand-flapping, rocking, sensory sensitivities and circumscribed interests. Through my interaction with children over the past years, I have noticed similar reactions and attitudes from the children's caregivers and other professionals. My motivation for this research study is to further examine the reasons for these similarities in perceptions and the impact of caregiver and professional attitudes on children's lives.

As you are a caregiver/ parent of a child with autism spectrum disorder or a child with vision impairment, your participation in the study would be highly appreciated.

If you agree to take part, you will be asked to take a short (10 minutes) video of your child revealing a repetitive behaviour and will be interviewed for up to 45 minutes.

Please read the following information carefully and do not hesitate to come back with questions if something is not clear.

Then, if you are happy to take part in the study, please complete the enclosed consent form.

It will be my pleasure to have a discussion with you and talk about your experiences, perceptions and thoughts.

Sincerely yours,

Katerina Tavoulari,
Doctoral Researcher

Additional information:

Who is responsible for the data collection in this study?

In this study, the only person responsible for the data collection is myself. The data will be collected via interviews and my personal research diary and will not be shared with other persons or organisations. The digital records of this study will be kept strictly confidential. Research records will be kept in a locked file for at least ten years and all electronic information will be encrypted and secured using password-protected files. Nobody, except the study's supervisors and the lead investigator will have access to the digital recordings. Only the lead investigator (myself) will have access to the personal data of participants (name, contact information). It is stressed that all data presented in the study's report or other academic papers will be completely anonymised.

What are the benefits of taking part in this study?

By participating in the study, you will help to improve the level of understanding of targeted children's repetitive behaviours (and their underlying causes) and adults' reactions/ attitudes of adults towards these. The comparison of blind children and children on the autism spectrum might help researchers to move beyond traditional perceptions, by focusing on similar patterns in reactions.

Ultimately, this research study might also be published in academic papers.

What are my rights as a participant?

Taking part in the study is voluntary. Everyone invited may choose not to take part or to subsequently withdraw without giving a reason, during the interview or at any time prior to 2 months after the completion of all interviews, i.e., until the middle of March 2019. If a professional withdraws, the caregiver involved in the research study will not be informed, so that no threat to the relationship between them will be posed.

If you decide to give your consent to participate in the study, you will be asked to bring either a video (no more than 10 minutes) of your child addressing any kind of repetitive behaviour or an object with which you think your child presents repetitive movements. Then, we will discuss the child, for approximately 45 minutes. Our conversation will be audio recorded by me.

Are there any risks?

There are no anticipated risks associated with your participation in the study. However, if you have any concerns or encounter any discomfort, you have the right to withdraw at any time up to 2 months after the completion of all interviews (i.e., in March 2019) without giving any explanation.

Further information

This research has been reviewed and approved by the Ethics Committee of the University of Birmingham. If you have any further questions or concerns about this study, please contact the lead investigator or any of the two supervisors:

Lead Investigator	Lead Supervisor	Second Supervisor
Ms Katerina Tavoulari[22]	**Dr Liz Hodges**	**Dr Kerstin Wittemeyer**

Thank-you for considering taking part in this study.

Please keep this information sheet for your reference.

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[22] Contact information such as email addresses and telephone numbers were provided.

UNIVERSITY OF BIRMINGHAM

School of Education,
Disability, Inclusion & Special Needs Department

PARTICIPATION INFORMATION SHEET FOR PROFESSIONALS

Research project title:

"Disability, attitudes and stigma in Greek society": Exploring the perceptions of caregivers and professionals regarding the repetitive behaviour of children with vision impairment and children on the autism spectrum (a comparative study).

Lead Invesigator: Ms Tavoulari Katerina, Ph.D. Researcher

Lead Supervisor: Dr Liz Hodges, Senior Lecturer in Deafblindness and Multisensory Impairments

Second Supervisor: Dr Kerstin Wittemeyer, Lecturer in Autism

Associated funding body:

"A. G. Leventis Foundation" (Zurich Secretarial Office: Tüdistrasse 44, P. O. Box 1527, CH-8027 Zürich / Switzerland) and the "Bakalas Foundation" (20 Panepistimiou Street, P.C. 10672, Athens)

Dear Madam/ Sir,

You are being invited to take part in a research study that is being conducted as part of my PhD at the University of Birmingham. Before you decide whether to take part, it is important for you to understand who I am, why the research is being conducted and what it entails.

My name is Katerina Tavoulari and I am a qualified special educator. I have been teaching children on the autism spectrum and children with vision impairment and multiple disabilities for the past seventeen years.

The purpose of the study is to investigate how people (caregivers and professionals) perceive the repetitive behaviours of children with vision impairment and children with autism spectrum disorder.

Repetitive behaviours refer to patterns of movements and activities of children with autism and children with vision impairment, such as hand-flapping, rocking, sensory sensitivities and circumscribed interests. Through my interaction with children over the past years, I have noticed similar reactions and attitudes from the children’s caregivers and other professionals. My motivation for this research study is to further examine the reasons for these similarities in perceptions and the impact of caregiver and professional attitudes on children’s lives.

Since you are a qualified professional (e.g., special educator, psychologist, speech-language therapist, occupational therapist, school nurse, social worker, etc.) of a child on the autism spectrum or a child with a vision impairment, your participation in the study would be highly appreciated. Also, you should be informed that the child’s caregivers have given their permission for you to talk to me about them.

If you agree to take part, you will be asked to take a short (10 minutes) video of your student revealing a repetitive behaviour and will be interviewed for up to 45 minutes.

Please read the following information carefully and do not hesitate to come back with questions if something is not clear.

Then, if you are happy to take part in the study, please complete the enclosed consent form.

It will be my pleasure to have a discussion with you and talk about your experiences, perceptions and thoughts.

Sincerely yours,

Katerina Tavoulari,
Doctoral Researcher

Additional information:

Who is responsible for the data collection in this study?

In this study, the only person responsible for the data collection is myself. The data will be collected via interviews and my personal research diary and will not be shared with other persons or organisations. The digital records of this study will be kept strictly confidential. Research records will be kept in a locked file for at least ten years and all electronic information will be encrypted and secured using password-protected files. Nobody, except the study's supervisors and the lead investigator will have access to the digital recordings. Only the lead investigator (myself) will have access to the personal data of participants (name, contact information). It is stressed that all data presented in the study's report or other academic papers will be completely anonymised.

What are the benefits of taking part in this study?

By participating in the study, you will help to improve the level of understanding of the reactions/ attitudes of adults towards these children's repetitive behaviours (and their underlying causes). The comparison of blind children and children on the autism spectrum might help researchers to move beyond traditional perceptions, by focusing on similar patterns in reactions.

Ultimately, this research study might also be published in academic papers.

What are my rights as a participant?

Taking part in the study is voluntary. Everyone invited may choose not to take part or to subsequently withdraw without giving a reason, during the interview or at any time prior to 2 months after the completion of all interviews, i.e., until the middle of March 2019. If a professional withdraws, the caregiver involved in the research study will not be informed, so as not to disturb the relationship between them.

If you decide to give your consent to participate in the study, you will be asked to bring either a video (no more than 10 minutes) of your student presenting any kind of repetitive behaviour or an object with which you think the child addresses repetitive movements. Then, we will discuss the child, for approximately 45 minutes. Our conversation will be audio recorded by me.

Are there any risks?

There are no anticipated risks associated with your participation in the study. However, if you have any concerns or encounter any discomfort, you have the right to withdraw at any time up to 2 months after the completion of all interviews (i.e. in March 2019) without giving any explanation.

Further information

This research has been reviewed and approved by the Ethics Committee of the University of Birmingham. If you have any further questions or concerns about this study, please contact the lead investigator or any of the two supervisors:

Lead Investigator	Lead Supervisor	Second Supervisor
Ms Katerina Tavoulari[23]	**Dr Liz Hodges**	**Dr Kerstin Wittemeyer**

Thank-you for considering taking part in this study.

Please keep this information sheet for your reference.

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[23] Contact information such as email addresses and telephone numbers were provided.

Appendix 5

Post-Information Form

School of Education,
Disability, Inclusion & Special Needs Department

POST-INTERVIEW FORM

Research project title:

"Disability, attitudes and stigma in Greek society": Exploring the perceptions of caregivers and professionals regarding the repetitive behaviour of children with vision impairment and children on the autism spectrum (a comparative study).

Research Investigators – Contact Information:

Ms Aikaterini Tavoulari, Doctoral Researcher

Dr Liz Hodges, Senior Lecturer in Deafblindness and Multisensory Impairments

Dr Kerstin Wittemeyer, Lecturer in Autism

Thank you for agreeing to participate in this study. We appreciate your willingness to assist in this research project and are grateful that you have shared your insight into a topic that might have been difficult to talk about.

Your contribution to this research study is invaluable and we hope you enjoyed the experience.

We would like to point out, following participation in the research study, every participant will have the right to access a brief summary report of the results, once the research study is completed. Thus, once the study is conducted you can receive, upon request, a copy of the summarised findings across all participants, in which there will be no specific mention to your child/ student/ interview.

Please tick the applicable box:

I would like to receive a brief summary report of the results and my contact details are the following: ……. ☐

☐

I don't want to receive a brief summary report of the results..

Thank you again for participating in this study.

Kind regards,

Katerina Tavoulari

Appendix 6 & 7

Interview Schedule and Interview Questions

Subject: CAREGIVERS

Initials: ………………….

Date: ……………………

Your own vision: Sighted ☐

Vision impairment (please specify) ☐ ……………………………

Child's disability: Vision impairment ☐

Autism spectrum disorder ☐

Child' s age: ……….

The interview comprises 4 parts. *In the first part*, we are going to look at the video/ toy you brought and after that we are going to have a little chat about it. *In the second part,* we will talk about the kind of repetitive behaviours your child might display and how those might have changed over time or across situations. *In the third part*, I would like you to think about why your child might adopt some of the behaviours you described. *In the last part*, we will talk about how you think those behaviours impact on your child and on others. The entire interview should last no more than 45 minutes and if you need a break at any point, please let me know. Finally, I would like to ask you to try to provide as many specific examples of behaviours and situations as possible.

PART 1 (what? when?)

1. Why did you choose this video/ toy?

2. Could we talk about what we just saw / your child playing with that toy? Is what we have just seen an example of typical behaviour your child displays on a regular basis? / Is this a toy your child spends a lot of time with – and how does she/ he use it?

3. Definition of Repetitive Behaviours: Restricted repetitive patterns of movements, such as hand-flapping, body rocking, spinning objects, sniffing, as well as repetitive vocalisations or speech (echolalia), which don’t appear to have a clear functional purpose. After listening to this definition of “repetitive behaviours”, is that something that reminds you of your child? Could you please give me an example of your child’s repetitive behaviour?

4. Are there any differences in the repetitive behaviour at different times of the day?

5. Are there any variations across different types of activities?

6. Are there any differences depending on the people with whom your child interacts?

7. Have you noticed any differences at different ages, as your child is getting older/ more mature? For instance, when she/ he was a baby? Or when she/ he started to walk, went to nursery, started pre-primary and primary school, now?

8. How do you usually react when the child displays a repetitive behaviour? For instance, do you i) try to stop the child (i.e., by holding her/ his hands, by hugging the child, by asking the child to stop)? ii) wait until the child stops the repetitive behavior? iii) try to redirect the child’s attention to something else (i.e., by offering food/ offering a game)? iv) avoid eye contact with the child until she/ he stops?

PART 2 (why?)

1. Some possible functions of repetitive behaviours might be enjoyment, boredom, anxiety, pain, anger or sensory sensitivities. It might also be that your child is trying to request or refuse something using these behaviours. So, taking for example the behaviour of *[refer to one of the behaviour examples given by the interviewee]*, do you think that your child displaying this behaviour can be linked to any of these emotions or functions? *[Then I will ask about a few more of the behaviours described by the caregiver in the same way.]*

2. Do you (usually) tend to explain (to yourself/ to others) your child's behaviour/s by any of the above emotions/functions?

3. If not, what do you think causes your child to display these behaviours? *[Make sure to get clear examples.]* What seems to trigger this behaviour and/ or to increase its frequency/ intensity? *[Go through a number of behaviour examples with the interviewee and ask this about each of them.]*

PART 3 (how?)

1. How do you think the repetitive behaviours you have described might impact on your child's:

    - Health (e.g., does she/ he hurt her/ himself as a result of the behaviour? is it affecting his/her diet or ability to engage in exercise?)?
    - Learning (e.g., do you feel that teachers struggle to engage your child in learning activities due to the behaviour/s? is your child's attention occupied with the behaviour and she/ he therefore seems to learn less from his/her environment?)?
    - Level of engagement in leisure activities (e.g., limited range of activities to be involved in due to the nature of the behaviour, fewer peer relations due to the behaviour, reduced interest in joining activities/games/interactions)?

- Interaction with peers and with family members (e.g., do peers avoid the child when they display a behaviour that the other children perceive as odd? / do family members avoid inviting you to large family meals as your child's behaviour might have been perceived as disruptive? does your child seem less interested in interacting with peers and family members due to engaging in the behaviour/s?)?

(For each of those, I will go through examples of behaviours they might have mentioned earlier on. The examples I have written in brackets are going to be used if needed, depending on the pace of the discussion.)

2. What is the biggest challenge in trying to manage your child's repetitive behaviour (i.e., trying to understand your child's behaviour, trying to stop it, trying to cope with other people's comments/ reactions?) How do you overcome or try to address that challenge?

3. Do you feel that repetitive behaviour has an impact on your family (i.e., can you all go to the cinema together as a family? can you easily organise a birthday party for your other child?)? if so, please explain.

4. Is there a member of your family who has ever expressed feelings or comments related to the child's repetitive behaviour?

5. Does the child' repetitive behaviour have an impact on you? (Impact could be related to your feelings, your health, your relationship with your child, your habits, activites, etc.)

Any additional thoughts?

Subject: **PROFESSIONALS**

Initials: ……………………

Date: ……………………….

Your own vision: **Sighted** ☐

Vision impairment (please specify) ☐ ………………………

Background/ Experience: **Vision Impairment** ☐

Autism Spectrum Disorder ☐

Other areas of special education ☐

Months/ Years working with the student and her/ his family: ………………………

Months/ Years working in special education: ………………………...

Child's disability: **Vision impairments** ☐

Autism spectrum disorder ☐

Child's age: ………………

PART 1 (what? when?)
1. Why did you choose this video/ toy? 2. Could we talk about what we just saw / your student playing with that toy? Is what we have just seen an example of typical behaviour your student displays on a

regular basis? / Is this a toy your student spends a lot of time with – and how is she/ he using it?

3. Definition of Repetitive Behaviours: Restricted repetitive patterns of movements, such as hand-flapping, body rocking, spinning objects, sniffing, echolalia. They could be labeled as physical behaviours, distinguished by their lack of developmental and social appropriateness. After listening to a definition of "repetitive behaviours", is that something that reminds you of your student? Could you please give me an example of your student's repetitive behaviour?

4. Are there any differences in the repetitive behaviour at different times of the day?

5. Are there any variations among different types of activities?

6. Are there any differences depending on the people with whom the student interacts?

7. In case you have known the child for a long period of time, have you noticed any differences at different ages, as the child is getting older/ more mature? For instance, when you first started working with the child? Or during any stressful/ difficult period the child might have gone through? Now?

8. How do you usually react when the child displays a repetitive behaviour? For instance, do you i) try to stop the child (i.e., by holding her/ his hands, by hugging the child, by asking the child to stop)? ii) wait until the child stops the repetitive behavior? iii) try to redirect the child's attention to something else (i.e., by offering food/ offering a game)? iv) avoid eye contact with the child until she/ he stops?

<u>PART 2</u> (why?)

1. Some possible functions of repetitive behaviours might be enjoyment, boredom, anxiety, pain, anger or sensory sensitivities. It might also be that your student is trying

to request or refuse something using these behaviours. So, taking for example the behaviour of *[refer to one of the behaviour examples given by the interviewee]*, do you think that your student displaying this behaviour can be linked to any of these emotions or functions? *[Then I will ask about a few more of the behaviours described by the caregiver in the same way.]*

2. Do you (usually) tend to explain (to yourself / to others) your student's behaviour/s by any of the above emotions/ functions?

3. If not, what do you think causes the student to display these behaviours? *[Make sure to get clear examples.]* What seems to trigger this behaviour and/ or to increase its frequency/ intensity? *[Go through a number of behaviour examples with the interviewee and ask this about each of them.]*

PART 3 (impact?)

1. How do you think the repetitive behaviours you have described might impact on your student's:

    - Health (i.e., does she/ he hurt herself/ himself as a result of the behaviour?)?
    - Learning (i.e., do you feel that professionals seem to have engaged the child in fewer learning activities as they struggle to work around those behaviours)?
    - Level of engagement in leisure activities (i.e., limited range of activities to be involved in, as the child has to be guided by someone in order not to display repetitive behaviour?)?
    - Interaction with peers and with family members, in the case you are aware (i.e., do peers avoid the child when they display a behaviour that the other children perceive as odd?/ do family members avoid inviting the family to large family meals as the child's behaviour might have been perceived as disruptive?)?

(For each of those, I will go through examples of behaviours they might have mentioned earlier on. The examples I have written in brackets are going to be used if needed, depending on the pace of the discussion.) 2. What is the biggest challenge in trying to manage your student's repetitive behaviour (i.e., trying to understand the child's behaviour, trying to stop it, trying to cope with other people's comments/ reactions?). How do you overcome or try to address the above challenge? 3. Does the child' repetitive behaviour have an impact on you? (Impact could be related to your feelings, your reactions to the child's actions, your thoughts, your habits and routines in the classroom, etc.) 4. Have you ever heard/ seen anything related to your student's repetitive behaviour by your colleagues?
Any additional thoughts?

Appendix 8: Additional Quotes from my Research Diary (2005 - 2019)

1.	**31/ 10/ 2007** Today I tried to use imitation in order to stop FT's (diagnosis: pervasive developmental disorder) stereotypical movements. Must I, though? It seemed to calm her down temporarily, but then she had some unexpected outbursts. Is she repressed, perhaps? The headteacher looks at me askance. As if I am to blame for the child's movements. I don't want to always be stopping her.
2.	**29/ 1/ 2012** My communication and coordination with the orphanages of my students is truly very challenging. I wish for a common strategy with the staff or at least the ophthalmologist they consult with. I felt enraged today, but I managed to avoid falling out with anyone. VP walked in with wounds on her head (two days after the eye surgery she had), because, as they told me, she hit her head and we as specialists need to teach her not to do it.
3.	**21 / 5/ 2013** I don't know how to handle this! Is it possible that every child is different and has their own pace when learning? Should I stick to the syllabus for each disability? Am I obliged to consult ICD and DSM? However, I am also assessed by the counsellor on the basis of whether I take initiative and use innovative methods.

4.	15/ 11/ 2014 I have been working with blind students for 2 ½ months now and their behaviour increasingly reminds me of my autism students, day after day. Their movements, the sounds they make, their reactions. I need to look further into this.
5.	4/ 3/ 2016 I first read this book (the only comparative work I have found about VI and ASD) edited by Linda Pring, almost 10 years ago. I thought that returning back to it today and after so many years of discovering the issue of stereotypies, would be beneficial for me. I I found that reading it was still interesting, but I felt anger and disappointment at some points. I strongly believe now that people should redirect their attention from ideal intervention methods to something else. What exactly though?

Appendix 9: Selected Quotes from the Interviews

I decided to include part of the quotes I have used in Appendix 9, in order to form categories, subcategories and by extension themes, in the context of the data analysis. As has already been mentioned, the aim was increasing credibility and trustworthiness through transparency of research methodology. The following quotes were selected at random. The volume of quotes recorded via NVivo was substantial. For this reason, I tried to include around 10% of the quotes in each category in the tables that follow to act as a sample.

VISION IMPAIRMENT	
Categories	Subcategories
Self-harming behaviour: *"She indicates a self-harming behaviour, often hitting her head."* (VIPROF11) *"When she is angry, she'll want to go, she'll start shouting, start biting herself. This is not acceptable; we aim to stop it!"* (VIPROF18) *"When she gets very angry, she scratches herself and the people around her! Sometimes she turns her head either right or left saying 'atha'. I think that she communicates her psychological mood in that way! It is like she wants to say: 'I don't want to!*	**Putting a stop to the behaviour**

Leave me alone! However, we need to stop her somehow!' " (VICAR16)	
Disability: *"Although she doesn't have a diagnosis for the ASD, the child indicates that kind of RB. She does it in a kind of stereotypical way. I believe that Christina has autistic features. For instance, when she walks, she does it in a very specific autistic way."* (VIPROF16) *"According to the neurologist, RBs have a neurological base and they do affect my child's mobility."* (VICAR2) *"Some of the things Liza does we cannot separate them from the fact that she doesn't only have vision problems. She also has the de-institutionalisation problem. In other words, her emotional state, even her movements... come out. I was just thinking now, that, once, for example, Liza, in the early days, I would say to her, 'Come, let's get dressed' and she'd say 'No! No! No! No!' and she could be sitting naked on the bed for two hours after her bath. (…) that*	Terminology used

wasn’t a result of her bad vision, but of the bad emotional state she was in… Because as I’ve told you before she came to me she had been with another seven families. Or let’s say, she would pierce her skin and it would bleed. And that was out of insecurity. And now she says to me, ‘Back then, because I had changed families so many times and had no security I would be staying – I wasn’t sure I would be staying with you – I did that thing because inside I felt’ to quote her ‘as if I was homeless’. Also, one of the reasons Liza was sent away from all those families, as I was told in secret, not told officially – by the institution –was… she would chatter non-stop. Today Liza is a perfectly normal child and I can say totally ordinary. We discussed it because she herself attempted to discuss it. And she repeated the same question many times. But that wasn’t the result of her bad vision. She herself explained and said: ‘I wanted to attract the others’ attention so that they would know I am here too’.” (VICAR5)	

"There is differentiation between an RB and a stereotyped behaviour. In the first case I try to understand what the child wants. In the latter case I try to transform the behaviour into something more functional, through the use of music.". (VIPROF2)	
"Or what I said before, pressing her eyes. I believe as she can't see well, they triggered something and so she pressed them." (VICAR8) *"I think the issue is blindness. Maybe he sees some stars, that's what they call them. If we press our eyes, we see them too."* (VICAR15) *"Sensory stimuli. I mean. This gives her sensory pleasure… some pleasure. Sometimes when there is some sort of upheaval, she might shut herself in for a bit and press her knees against her eyes…"* (VICARs8) *"I think it's mostly simply that he enjoys the sensory aspect. I mean. Just as a baby wants to be rocked to calm down and you can immediately see it relax and calm down. This*	Sensory need

rocking, you know, like when a mum moves a buggy back and forth or a swing. It's the proprioceptive system that needs to be regulated in a way, to relax, right? So, he gives that to himself because at that point that helps him self-regulate and relax etc. Right. But then if you also want to get in there and create a relationship, and interact too, communicate with this child, who right then is in that state and you make them understand that right now with the rhythm at which I'm playing and being part of what he does it's exactly like mum saying: 'Right. Let's go. Yes. Come, we'll do this together now, not on your own. Let's do it together. I'll help too'. But at some point, this togetherness is so nice that he starts craving the relationship too. Not just the process of rocking but also forming a relationship with the person involved in it with you, because you accept him. You accept him, go with him, give the whole thing meaning and then he doesn't have the same need as before, because he can get out of it and interact and do something else." (VIPROF12)	

"I believe that she has that behaviour every time that she wants to regulate and organise herself; to reduce her stress levels." (VICAR2) *"…it depends on her mood, on how calm she is. Repetitive movements may have to do with the fact that she wants to regulate herself, to become organised, to help her stress levels, to reduce her stress…?"* (VIPROF2) *"For example, when something happens at home that upsets her, and she feels like isolating herself to self-regulate."* (VICARs8) *"I believe all this jumping up and down isn't functional, it has no functional purpose. He only does it because it offers him something right there and then, some form of self-regulation."* (VIPROF14) *"I don't take it as a message towards me. You could say perhaps it's mostly lack of organisation and that he feels like it's a chaotic process for him, which he can't handle and which he*	Self-organisation/ regulation

gets rid of through a repetitive movement due to the lack of time organisation in the activity. I don't think he does it deliberately to evade the activity because... I just think he can't handle it so then what I do is to escalate the activity even more and give him clearer instructions and break it up into smaller steps, that is." (VIPROF6)	
Speech: *"Echolalia is a kind of RB that is not characterised by a specific functional aim."* (VIPROF15) *"Another stereotypical movement is her echolalia… For instance she'll say... er... we have rituals, e.g., you'll say 'Done' and I'll say 'Perfect'. She says I'll say 'Perfect'. And I say you'll say 'Done' and I'll say 'Perfect' if you do it right."* (VIPROF11)	
Communication: *"She would communicate to me if something bothered her. But couldn't verbalise it. So that could make me feel like, 'Ok, so now what? Are we*	**Interpretations**

going to spend all our time on this leg? And then I understood..." (VIPROF16) *"Whenever he wants to communicate something, he prefers not to ask for it but start that RB."* (VICAR6) *"We can say that she is happy with music and expresses this by bouncing her body. With other activities that she doesn't like, she may hit her head. This is our code; a kind of communication for us."* (VIPROF2) *"With stereotypical movements, I also make them meaningful... that is, I create, I play on that very rhythm of the stereotypy. Whatever that stereotypy might be..."* (VIPROF12)	
Feelings: *"When Dimitris is happy, he moves his hands and fingers like this…"* (VICAR15) *"He can't handle this feeling, that someone is sad or cries, he only wants... 'Hère' (=rejoice) he says all the time. 'Hère', 'Hère', 'Hère' so that*	Joy

I'm happy, cheerful. That's all." (VIPROF14) *"Out of joy. Out of joy he keeps going 'Ooooooo'."* (VICAR13) *"She does it often when she feels happy and generally when we address her, when we speak to her."* (VIPROF11) *"He does it, I think, mostly at the end of the day, mostly for his own pleasure. He likes jumping up and down and spinning at the same time around himself. He shows his joy that the school day is finishing."* (VIPROF14) *"When she's happy she might, say, jump up and clap out of happiness or ask for kisses. All the time!"* (VICAR16)	
"I think sometimes it might also be his anxiety about what he's trying to do. If you give him a more anxiety-inducing, more stressful material in this he'll take it off and leave in that way." (VIPROF15)	Anxiety/ Stress

"Self-harm is slightly different from other simple forms of stereotypies, such as visual or kinetic stereotypies. Such simple forms may be due to a high level of stress." (VIPROF16)	
"It is a matter of insecurity. My child feels insecurity because of the sight loss and thus he presents RBs." (VICAR14)	Trust/ Lack of Trust
"When she meets someone, she doesn't know…. For instance, my first meeting with Sofia was catastrophic. She didn't even want to enter the room, she avoided me and wanted to leave. It took half a year until she started to feel comfortable with me, to enter the room and sit through our 30-minute session. (…) The same with the speech therapist. The speech therapist has also been coming for a year and they have made a great effort to be able to be calm in the classroom and to feel comfortable with the premises and himself." (VIPROF18)	
"Even when he was small what he always does is he jumps up and down	Boredom

when he seems bored or when he is waiting for something or has nothing specific to do. So, an RB for example is this constant jumping. Us saying 'Stop', him running around the house. An act like he's bored. That's how I interpret it..." (VICAR6)	
"When he gets very angry, he scratches himself and sometimes the people around him! It seems like an indication that he doesn't want to participate anymore!'" (VICAR15)	Anger
"And the issue of strong smell, generally around food. And everything. Constantly. You know, she bends down and smells... I think she does this RB more because she can't see well." (VIPROF18) *"Not everything is relevant to her. For instance, the strong sense of smell. This is because of her diagnosis."* (VICAR8) *"The strong sense of smell. She also makes certain sounds like screams when she smells other people or just*	Olfaction

objects. It's like she receives a temporary sense of satisfaction." (VIPROF8)	
Ritual behaviour or Challenging behaviour: *"She follows a specific daily routine; very specific actions in a very specific order. If this is not a stereotypy, then what is?"* (VIPROF11) *"Every time I asked him to practise on the Braille machine, he had the same challenging reaction: he sang the same song and spat. But this is not an RB"* (VICAR5).	Ritual Challenging
Contradictions: *"I always tell him that there is no reason for him to exhibit a stereotypy. My lovely Nikos, please do not do this. Don't run. Don't jump. There is no reason!".* (VICAR6) *"Of course, there are repetitive motives of movements, the clapping, the regression of the body, the rotation of objects…yes. (…) Hmmm… she does not rotate objects, no, she*	

just wants to put them in order." (VICAR2)	
Impact: *"I think she has an issue in her communication because she doesn't know how to express herself. (…) She needs someone by her to say: 'Would you like to play? Would you like to talk with the others? Your friends are here. Your friend is here. Come play with him, do something. Sing a song. Tell him what you've eaten.' She needs a person. So this deters her. When she presents echolalia, she shuts herself in and that is an obstacle to communication."* (VIPROF16) *"He makes these nervous and spastic movements with his arms. And in the past the other children would make fun of him and say, 'What are you doing? Knitting? Knitting?'"* (VICAR14) *"When this (self-harm) took place, the programme would 'fall behind'. We could not proceed… out main concern was for the child not to hurt herself and not following the programme."* (VIPROF8)	**Impact on the Child (relationship with peers, intervention programme affected)**

"His free play is affected a lot when he starts jumping and spinning, because he can't sit down and organise it. He just wanders around with a toy in hand. He doesn't really play with it. So, I think it's his end functions that are affected by this. That of communication, of free play, of exploration." (VIPROF6) *"So, this may be raising her anxiety levels. And this may in turn be blocking her even more and preventing her from developing her skills. Either in a primary or a secondary way."* (VIPROF12)	
"When the child starts socialising, you must be very strong too to handle all the bullying you also will receive – because you do also receive the bullying your child receives, it comes to you too." (VICAR14) *"It puts me in a difficult position and I feel embarrassed sometimes when she becomes hysterical. Like when you see a child outside screaming…"* (VICAR8)	Impact on the Family (embarrassment, handling the child's anger, anger, stress, sadness, siblings)

"I don't know how to control this thing. How can I help him stop it, because as a parent I worry that later on when he's older and will be a teenager and will find himself in different situations, I wouldn't like him to be doing that in a group of kids." (VICAR14) *"One of these days he'll go out there to flirt. He might see a girl he likes... when he's a teenager. Now I wouldn't like it if he was in a date... But then you'll say, you're looking too far ahead. No I'm not. There are some things that worry me. And say he starts doing these... some spastic movement or his hands like that. It's something I don't know if I can help Fotis with so that he gets to a point where he can control it and that worries me."* (VICAR14) *"What makes me exhausted and upset is when we go out and walk around and I can see other children walking and not behaving like that... I mean I'm happy that she's having fun but I'm dying inside."* (VICAR16)	

"But it's my eldest who feels it the most. Especially when he sees her behaving like that, I understand him. Perhaps that's why he wants to be a doctor. It affects him deeply. Sometimes he doesn't show it, but I can tell, especially when he sees her RBs." (VICAR16)	
"I do what I can to isolate her, to have stability in her programme so that any changes do not cause more tension. I introduce changes bit by bit. Small changes in her programme. (…) In other words, when it starts, just by saying "stop", it is not something that can be stopped. I cannot set limitations on her body. She might stop, she might continue; in that case, I have to stop the session and let her go." (VIPROF18) *"It throws you. Fotis has incredible attention deficit. You are about to do something and he throws you by saying something else. He won't let you work. It's intense. Right. I think that it does affect us so we always try to draw him back in."* (VIPROF14)	Impact on the Professional (type of intervention chosen, decision making, disappointment, satisfaction, anger)

"Sometimes it might affect me emotionally. It annoys me a little sometimes when it's too intense and he won't come round easily. I say: 'Now stop it, Dimitris'." (VIPROF15) *"This gives me tremendous satisfaction. It's like doing a task analysis. I mean, it's a challenge, both interpreting her behaviour and trial and error. Trying different things, and finding things that might work or not and through this trial and error you anyway don't approach it in a developmental way but it's also about what works on the child."* (VIPROF18)	
"During the interdisciplinary groups, this is the first topic of discussion. (…) We do not have time to discuss the other children, or other issues…" (his attitude while speaking is aggressive)." (VIPROF6) *"We look for ways to improve her learning, which is affected by this RB she presents. In meetings, we're always talking about Christina and seeking ways to handle her RBs."* (VIPROF16)	Impact on the Interdisciplinary Team (intervention program affected, relationships)

AUTISM SPECTRUM DISORDER	
Categories	Subcategories
Self-harming behaviour: *"So, something that is Elpida's trademark... the RB she uses, the self-harming RB, during which she bangs her head either on a flat surface, usually the floor, always a hard surface, or a vertical surface like a wall."* (ASPROF20) *"She'll jerk her head backward. When she wants to be taken out of the pushchair, in other words to express a need or when she wants to avoid something, meaning the pushchair again, to avoid that."* (ASPROF20) *"He scratches his cheek to the point of drawing blood, when he is stressed."* (ASPROF27) *"Whenever he feels bored, he starts biting his hand."* (ASCAR31) *"I feel so embarrassed when looking at the other children playing at the playground, while mine is banging his*	**Putting a stop to the behaviour**

head with his hand because he is happy. He is happy, ok, but I am not!" (ASCAR23) *"It's so disheartening watching him scratch – tear at his cheeks with his nails. I have been a professional for years, but a mother too, and I feel for his. It makes me sad."* (ASPROF21) *"Self-harm is part of the disability. All my autistic students, they stereotype in one way or another, and when they do they injure themselves."* (ASPROF1)	
Disability: *"In any case, according to the DSM-V, a self-harming behaviour is, say, expected. It's part of the evaluation criteria."* (ASPROF1) *"It is not about whether it serves any purpose. He clearly just isn't capable of replying, apparently couldn't, I imagine and so due to his developmental disorder he exhibits echolalia."* (ASPROF27)	Terminology used

"I imagine, as I don't have much knowledge about it, that the thing in question must be of a neurological nature, from what I read and hear. Which is why he has this sensitivity and perhaps his nervous system is more sensitive than that of other children's or people's." (ASCAR22) *"Obsessions and stereotypies in his behaviour when he became stressed by an external stimulus."* (ASPROF31) *"As he gets older, I think that his behaviour becomes more stereotypical."* (ASCAR22) *"My role as a mother is to restrict the autistic symptoms, to tone them down. They are autistic signs, let's say, that go hand in hand with the syndrome..."* (ASCAR21) *"Aaah, I have called him autistic several times in the past (laughs). Sometimes I feel that it is an RB that he doesn't provoke at all. Other times though, I think that he receives a kind of satisfaction from it."* (ASPROF24)	

"She might be doing that thing with her eyes. Opening and closing them with her fingers. Like she's playing with her sight. Especially when it's sunny, she sits in the sun and does it." (ASCAR3) *"Shuts his ears"* (ASCAR23) *"And he does it mostly during the break when it's sunny, when it's... and with all this noise with the children, and he has issues with his ears, he doesn't like hearing things, and he shuts his ears. And when it's sunny, he chooses to play with the light in this way. (…) Not play. He likes this in a sensory way."* (ASPROF1) *"During relaxation time, for example, he doesn't do it. Only during the break, which I think has got to do with the fact that there's noise from the other children and again it's a way for him to defend himself, to regulate himself again in relation to the other children. And he does it during group work."* (ASPROF22)	Sensory need

"He is a child who likes lying down and sitting on the floor and snuggling. And so, this part gives him some satisfaction." (ASPROF23) *"She generally bangs her head. She prefers hard surfaces so as to feel the stimulus. Because if it isn't then she can't feel it. So that she gets real friction, like pain."* (ASPROF20)	
"It's soothing for the child. For that reason, I think he's not so much trying to avoid, as to handle situations. He will remain here, he wants to do that or he knows that he must do it but tries to do it on his own terms. (...) Exactly like self-regulation! Like the way many of us have a cigarette or play with our phones. (ASPROF30) *"Right, so these two movements she also uses as we have observed in order to self-regulate or to de-stress after a particular situation. I mean... pleasure is perhaps too specific a term to use but it certainly has a positive effect. She uses these two movements in a positive way (...) But also in the*	Self-organisation/ regulation

class and in the environment when she isn't involved in an activity. She uses those movements clearly to perhaps relax herself after being exposed to something that stimulates her. Which means that these movements offer her some kind of relief." (ASPROF20)	
Speech: *"He doesn't have RB. What he has is echolalia; meaningless echolalia. He does it without having had an acoustic stimulus. He just does it randomly."* (ASCAR21) *"You might ask him a question and he'll reply with the same question. Bear in mind that echolalia is the only means of communication for him…his only use of speech"* (ASCAR4)	
Communication: *"He does it when he really wants to say what he wants. It took me time to understand…"* (ASPROF23) *"So, something that is Elpida's trademark... the RB she uses (…) can be linked mostly manipulatively to*	**Interpretations**

communicating, (…) by banging her head she wants to show that she wants something, er… she has a need. I understood this by working with her over a long time." (ASPROF20) *"When he has that behaviour, he always tries to enlist an adult. It's a kind of interaction and communication with the other."* (ASPROF22) *"I try to explain why he does it. Why he tears and throws the books. Why he wants to upset us. If I can't explain it to myself, then I can't offer any reassurance to his sister, who gets quite rightly annoyed."* (ASCAR22)	
Feelings: *"He might feel stressed, he might not know what exactly he must do and he handles it this way."* (ASCAR30) *"He feels anxiety, frustration, that…how can I put it now…he is stubborn, he wants something and he wants it now. That's why he exhibits RBs…"* (ASPROF27)	Anxiety/ Stress

"When he is stressed his speech becomes slower or he stutters a bit. When he thought that everyone was looking at him, even when he was in the car, he wouldn't come out at all." (ASCAR24) *"He gets very stressed and has RB when his mother is away and he's alone with his dad and a cousin*." (ASPROF27) *"The RB that has upset me in the last six months is that he seems to now be presenting a form of stuttering. I mean, when he wants to, he overcomes it and speaks normally. When he doesn't, he can't start making a sentence unless he has repeated the first syllable of the sentence about ten times. (…) Because we had a couple of incidents when we didn't sleep at night. We stayed up to keep him company. And one of these times he explained to me that he couldn't sleep because he worries about something happening to him, and he doesn't know what that is. That's why he had that kind of RB*." (ASCAR4)	

"When it's Saturday or Sunday and he understands he doesn't have school and he gets up very early on his own (laughs) to turn on the tv and play with his toys, have breakfast and always he repeats during breakfast: 'No school for me today.' " (ASCAR4)	Joy Satisfaction
"He always brings the board games we use and puts them in specific order. The one we play them in. If you change it he gets angry. Or he always has a specific order of activities. As soon as we are finished, I must leave immediately. He gets angry when I speak with his mother and stay longer." (ASPROF27) *"This movement with his arm forward and backward is linked to strong feelings e.g., when he is angry."* (ASCAR27)	Anger
"He is easily offended. I once showed him where to colour, and I said you are colouring outside the lines, he started shaking his head and flapping his arms repetitively." (ASPROF22)	Insult

"Speech-related RBs are mostly linked to fatigue. This fatigue is mostly mental, e.g., after intense studying for school and social, e.g., after an event such as a party where he will need to interact with a lot of people. Afterwards, he feels the need to wind down and shut everyone else out and this behaviour helps him." (ASCAR30)	Fatigue
"Right, he doesn't like feeling bored. He doesn't like it. I mean, when he does get bored, he's more likely to do something like that and for me that's a way of knowing he is bored and wants to do something different." (ASPROF31)	Boredom
"When he shuts his ears I don't react much anymore, until he opens them, and I go and say, for instance, 'I want you to open your ears.'" (ASPROF22)	Hearing sense
Ritual behaviour or Challenging behaviour: *"One has got to do with his desires. Meaning, whether he has associated a particular time of the day with*	Ritual behaviour

something he particularly wants." (ASCAR4) *"RBs as an indication of obsession, about our lesson day and time. He wouldn't accept any changes. If I was even ten minutes late, he would be very stressed during our session. If I requested a change of day for personal reasons, he would not accept it."* (ASPROF23) *"It's as if he has a built-in clock. Everything must be done as scheduled. Otherwise he starts stereotyping. I try to inform him of any changes and to consider his wants."* (ASPROF27). *"Because I told him 2 or 3 times where to write, he tore the paper, shouted, and started hitting his head repetitively."* (ASPROF27)	Challenging behaviour
Contradictions: *"No! No! Nothing at all! The only thing is that he puts his toys in lines. Rather than play with a car, he could be looking at its wheels or putting them in a line repetitively."* (ASCAR31).	

"My daughter's RB does not affect me at all!" while ASCAR3 earlier has said: *"You cannot imagine how embarrassed I feel every time she exhibits such a stereotypical behaviour in front of other people!"*	
Impact: *"Now as for himself, I think sometimes he also realises that… when he can't fulfil his wishes, he feels disappointed and sad, therefore he indicates RBs."* (ASCAR4) *"It definitely affects her health first of all. I mean head injuries. Sometimes we try to see if she will continue. I mean if she's on a mattress we might see some... we might see her do the movement where we know the environment is safer and she won't harm herself. We'll let her for a while to see if it's indeed for relief, while normally we'd stop her. If she is on a hard surface you can definitely not let her because she'll injure herself immediately. I mean, she could even injure herself with her hands. Even in*	**Impact on the Child (disappointment, health, fatigue, stress, annoyance, interaction with peers)**

the pushchair she could be trying in that way and hit it with her head. So, it definitely affects her health." (ASPROF20) *"It's an obstacle for him in approaching other children, in playing with them, in building relationships…"* (ASPROF1)	
"Mainly the family (…) we become a little exasperated that he can't understand that he doesn't need to be repeating this." (ASCAR22) *"Of course, the general state of my child has affected our family and social life, as it's hard to plan an activity together. My husband usually makes comments on our child's behaviour."* (ASCAR22) *"His obsessions always mess up our schedule. We spend all that money on books he tears and therapists who cannot complete their intervention programme."* (ASCAR23) *"Due to fatigue, right? We are very tired because of our daily life and*	Impact on the Family (exasperation, annoyance, fatigue, environmental adjustments, anger, sadness, depression, stress/ anxiety)

when we find ourselves in an RB situation or something, like he absolutely must open the fridge and get the ice cream out, because he believes there is ice cream, while there may be none, he will open the fridge, the freezer.” (ASCAR4) *“We have some feedback from the family. It’s this. That we know that there it’s a perfectly adjusted environment with soft surfaces everywhere, so that Elpida can’t hurt herself. And the family are also alert, that’s in the feedback. That’s it, as to the self-harm.”* (ASPROF20) *“I was all over the place, I felt annoyed, I was embarrassed, I cried, I was depressed. Why? Because all of this... I was expecting a child and what I got was an entirely different child. Ok? I couldn’t sleep. I worked, couldn’t sleep, was stressed. My marriage, I mean, almost cracked because of that. My mum cried day and night. It affected me a lot. (…) I knew from a friend in Australia. Her sister had an autistic child but my daughter was very low-functioning*	

with a lot of RBs. So, I was a mess. A big mess." (ASCAR20) *"The challenge is to make him independent before you leave this world... (...) He is my child. How can I not mind seeing his face bloodied? But it makes me stubborn too. To make him learn how to also deal with his negative emotions."* (ASCAR21) *"I feel anxious to find ways of curbing his stereotypies, outside the family, to find ways that are discreet and allow him to maintain his independence. Sometimes I feel anxiety about him becoming exposed, especially now that he's growing and the social requirements are greater while simultaneously my own ability to intervene diminishes."* (ASCAR23) *"My sister minded. She felt embarrassed whenever my child presented an RB. She lives in the countryside. It's the countryside, and I understand that and respect it. I don't blame her."* (ASCAR3)	

"To waste a lot of time out of the activity in order to spend time on the whole issue of him sitting down and collaborating. That's really important. I should have said from the start perhaps, the environment really plays a part." (ASPROF31) *"Of course, it also affects emotionally. Sometimes when the situation is intense it becomes tiring. I mean, every time you have to think of new ways, of what is needed…"* (ASPROF21) *"It's tiring. Both physically and emotionally very tiring."* (ASPROF30) *"Sometimes I feel desperate because of his RB. Especially when he bangs himself on the walls, like a bull. I feel useless; that I can do nothing for him in order to help."* (ASPROF20)	Impact on the Professional (type of the intervention chosen, fatigue, stress)
"It's not that it upsets me, because it's a situation in which we've sort of trained ourselves. It's just that, that we are always trying to interpret it. It's a constant uncertainty that we're always trying to find a solution to.	Impact on the Interdisciplinary Team

Something might always be wrong, something might work, or work for a while and then not anymore, or maybe not at all from the start. In other words, too many adjustments, way too many suggestions, a lot of collaboration with the colleagues to find suitable solutions, so that – most importantly – we don't get to that behaviour, the self-harming one, and what we'll do when we get to it. For example, we've come up with the idea of grabbing her shoulder and saying 'stop', and we'll have another stimulus lower where we'd grab her spine... like a pressure, she'll feel a pressure immediately, which we've seen work. Or then more relaxed, or in a louder voice, like saying 'Elpida, stop', strictly, or in a calmer voice. I mean we've tried multiple times to find various solutions." (ASPROF20) *"That's the truth. It's definitely tiring because we're all as a team always alert because admittedly it is a dangerous behaviour. If it didn't pose an immediate threat to her health, I mean even doing a... like a blow to her head, I mean, maybe... that would*	

work differently. But we are talking about an urge to bang your head on the floor, it’s a very strong urge, it could cause serious damage.” (ASPROF20)	