

**HELP-SEEKING BY HARD-TO-REACH FAMILIES FOR CHILDREN'S
EMOTIONAL AND BEHAVIOURAL PROBLEMS**

BY

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OVERVIEW

Volume I

Volume I comprises a literature review examining empirical research on help-seeking for children's psychological and emotional problems amongst hard-to-reach parents, and a qualitative research paper investigating hard-to-reach parents' experiences of accessing social and emotional support for their children. The final part of Volume I is a public domain briefing paper summarising both the literature review and research paper.

The literature review evaluated papers according to the extent of their focus and relevance to help-seeking by hard-to-reach groups specifically. Very few studies were found to have sampled this group with most using indicators of being hard-to-reach as independent variables. Socioeconomic factors were found to have both a practical and perceptual influence on help-seeking and the role of parental perceptions of services was particularly significant. Help-seeking models incorporating parental attributions and meaning-making and the role of social context were found to be particularly appropriate for this group.

The empirical paper describes how eight parents accessing a voluntary sector organization in the West Midlands were recruited and interviewed about their experiences of help-seeking in the past and present. Transcripts were analysed using Interpretative Phenomenological Analysis and themes relating to power and disempowerment, ambivalent feelings towards support, and access to internal and external resources are reported.

Volume II

Volume II comprises five Clinical Practice Reports:

Clinical Practice Report 1 describes the case of a twelve-year old boy referred to a community Child and Adolescent Mental Health Service (CAMHS) for problems with anger. The child's difficulties are formulated from a cognitive and a systemic perspective and a critical appraisal and comparison of the two models are presented.

Clinical Practice Report 2 is a service evaluation conducted with a voluntary sector organisation based in Birmingham and providing support to disadvantaged families. It sought to determine whether the organisation's work is aligned with the outcomes laid out in Every Child Matters and if so, what evidence is being collected that demonstrates this.

Clinical Practice Report 3 presents the case of a twenty-four year old man referred to a community adult mental health service for help with obsessive compulsive disorder and a single-case experimental design is described.

Clinical Practice Report 4 is a case-study of a piece of psychodynamic work undertaken with a 31 year-old woman with mild learning disabilities who was referred to a specialist Psychotherapy Service after suffering a miscarriage.

Clinical Practice Report 5 was an oral presentation of a case study describing work done with an adoptive family whose daughter was referred to a specialist looked-after-children (LAC), CAMHS service after concerns about the girl's ability to manage her emotions and socialise with her peers.

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**HELP-SEEKING AMONGST HARD-TO-REACH PARENTS WHOSE CHILDREN
HAVE EMOTIONAL AND BEHAVIOURAL PROBLEMS: A REVIEW OF THE
LITERATURE**

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ABSTRACT

The relationship between risk factors for child mental health problems and parental help-seeking remains poorly understood, particularly for hard-to-reach groups. This paper examines empirical research on help-seeking amongst hard-to-reach parents in an attempt to identify what is known about the specific issues faced by this group and how these relate to existing help-seeking models.

Papers are evaluated according to the extent of their focus and relevance to hard-to-reach groups. Very few studies were found to have sampled this group specifically, with most using indicators of being hard-to-reach as independent variables. The contribution of these findings to an improved understanding of help-seeking amongst hard-to-reach parents is discussed and methodological issues highlighted.

In summary, socioeconomic factors were found to have both a practical and perceptual influence on help-seeking and the role of parental perceptions of services was particularly significant. Findings are presented using a multi-sector model of help-seeking but models describing parental attributions and meaning-making were also found to be relevant. Implications for future research and clinical practice are discussed.

INTRODUCTION

Context and rationale

It is widely acknowledged that untreated emotional and behavioural difficulties in children can have a significant impact on development, on functioning in adult life, and upon society as a whole (Dunlap, et al., 2006; Ford, Hamilton, Meltzer & Goodman, 2007). However, only a small percentage of families whose children have psychological problems seek help (Morrissey-Kane & Prinz, 1999; Srebnik, Cauce & Baydar, 1996). Whilst there has been a great deal of research exploring the risk factors for child mental health problems (McKay & Bannon, 2004; Rutter, 1987), the relationship between these and subsequent help-seeking or service utilization remains poorly understood (Fisher, et al., 1997; Jensen, Bloedau & Davis, 1990).

Several empirical reviews of help-seeking for children with emotional and behavioural problems have been undertaken to date. Logan and King (2001) undertook a conceptual and empirical review of parents roles in accessing help for adolescents using a 'pathway to care' model they developed. Their review focused specifically on the earliest steps in this pathway, namely parental awareness and recognition of the young person's difficulties. Zwaanswijk, Verhaak, Bensing, van der Ende & Verhulst's (2003) review also examined parental and adolescent problem recognition and help-seeking but included children from 0 to 18 years and incorporated literature relating to problem recognition by the GP. Sayal (2006) undertook a similar review but focused on studies involving children under the age of 12. Similarly to Zwaanswijk et al. (2003), Sayal examined literature pertaining to parental help seeking and problem recognition by the GP but papers relating to filters higher in the model were also included, namely referral to and use of specialist services. Morrissey-Kane and Prinz

(1999), and McKay and Bannon (2004) conducted conceptual reviews on the role of parental cognitions in engagement with child mental health issues, and engaging urban youth from minority groups respectively.

These reviews have identified that for adolescents, help seeking is influenced by characteristics of the adolescents' problems (particularly whether they were internalizing or externalizing); family stress and level of functioning; parents' knowledge and personal experience of mental health problems and services; the quality of the parent-adolescent relationship; the degree of comorbidity experienced by the young person; and perceived parental burden (Logan & King, 2001).

These factors have also been found to impact upon whether parents of children under the age of 12 recognise their child's difficulties. Only a small percentage of these children subsequently present to the GP for help and whether or not this happens depends upon the child's age and gender plus parental perceptions of problems (Sayal, 2006). Additional variables found to influence problem recognition and help seeking amongst children of all ages are parental attributions, the presence of medical and school related problems, informal help seeking, family size and cohesion, discipline effectiveness, poverty, and ethnic background (Morrisey-Kane & Prinz, 1999; McKay & Bannon, 2004; Zwaanswijk et al., 2003).

These reviews provide a useful summary of the influences upon help-seeking for children's psychological problems, and in some instances, offer an explanatory framework to make sense of the help-seeking process (Logan & King, 2001).

However, where a top-down approach to the review has been taken (Sayal, 2006; Zwaanswijk et al., 2003), there is perhaps a risk that literature relevant to help-seeking but not encapsulated by the chosen model (e.g. informal help-seeking or

alternative pathways to care) has been overlooked. In addition, some of the reviews do not discuss methodological issues in the literature which may impact upon some of the claims made.

Crucially, none of the work described above has focused specifically on hard-to-reach families, a group known to exhibit a greater number of risk factors for child mental health problems but who are underrepresented in mental health services. This review aims to address this gap in the literature by:

1. Collating any empirical research on help-seeking amongst hard-to-reach parents.
2. Critically reviewing this research to determine what is known about help-seeking amongst this group.
3. Summarising findings in the context of what is known about help-seeking in general and the models used to describe and explain it.

What is help-seeking?

Rickwood, Deane, Wilson and Ciarrochi (2005) state that help-seeking is a process of translating psychological distress into the 'interpersonal domain' of seeking help and that this is influenced by the person's awareness of the distress and their ability and willingness to articulate it to others. Help-seeking for children has been defined as "seeking assistance from mental health services, other formal services, or informal support sources for the purpose of resolving emotional or behavioural problems" (Srebnik et al., 1996, p. 210). However, there does not appear to be a consensus in the literature regarding the breadth of this definition nor which elements exactly it is comprised of. The terms 'service use', 'service utilization', and 'service engagement',

are often also used in addition to, or as an alternative to, 'help-seeking' and whilst some authors have focused on service provision, other definitions include informal supports sought from peers (Logan & King, 2001, McKay & Bannon, 2004). A brief summary of some of the models developed to facilitate a better understanding of help-seeking for children's mental health problems is provided below.

Models of help-seeking

Srebnik et al. (1996) highlighted three key stages in her descriptive model (problem recognition, decision to seek help and support network and service utilization patterns) and asserted that these are influenced by the illness profile, predisposing characteristics (e.g. demographic characteristics and sociocultural values), and barriers and facilitators to care. The model is not specific to a particular age range but assumes that parents will play a key role in accessing support for their children.

Costello, Pescosolido, Angold & Burns (1998) also place a parent or other family member centrally to their explanatory model of help seeking which was modified from Pescosolido's Network Episode Model (NEM) (Pescosolido, 1991). This model takes a multi-sector approach which better captures the role schools and child welfare organizations might play in the way children access services. The model is applicable to children of all ages but recognizes that patterns of service use will change over the course of a child's development.

In contrast to the models above which attempt to describe and explain multiple influences on the help-seeking process, Morrissey-Kane and Prinz (1999) focus specifically on the parental attributional process as it relates to engagement in child mental health services. This model suggests that attributions associated with the

child and parent will impact upon parental affect and expectations and influence engagement in treatment. Motivation to engage in treatment will be particularly low where parents attribute the child's problems to factors within the child that he or she can control and will not change, whilst believing that they have no control over their child and are not responsible for improving the situation.

Whilst this model may provide useful insights into the role of parents in help-seeking, other models have concentrated on older children where adult influences may not be as powerful. Murray's (2005) model was developed using generalist stage process models of help-seeking enhanced by findings from qualitative research with 13-14 year olds. The author asserts that there are five stages to young people's help seeking, although these are fluid and influenced by problem legitimization and prior experiences of help seeking: 1) the perception of 'dis-ease'; 2) the motivation to act; 3) the perception that something can be done; 4) the decision to act; and 5) the choice of a particular source of help (e.g. telling a parent or other adult).

Logan and King (2001) also focus on adolescents but retain parents as central to the help-seeking process. Once again, the model is stage based but the authors have integrated ideas from the NEM and change theory in an effort to explain the cognitive, attitudinal and behavioural steps parents take before obtaining mental health care for their adolescent. The model is somewhat linear and individualistic and was devised predominantly as a framework for reviewing the literature on the parents' role in help-seeking for adolescents with mental health problems.

Zwaanswijk, van der Ende, Verhaak, Bensing & Verhulst (2005) sought to empirically test an entire help-seeking model created by combining Logan and King's (2001) model with the NEM and a five level model adapted for children by Verhulst and Koot

(1992). Although Logan and King's (2001) model was developed specifically in reference to adolescents, Zwaanswijk et al. (2005) assert that their model does not include adolescent help-seeking and focuses on parent-mediated pathways to care. Testing of the model revealed that a considerable number of children accessed mental health care via school-based service providers rather than the GP, calling into question models which concentrate on primary care pathways and lending support to the NEM.

Finally, another model focusing on older adolescents and young adults describes a circular help-seeking process influenced by individual beliefs about mental health problems, the social meaning of 'help-seeking' and treatment, and the action taken by individuals to address their difficulties (Biddle, Donovan, Sharp & Gunnell, 2007). The Cycle of Avoidance (COA) model describes a process of illness behaviour whereby the individual evaluates their distress and engages in an ongoing process of lay diagnosis to avoid a diagnosis of 'real' distress. Strategies such as normalization and 'coping' are used to facilitate avoidance and the threshold for defining a 'need' for help is not static. Actually seeking help is thought to make the distress 'real' and is thus perceived as negative.

In this model, lay diagnosis and help-seeking are inherently interlinked and there is no clear pathway or endpoint. Such a model would suggest that focusing on how individual's progress through a sequence of stages to obtain help pays insufficient attention to the influence of values and beliefs on illness behaviour. For younger children, it is possible that parents go through a similar process of evaluating the social meanings attributed to their child's mental health problems and 'being helped' when deciding whether or not to take action on their child's behalf. The COA is the

only model to include 'non' help-seekers in its development and may therefore be particularly relevant to help-seeking undertaken by hard-to-reach families.

Who are the 'hard-to-reach'?

The term 'hard-to-reach' describes children and families who are faced with so many psychosocial risk factors that any resilience they have to individual factors is overwhelmed by the number of stressors they are exposed to (Fonagy & Higgit, 2007). Hutchings and Lane (2005), use the term 'multi-stressed' and these stresses can be broadly divided into three areas: social, economic and parental. Examples of indicators for each of these factors are presented in Table 1. below:

Table 1. *Indicators of Families Being ‘Hard-to-Reach’*

Social factors	<p>Young parental age</p> <p>Educational level</p> <p>Poor social network</p> <p>Number of parents in family</p> <p>Parents’ occupational status</p>
Economic factors	<p>Low income</p> <p>Poor housing and living standards (including homelessness)</p> <p>Pollution</p>
Parental factors	<p>Substance abuse</p> <p>History of offending</p> <p>Disability or illness</p> <p>Ante / Peri natal problems e.g. unplanned pregnancy, substance use during pregnancy, need for intensive care after birth</p> <p>Impaired child-rearing e.g. neglect of physical healthcare, limited pre-school education, maternal unresponsiveness, harsh / negative parenting</p> <p>Frequent changes of residence / schools / parental figures</p> <p>Family breakdown e.g. separation, step-parents, parental conflict and domestic violence</p>

(Coe, Gibson, Spencer, & Stuttford, 2007; Fonagy & Higgit, 2007; Statham, 2004; Webster-Stratton, 1998)

The presence of one or two of these factors is unlikely to make a family 'hard-to-reach' but where they occur in combination, the risk of children going on to develop emotional and psychological difficulties increases, whilst their ability to access help diminishes (Fonagy & Higgitt, 2007; Hutchings & Lane, 2005; Snell-Johns, Mendez & Smith, 2004; Statham, 2004). Other terms used to describe this group include 'at risk', 'vulnerable' and 'in need', and the National Service Framework uses the term 'children in special circumstances' to encapsulate all children who are at risk of not achieving to the same level as their peers (Statham, 2004).

Specific groups considered more likely to be exposed to risk factors include: children who are 'looked after', ethnic minority groups, refugee and asylum seekers, children engaged in anti-social or offending behaviour, children who are abused, and travelling families (Coe et al., 2007; Correa-Velez & Gifford, 2007; Statham, 2004; Wolpert, Lavis, Wistow & Foster, 2007).

A key point acknowledged by most authors in this area is that the factors which place children at risk of poor outcomes are the same as those which make children and families less likely to engage with services. Indeed, hard-to-reach has been defined by some as families who are unwilling or unable to seek or accept professional help for their difficulties (Bradby et al., 2007; Sayal, Taylor, Beecham & Byrne, 2002; Wilson & Refson, 2007). Snell-Johns et al. (2004) describe this group as underserved and suggest that this may be due to individual, familial, community or cultural factors. Wilson and Refson (2007) suggest that some of the individual factors at play might include: feeling so overwhelmed by their circumstances that they do not have the resources to accept help; suspicion of or resistance to services; previous trauma

leading to a fear that past intrusions could be repeated; and practical barriers such as lack of childcare and transport difficulties.

Community influences on the under-utilisation of services include poor availability of services, inadequate transport links, and difficulties coping with 'toxic' neighbourhoods, whilst at a cultural or macrosystem level, culturally insensitive services, institutional racism and attitudes towards receiving help from professionals can all result in families being underserved (Snell-Johns et al., 2004).

Finally, terms used in the literature to encapsulate families experiencing stressors, groups subject to a high number of these, and those who do not access or accept help include 'socially excluded', 'socially disadvantaged', 'socially deprived' and 'socially isolated' (Fonagy & Higgitt, 2007; Garbers, Tunstill, Allnock & Akhurst, 2006; Hutchings & Lane, 2005; Rutter, 2006; Wolpert et al., 2007). In the following review, superordinate terms rather than specific groups or risk factors were used in the search strategy to ensure that the literature identified had as much relevance to all hard-to-reach groups as possible.

METHOD

Search strategy

Preliminary searches using specific terminology yielded very few citations and thus the search strategy was broadened out to ensure that any papers related to the 3 core areas of interest were identified (see Table 2).

On the 30th September 2008, searches were run using PsycINFO, Web of Science and CSA (ASSIA, Sociological abstracts & Social Services abstracts) for the period 1985 to 2008.

Table 2. *Search Terms*

Hard to reach	At risk populations High risk populations Risk populations Hard or difficult to reach Disadvantaged Economically disadvantaged Socially disadvantaged Underprivileged Social deprivation Social isolation Socioeconomic status Family socioeconomic level Income level Lower class Social class Underserv* In need Social* exclu* Social* inequali* Vulnerab* Special circumstances Multi-stressed
Help-seeking	Help seeking behaviour Health care seeking behaviour Health care utilization Assistance seeking (professional) Health service utilization Utilization (health care) Care or help or treatment seek*

	Problem recognition Pathways to care
Parents	Parents Adoptive parents Fathers Foster parents Homosexual parents Mothers Single parents Step parents Surrogate parents Family Biological family Extended family Family of origin Interethnic family Interracial family Nuclear family Schizophrenogenic family Stepfamily

These papers were then hand-sorted by applying the following exclusion criteria:

1. Papers which did not specifically investigate a 'hard-to-reach' group or collect data on a minimum of 3 characteristics indicative of being 'hard-to-reach'.
2. Papers where the focus was on help-seeking for parental difficulties rather than for children's emotional or psychological difficulties e.g. addiction.
3. Papers with a medical / physical health focus.
4. Papers where help-seeking was not specifically related to parents
5. Papers addressing a specific area of interest where findings were unlikely to generalize e.g. post 9/11 services, specific overseas cultural groups, children in foster care.
6. Papers presenting data on only the final stage of the help-seeking process (i.e. service utilization and treatment engagement) (Costello et al., 1998; McKay & Bannon, 2004; Morrissey-Kane & Prinz, 1999; Murray, 2005).

7. Discussion papers and literature reviews.

This resulted in 12 papers being identified (see Table 3) and the reference lists of these were reviewed to identify any additional citations. This process led to a further 6 being included in the review.

Table 3. *Results of Literature Search*

Database	Total no. citations	Hand sort
PsycINFO	92	1
Web of Science	274	9
CSA	432	2
TOTAL	798	12

Papers varied considerably in terms of the extent of their focus on hard-to-reach families and thus a grading system was developed to indicate how relevant findings might be to understanding help-seeking amongst this group (see Table 4). Definitions for this grading system are as follows:

Gold: The entire sample meets the definition for hard-to-reach as per the definition provided above. Either participants exhibit a minimum of 3 characteristics indicative of being hard-to-reach, or they are identified as low-income and / or disadvantaged. Papers sampling low-income and disadvantaged families are included in this group as these terms are indicative of multiple hard-to-reach factors such as low occupational status and poor housing.

Silver: A minimum of 50% of the sample are identified as hard-to-reach and / or there is explicit examination of a sub-group considered in need of care but not receiving it

Bronze: Hard-to-reach factors are used as independent variables to predict help-seeking or service use but participants are not sampled from an identified hard-to-reach group.

Table 4. *Studies Conducted Since 1985 Concerning Help-Seeking for Children with Emotional or Behavioural Problems Amongst Hard-to-Reach Groups or Groups with Characteristics Indicative of Being Hard-to-Reach.*

Study	Location	N	Study aims	Sampling / design	Subjects	Age	Degree of focus on hard-to-reach groups
Anderson et al. (2006)	U.S.	127	To identify potential perceptual barriers to mothers' help seeking.	Ethnographic analysis of qualitative interviews and focus groups with women who initiated treatment for their children at community health centres in four disadvantaged communities. Women met criteria for significant mood and anxiety disorder and African American women were oversampled.	Mothers	Not specified	GOLD: women from disadvantaged communities with mental health problems
Bussing, Koro-Ljungberg, Gary, Mason & Wilson Garvan (2005)	U.S.	259	To examine parental help-seeking steps for primary school students at high risk for ADHD.	A stratified random sample of children from a school district population of primary school students. Girls were over sampled by 2:1 to ensure adequate representation. Mixed methods design using inductive analysis (grounded theory) and deductive quantitative analysis.	Parents	6-14	BRONZE: Hard-to-reach factors (race and poverty) used as independent variables to predict help-seeking.
Bussing, Zima, Gary & Wilson Garvan (2003)	U.S.	389	To describe help-seeking steps, examine whether they vary by gender and ethnicity, and to describe barriers to	A district-wide stratified sample of children at high risk of ADHD and children with an unmet need for ADHD care. Telephone interviews with follow-up face-to-face interviews. Relational design	Parents	5-11	SILVER: More than 50% of the sample hard-to-reach. Specific focus on barriers to care for a group considered in need but not receiving care.

			service use.	using Chi square and logistical regression.			
Cunningham & Freiman (1996)	U.S.	6216	To analyse a model of the use of mental health-related services by children.	A cross-sectional survey of the US population. Four in-person interviews conducted using structured questionnaires. Data was analysed using multivariate analysis.	Parents	6-17	BRONZE: Hard-to-reach factors used as independent variables to predict service use.
Farmer, Stangl, Burns, Costello & Angold (1999)	U.S.	1007	To explore the use, persistence, and intensity of services for children's mental health problems across a variety of service sectors during a one year period.	Longitudinal epidemiological study within a predominantly rural region. Youths randomly selected from all public school districts in 11 counties. Parents completed a telephone screening questionnaire re child externalizing behaviour and data on service use was also collected. Logistic regression was used to model factors associated with service use.	Parents and children.	9, 11 or 13	BRONZE: Hard-to-reach factors used as independent variables to predict service use, persistence and intensity.
Flisher et al. (1997)	U.S.	1285	To determine need status from an epidemiological sample and document the correlates of unmet need for mental health services.	Probability samples obtained from four sites and parent / youth pairs interviewed simultaneously. The Diagnostic Interview for Children (DISC) was administered plus various measures of service use and family factors. Analysis carried out using logistic regression.	Parents and children	9-17	SLIVER: Specific focus on sub-group considered in need but not receiving care. Hard-to-reach factors used as independent variables to predict unmet need.
Gross, Julion & Fogg (2001)	U.S.	155	To understand what motivated low-income, ethnic minority parents to	Purposive sample of 11 day care centres serving low-income families of toddlers. Sample of parents who	Parents	2-3	GOLD: Low income, sole-parent families.

			participate in a parent training program.	consented to participate in a parent training group. Parents interviewed via telephone re motivation to participate in the program and expectations. Response categories analysed using frequency counts and chi-square.			
Harrison, McKay & Bannon (2004)	U.S.	253	To examine the preparation families took prior to bringing their child for mental health care, identify factors associated with service use and explore reasons for not utilizing services.	Single group longitudinal design examining attendance and non-attendance of children referred for mental health services. Logistic regression used to examine multivariate influences on service involvement.	Parents	Not reported	GOLD: Low income plus specific focus on sub-group considered in need but not receiving care.
Keller & McDade (2000)	U.S.	52	To determine attitudes toward parenting and help-seeking.	Low-income parents from racial minority groups whose children were enrolled in Head Start programs and who were identified by a Head Start volunteer as 'stressed-out'. Parents completed a survey in person on attitudes and opinions of parenting.	Parents	Not reported	GOLD: Very low income and accessing a service for at-risk families.
Nix, Pinderhughes, Bierman, Maples & The Conduct	U.S.	445	To determine whether the link between risk factors for conduct problems and low	Data from children and families in 3 cohorts of an intervention group 'Fast Track' offered in 4 geographical areas. Home interviews using 11 measures.	Parents and children	5-6	GOLD: Very low income and / or living in high-crime neighbourhoods. High % of sole parent families.

Problems Prevention Research Group (2005)			rates of participation in mental health treatment could be decoupled through the provision of integrated prevention services.	Regression analysis used to determine which of these related to participation in each of the 3 components of 'Fast Track'.			
Owens et al. (2002)	U.S.	116	To describe barriers to care, examine characteristics associated with these, to examine the effect of children's problems on parents and barriers to care, and to examine whether barriers vary by the type of care sought.	Data were obtained from a school-based prevention project. The impact on perceived barriers to care of the children's psychosocial problems on parents plus sociodemographic and parental factors were explored using bivariate and multivariate (logistic regression) analyses.	Parents and children	Seventh grade	SILVER: More than 50% of the sample hard-to-reach. Hard-to-reach factors used as independent variables to predict perceived barriers to care.
Pavuluri, Luk & McGee (1996)	N.Z.	320	To identify the filters and perceived barriers to seeking help. Also to identify who and how many are seeking help and from whom.	Pre-school children from 8 pre-school centres screened then assessed via semi-structured interviews. Comparisons made between help-seekers and non-help-seekers plus logistic regression to examine predictors of help-seeking.	Parents and children	30-60 months	SLIVER: Specific focus on sub-group considered in need but not receiving care. Hard-to-reach factors used as independent variables to predict help-seeking.
Richardson	U.S.	235	To examine factors	Exploratory, descriptive study	Parents	5-19	GOLD: Low income and

(2001)			that may influence parents' decision to seek mental health care for their children and adolescents including expectations about outcomes, the provider / client relationship, social and cultural factors and the accessibility of mental health services.	using a convenience sample of urban adults with a special focus on recruiting low-income and Black parents. Parents interviewed using the Expectations of Mental Health Care survey and a demographic questionnaire. Data analysed using descriptive statistics.			Black parents.
Verhulst & van der Ende (1997)	Holland	2227	To assess factors thought to be possible determinants of referral for mental health services and to assess the association of these features with recognition by parents that the child is not functioning well.	Stratified and multistage cluster and random sampling design. Parents interviewed using the CBCL and parts of the Young Adult Self-Report (YASR) and the General Functioning subscale of the McMaster Family Assessment Device. Uni and multivariate analysis to assess possible determinants of need and utilization.	Parents	4-18	SILVER: More than 50% of the sample hard-to-reach. Specific focus on sub-group considered in need but not receiving care. Hard-to-reach factors used as independent variables to predict help-seeking.
Wu et al. (1999)	U.S.	1285	To examine the relationship of depressive and disruptive disorders with	Probability samples of children obtained in 4 geographical areas from a larger multi-site community study. Structured in-person interviews conducted	Parents and children	9-17	BRONZE: Hard-to-reach factors used as independent variables to predict service use.

			patterns of mental health service utilization in a community sample of children and adolescents.	in families' homes separately for parents and children using the DISC and a Service Utilization & Risk Factors Interview. Uni and multivariate analysis to assess possible determinants of service need and utilization.			
Wu et al. (2001)	U.S.	206	To examine patterns of mental health service use among depressed children and adolescents and factors associated with help-seeking and treatment modalities.	Children and adolescents assessed as part of a larger survey of mental health service use in 5 service systems and in the community who met DSM-III-R criteria for depressive disorders. Interviewed about childhood psychopathology, mental health service use and a wide array of risk factors. Uni and multivariate analysis to assess possible determinants of service utilization.	Parents and children	9-17	BRONZE: Hard-to-reach factors used as independent variables to predict service use.
Zahner & Daskalakis (1997)	U.S.	2519	To identify factors associated with service use for child psychopathology in three settings: mental health, general health and school.	Cross-sectional design using a population-based sample drawn from classroom enrollment lists. Used multivariate logistic regression to examine the role of 3 groups of variables (socio-demographics, child's illness profile and parental attitudes) on the use of mental health, general health & school-based services.	Parents	6-11	BRONZE: Hard-to-reach factors used as independent variables to predict service use across 3 service settings.
Zwaanswijk et	Holland	246	To devise and test	Sample of parents of children	Parents	4-11	BRONZE: Hard-to-reach

al. (2005)	<p>a model describing the process of help-seeking for child psychopathology in professional and informal service settings.</p>	<p>with emotional or behaviour problems interviewed using the DISC and about their help-seeking actions. Structural equation modeling used to investigate associations between child, family and context characteristics and help-seeking stages.</p>	<p>factors used as independent variables to predict service use.</p>
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RESULTS

Structure of the review

The eighteen papers identified will be examined from two broad perspectives. Firstly, their contribution to understanding the specific issues faced by hard-to-reach groups and secondly, methodological issues which may compromise the validity of any claims made. The methodologies used by papers across these three areas are summarized in Table 5.

Table 5. *Summary of Methodologies Used According to Papers' Focus on Hard-to-Reach Groups*

FOCUS ON HARD TO REACH	QUANTITATIVE			QUALIT ATIVE	MIXED METHOD	DESCR IPTIVE	TOTAL
	LONGITUDINAL	RELATIONAL	COMPARATIVE				
GOLD	1		1	1		3	6
SILVER		4	1				5
BRONZE	1	5			1		7
TOTAL	2	9	2	1	1	3	18

Papers exclusively examining hard-to-reach groups

There were six papers identified that focused specifically on a group considered to be 'hard-to-reach'. Anderson et al. (2006) found that differences between mothers' and health professionals' perceptions of the causes of distress, and mothers' beliefs that clinicians have excessive power over their lives act as barriers to receiving care. This was the only qualitative paper identified and although it was described as an ethnographic analysis, there is no description of interviewers immersing themselves in the cultural lives of the women interviewed. The relatively large sample size may

have led to the depth of insight being compromised and the way in which themes were identified is not clearly described. Although the paper does not seem to take a truly ethnographic approach, the attempt to gain the perspective of a traditionally under-researched group is welcome. However, there is no real analysis of the possible impact of the interviewers' culturally powerful position on participants' responses and this makes it difficult for the reader to make an informed decision about the transferability of some of the factors women identified to other contexts.

The only three descriptive papers identified in the search focused specifically on hard-to-reach groups. Gross et al. (2001), found that parents were motivated to participate in parent training by a desire to be better parents. The location of the training was considered important both in terms of convenience and because being situated in a centre already known to parents appeared to elicit trust in the program. The personality and trustworthiness of staff recruiting for the program was key, as was the relevance of the program to the parents' goals. However, confidence in these findings is limited by the fact that interviews with participants were not recorded and that cross-checking of response categories occurred within the research team.

Keller and McDade (2000), also focused on parents enrolled in a specific program (Head Start) and found that they were less likely to believe in or seek help than those with higher incomes. However, this difference was not tested statistically and parents in the probability sample were over ten years older than those accessing Head Start. Hard-to-reach parents' reported that fear and mistrust were key issues in decisions not to seek help from professional sources, as were practical issues such as transport and childcare. Informal supports were also considered unreliable and lacking in credibility.

Negative expectations about mental health care were also a key feature of Richardson's (2001) study. Parents did not trust providers and there were concerns about stigma should their child's use of services come to light. These kinds of expectations were more negative than expectations about the effectiveness of treatment or issues such as cost and transport. Both the Keller and McDade, and the Richardson studies used data elicited via survey and being descriptive, no conclusions can be drawn regarding causality. With regard to survey development, whilst Richardson reports moderate internal consistency and describes the efforts made to establish content validity, no such information is available for the Keller and McDade survey.

The two remaining papers in this group used fixed designs, one longitudinal and the other, a comparative study of three cohorts in an intervention program. Harrison et al.'s (2004) longitudinal study of pathways to care found that the severity of the child's symptoms did not distinguish between parents who attended mental health appointments and those who did not. Parents with more social support were more likely to use services whilst those who perceived that they had difficulties with discipline were less likely to seek help. One limitation to this study is that service utilizers were defined as those who had attended a specific mental health agency at least once and thus, even individuals who did not return after their first appointment were classified as service users. Furthermore, many important cultural and social factors that may have influenced help-seeking were not explored.

Taking an evaluative approach, Nix et al. (2005), examined three separate but related service delivery strategies in an effort to determine what kinds of programs foster participation amongst hard-to-reach families. There was a complex relationship

between independent variables and the likelihood of parents engaging with the 3 different intervention components (school-based services, therapeutic groups and home visits). Those engaging with all 3 interventions had higher SES, lived in less dangerous neighbourhoods, and were less likely to be African American or from a single-parent household. Families who received more home visits had lower SES and were more likely to be African American, to be from a single-parent household, to display less warm parent-child interactions, and to live in the most dangerous and poor areas. Families unlikely to access any of the interventions were relatively well-off and lived in better neighbourhoods. They also tended to include a younger mother who reported symptoms of depression and where fewer stressful life-events were reported.

This study reported on a large and diverse sample and explored 11 independent measures. However, the reliability and validity of some of these cannot be assured; for example, harsh discipline was assessed based on the interviewer's rating of a mother's use of punitive discipline and this is subject to both participant and interviewer bias. More fundamentally, the intervention was not designed to examine predictors of service use and variation in the type of program accessed by families across geographical areas could compromise the power of some of the comparisons made.

To summarise, hard-to-reach families report that having different perceptions about the causes of distress to professionals (Anderson et al., 2006), fear and mistrust of professionals (Anderson et al., 2006; Keller & McDade, 2000; Richardson, 2001), practical issues such as transport and childcare (Keller & McDade, 2000), having difficulties with discipline (Harrison et al., 2004), and negative expectations about

mental health care, including concerns about stigma (Richardson, 2001) can all impact negatively on help-seeking. It is also noteworthy that in one study, there was evidence that families comprised of a younger mother suffering from depression are particularly unlikely to access services (Nix et al., 2005). Conversely, service or program location, the personality and trustworthiness of staff, and the relevance of the help being offered to parenting goals, facilitated engagement with services (Gross et al., 2001).

Some significant methodological issues have been identified in these papers which compromise confidence in the findings described above. The qualitative paper does not appear to adhere to some of the defining features of the methodology chosen and there is insufficient transparency regarding the development of themes. The reliability of data collection in the descriptive studies cannot be assured and there are issues surrounding sampling and the validity of independent variables in the quantitative studies. However, these were the only six papers identified which focused specifically on hard-to-reach families and in designing research studies with this vulnerable group, issues relating to trust and engagement will need to be balanced with the requirements of rigorous research design.

Papers sampling a significant percentage of hard to reach families or investigating those in need but not receiving care

This group comprised five papers, four of which used a relational design and logistical regression analysis to predict service use, barriers to treatment or unmet need. Flisher et al. (1997), report that 17.1% of their epidemiological sample had an unmet need for mental health services (defined as a diagnosis of a mental health problem but no mental health service use in the previous six months) and that this

was associated with: low SES; reports by the parent and young person that the latter had poor mental health; parental psychopathology; poor school grades; and parent reported access barriers. Definition of unmet need in this instance is somewhat questionable as parental perceptions of need and how this could best be met is not considered.

Verhulst and van der Ende (1997) used a non-clinical sample, over 50% of whom were classified as being at a low educational and occupational level. They found that where parents perceived their child's problems as severe, there was an increased likelihood of referral to mental health services. Parents were more likely to view their child's behaviour as problematic if they had high levels of problems themselves and factors such as a change in family composition and problems with the way the family was functioning were strongly associated with both problem perception, and service utilization. Academic problems were also associated with service need and use.

These findings and the fact that the authors did not find any significant associations between socioeconomic and help-seeking variables are somewhat contrary to those reported elsewhere. This may be because of elements unique to health policy or societal attitudes in the Netherlands and thus results may not be generalisable elsewhere.

Bussing et al. (2003) and Owens et al. (2002) focus on barriers to help-seeking and service use, the former focusing specifically on children at high risk for attention deficit hyperactivity disorder (ADHD) and the latter on children assessed as being in need of general mental health services. Bussing et al. specifically examined a sub-group of respondents whose children met DSM-IV criteria for ADHD but had not received any treatment in the past 12 months. The three most common reasons

given by parents for not receiving help were being unsure where to get help, the problem got better by itself and the child improved enough to no longer require treatment. Poverty was associated with there being no perceived need, stigma, financial barriers, and an expectation that treatment could not help.

Parental perceptions were a prime focus for Owen's et al. (2002) who investigated whether types of barriers to care were associated with the effect of the child's problems on parents, sociodemographics, parent stressors and children's mental health history. The most commonly reported barriers were those related to structural constraints such as services being inaccessible, perceptions of mental health problems (e.g. that the problem was not serious), and perceptions of mental health services (e.g. negative experiences of mental health professionals). Although sociodemographic variables were not associated with barriers to care, other hard-to-reach factors such as managing multiple stressors and being unemployed were associated with structural barriers and barriers related to perceptions of mental health problems.

Both these studies were conducted in fairly homogenous areas, potentially limiting the data's generalisability to other contexts. There may also have been additional influencing factors on parents' reports of barriers which were not accounted for, such as parental psychopathology and mental health service use. Sampling is a potential limitation to both papers; Owens et al. (2002) only interviewed parents who had identified a need for care and thus those parents unable to recognize the presence of a problem were not included. Bussing et al. (2003) excluded households who did not have a telephone which may have resulted in many hard-to-reach families being unable to participate.

The final paper in this group compared parents of pre-school children who sought help with those who did not on a number of sociodemographic variables (Pavuluri et al., 1996). Children were attending pre-school centres across Dunedin (New Zealand) and parents were asked to complete questionnaires and interviews to identify who was seeking help from whom and what barriers they identified. Among those children with a behaviour disorder, only 19% of parents had sought help and those families characterized by parental separation, low income and multiple adversity were not seeking help, despite the association of these factors with behavioural problems in children.

Whilst it is refreshing to see research conducted somewhere other than the U.S., the value of this study in understanding hard-to-reach families is limited. Reference is made to the reasons why 14.3% of parents did not respond to the initial questionnaire and one wonders whether this group may comprise a significant proportion of individuals who are hard-to-reach. Also, the study focused on pre-school children whose parents may be influenced by different factors when considering whether or not to seek help than the parents of older children (e.g. some mothers felt it was not appropriate to seek help for such young children).

To summarise, Flisher et al. (1997) assert that unmet need is significantly associated with indicators of economic disadvantage and that barriers to receiving help are also linked to poverty. Many of the barriers to service identified by Bussing et al. (2003), Owens et al. (2002) and Pavuluri et al. (1996) are also associated with hard-to-reach factors either directly (financial constraints, multiple parental stressors, parental separation), or because economic hardship impacts upon perceptions of need, stigma, treatment effectiveness and service accessibility. However, Verhulst and van

der Ende (1997) did not find any significant associations between socioeconomic and help-seeking variables which is at odds with the majority of literature in this field. It could be that the social welfare system in the Netherlands reduces the impact of low income on some of the structural barriers described and that societal attitudes are such that stigma and negative perceptions of services are reduced.

From a methodological perspective, none of these papers claim to focus on hard-to-reach families and in some cases, less than 50% of the sample meet the definition for hard-to-reach provided in the introduction to this review. Indeed, two of the five papers used clinical samples which by definition means that individuals not accessing services were excluded. Significant differences between health and social care systems in the U.S., Netherlands and New Zealand mean that the generalisability of findings to other countries is limited. It is also noteworthy that two of the five papers examined very specific groups (children with ADHD symptoms and pre-school children) and thus findings may not be applicable to children of different ages and with different diagnoses.

Papers using hard-to-reach factors as independent variables

This group of papers included the only study using a mixed-methods approach with a community sample of children considered to be at risk for developing ADHD (Bussing et al., 2005). The authors placed particular emphasis on the impact of race on help-seeking and although this is not a 'hard-to-reach' factor as defined in this review, research suggests that individuals from minority ethnic groups are less likely to seek help from mental health services (Alegria et al., 2002; McMiller & Weisz, 1996; Zwaanswijk et al., 2003). Indeed, in this study, African-American youths were more likely to suffer higher rates of poverty and lower socioeconomic status than their

Caucasian peers, and African-American parents were more likely to seek help from family than from health professionals.

Although the mixed-methods approach taken in this study allowed for an in-depth exploration of the topic, it is of course subject to limitations associated with both qualitative and quantitative designs. Regarding the use of grounded theory for the qualitative component, theoretical sampling was not possible as all data was collected prior to analysis and this limitation is exacerbated by the use of a pre-existing model to code data used in the deductive analysis. Participants also came from a fairly limited geographical area and their reports of the help seeking steps taken were not verified by the family members, teachers or mental health professionals concerned.

Farmer et al.'s (1999) longitudinal study using epidemiological data drew upon Costello et al.'s (1998) model to consider predisposing, illness and enabling / inhibiting factors pertinent to the help-seeking process. Relatively few children with mental health problems accessed help via the mental health sector and need was predicted by, amongst other things, parents perception of the impact of the child's problem and the parent's own history of psychiatric problems.

Although 27% of the sample was living below the poverty line, this study did not focus specifically on this group, so findings cannot be generalized to the hard-to-reach groups per se. Also, although a parental history of psychiatric problems could be considered a disability or illness (and thus, a hard-to-reach factor; see Table 1), its relationship with help seeking is unclear. Some researchers report that greater awareness of symptomatology and the services available to treat mental health problems lead to an increase in the likelihood of help being sought (Costello et al.,

1998; Zwaanswijk et al., 2005), whilst other papers report reduced service use by parents with mental health problems (Nix et al., 2005) . Other limitations to this study include the age of the data (collected over 10 years ago), reliance on parental reports of service use, and its focus on a rural region of the U.S., potentially limiting generalisability.

The remaining five papers in this group used relational designs with an emphasis on specific diagnostic groups (Wu et al., 1999; Wu et al., 2001), the types of services accessed (Zahner & Daskalakis, 1997) or help-seeking in general (Cunningham & Freiman, 1996; Zwaanswijk et al., 2005). Both the studies carried out by Wu and colleagues provide useful information about children diagnosed with specific disorders but the help-seeking process undertaken by families of these children may be different to that undertaken by children with other mental health problems.

Children with depressive disorders are less likely to receive specialist mental health services than those with disruptive disorders and this may be mediated via perceived needs. Parental recognition of symptoms, level of knowledge about mental health problems and treatment, and health insurance status may all influence whether or not a child receives services and from whom (Wu et al., 1999; Wu et al., 2001).

Zahner and Daskalakis (1997) used population survey data, potentially increasing the generalisability of their findings. They found that social class had no association with service use and this may be attributable to the fact that general health and school-based service use was investigated in addition to the use of specialist mental health services. The authors caution that their measurement of associations between SES and service use may not have been sufficiently sensitive. Furthermore, insurance

status was not recorded yet this has been shown to influence help-seeking in other U.S. based studies (McKay & Bannon, 2004; Zimmerman, 2005).

Contrary to Zahner and Daskalkis' (1997) findings, Cunningham and Freiman (1996) found that the probability of mental health service use amongst high income families whose children had poor mental health increased at a much greater rate than it did for low income families. However, this study drew upon data collected over 20 years ago and the impact of health insurance was not controlled for. Zwaanswijk et al. (2005) aimed to test a model of help-seeking for child psychopathology and found no relationship between sociodemographic variables (e.g. family income) and help-seeking. They attribute this to the Dutch health care system where service access is not mediated by ability to pay. However, with regard to help-seeking via teaching staff, poorly functioning families in-need experienced barriers in actually seeking help. Results need to be interpreted with caution as the primary aim of the study was to test a model of help-seeking rather than identify factors which may influence help-seeking. In addition, perceptual factors were not examined and the sample did not include families exhibiting known hard-to-reach factors (e.g. single-parent families and less educated parents).

The papers reviewed in this section do not examine hard-to-reach parents specifically but were reviewed to identify any associations between known hard-to-reach factors and help-seeking. Bussing et al.'s (2005) finding that African-American parents are more likely to seek help from family members than professionals may relate to hard-to-reach groups as people from minority groups can also find it difficult to access services (Statham, 2004). However, further research would be necessary to identify

whether it is factors associated with social exclusion or cultural differences that are most influential.

None of the factors identified by Wu et al. (1999; 2001), or Farmer et al. (1999) relate directly to being hard-to-reach although some of the perceptual influences may themselves be influenced by hard-to-reach factors. Parents facing multiple adversity may struggle to pick-up on their child's distress, reducing the likelihood of their child receiving help. Whilst Cunningham and Freiman (1996) found a clear association between low income and a reduced likelihood of children using mental health services, two of the studies found no such link (Zahner & Daskalakis, 1997; Zwaanswijk et al., 2005). However, it was suggested that good access to services in the study areas may provide an explanation for this.

No firm conclusions about how hard-to-reach families seek help can be drawn from this selection of papers as there was no focus on hard-to-reach groups and the primary aim of most of the studies was unrelated to this area of interest. Two of the papers used data that is over ten years old and sampling issues plus international differences in service provision limit the generalisability of findings. In particular, the role of insurance in the U.S. has a fundamental impact on help-seeking for the families who live there and should be controlled for (Sayal, 2006).

CONCLUSIONS

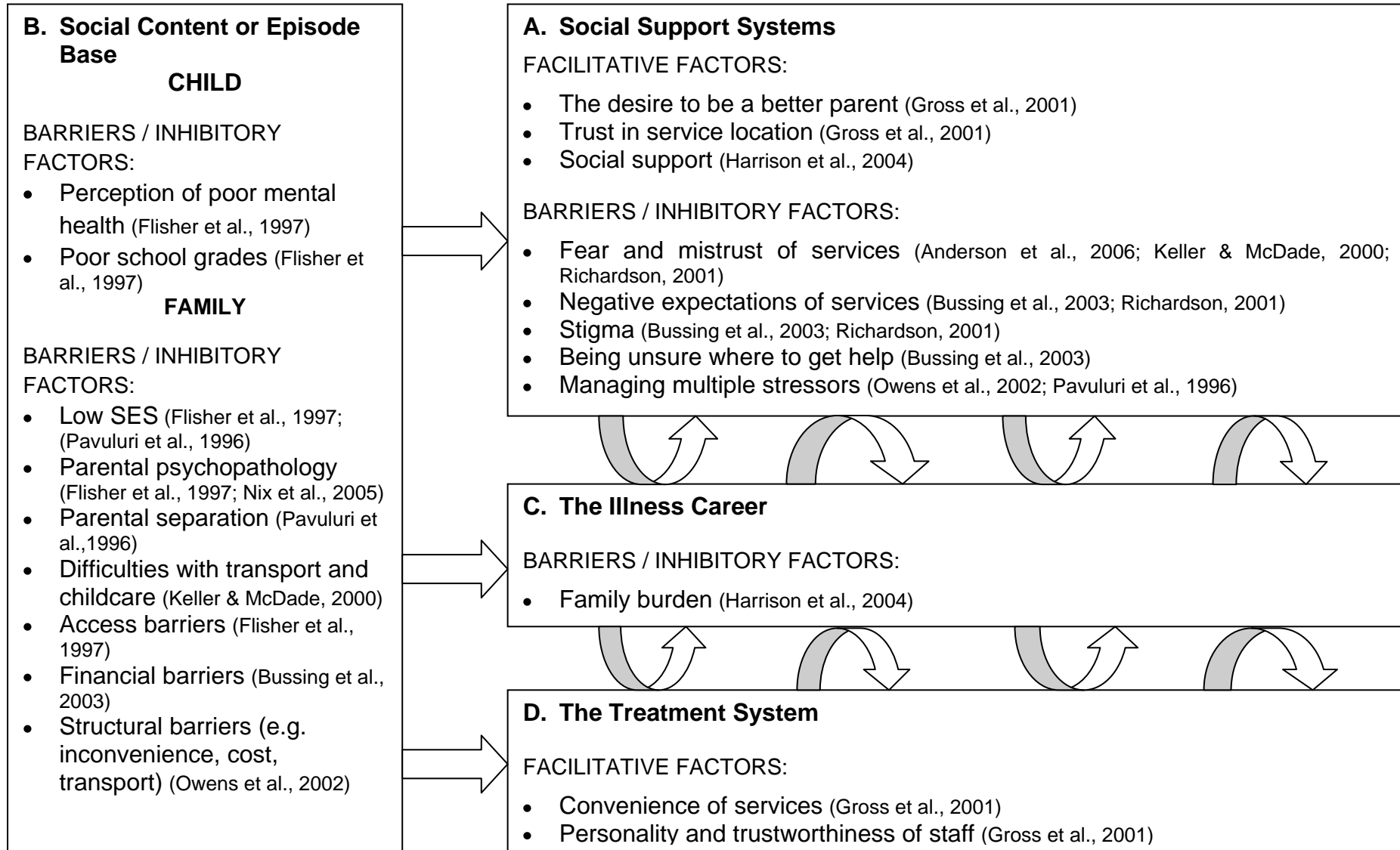
Despite a significant body of research investigating risk factors for child psychopathology and help-seeking, little work has been done to date to investigate help-seeking amongst groups considered 'hard-to-reach'. This group share many characteristics with families whose children are at high risk of experiencing mental health problems yet they do not appear to access services as readily as better resourced groups. It was therefore considered important to undertake a review of literature exploring help-seeking amongst hard-to-reach families specifically, in order to determine what is already known and consider how well existing models of help-seeking explain the process undertaken by this group.

Firstly, it is important to note that some of the models discussed in the introduction to this review are specific to younger children, adolescents or young adults, yet the research encapsulated in this review includes families with children aged from two to nineteen. Also, Morrissey-Kane and Prinz's (1999) model and Biddle et al.'s (2007) model focus on the parent or young person's intra-psychic processes as they relate to help-seeking and thus do not explain the role of structural and ecological factors identified in the research.

Only Costello et al.'s (1998) Network Episode Model (NEM) seeks to explain help-seeking amongst families with children of all ages and includes the influence of socioeconomic factors on social support systems (including family and peer-group beliefs and attitudes), illness factors, and the role of services (see Appendix I). Whilst this model was not developed specifically to represent help-seeking amongst the hard-to-reach, findings from the gold and silver papers in this review corresponded with the four interconnected elements of the model.

Figure 1 presents a stripped-down version of the model to highlight how hard-to-reach factors may interact with one another to either inhibit or facilitate help-seeking for this group. It should be noted that findings were included in the model on the basis of their relevance to the hard-to-reach rather than the methodological quality of the papers they were drawn from. Some of the bronze papers were rigorously conducted but their findings are not included in Figure 1 as their emphasis on individual hard-to-reach factors rather than hard-to-reach populations mean we cannot have as much confidence in their relevance to this group.

Figure 1: Findings from Gold and Silver Standard Papers as They Relate to Costello et al.'S (1998) Revised Network Episode Model of Access to Care.



The model illustrates how socioeconomic factors can impact on both practical and perceptual influences on help-seeking. It has been modified slightly in order to account for the fact that there seem to be both inhibitory and facilitative influences on accessing mental health care for hard-to-reach families. It is also important to note that the two models which focus on the attributions and meanings of mental health problems and treatment could provide valuable additional information about the factors encapsulated in part B of the NEM. In particular, the cycle of avoidance (COA) (Biddle et al., 2007) may help to better understand 'non-help-seeking' a term which may have parallels to hard-to-reach parents who do not identify a need yet whose children are judged by statutory services to require intervention.

The studies that focused exclusively on hard-to-reach families have provided useful information about help-seeking for this group and the role of parental perceptions of services seems particularly pertinent. However, this is a small body of research, half of which was purely descriptive in nature. Some of the papers focused on specific programs, so findings may not be generalisable and methodological issues such as definitions of service use, lack of clarity about methods used to code qualitative data, and the use of unvalidated surveys place some limitations on the confidence we can have in the findings.

'Silver' and 'bronze' papers were not designed to examine help-seeking amongst hard-to-reach families and geographical differences, the use of clinical samples, a focus on groups with specific diagnoses or very young children, reliance on parental self-report, and failure to account for possible confounding factors place limitations on the reliability of findings. In addition, definitions of need used in some of these papers are potentially problematic, particularly where need has been defined as the

presence of a diagnosable mental health problem. Given the fact that symptomatology does not relate directly to service use and that parental perceptions of a child's difficulties are key, it would seem vital to consider parental perception of need when conducting research with this group.

This is echoed in Srebnik et al.'s (1996) guidance on conducting research on help-seeking where the following recommendations are made: a) pay attention to subjective mental health service need; b) use a combination of qualitative and quantitative methods; c) corroborate self-reported service use; and d) give due attention to informal sources of support and services. Insights gained from conducting this review indicate that it is also important to clearly define the particular cohort of hard-to-reach families of interest. Broadly, these could be understood in the following way:

1. Families receiving a service but not fully engaging or benefiting from it. Child may or may not have a diagnosable mental health difficulty. Parents are experiencing an unmet need.
2. Families who have expressed a need for help but are not currently accessing services (either for perceptual or structural reasons). Child may or may not have a diagnosable mental health difficulty. Parents are experiencing an unmet need.
3. Families who either feel that needs are being met via informal means, or do not perceive a need at all. However, the child meets diagnostic criteria for a

mental health difficulty¹ and thus the family are judged to be in need by statutory services.

The literature on help-seeking amongst mainstream families provides a useful framework for the continued work that is required to understand help-seeking for hard-to-reach groups. There is a need for more rigorously designed and conducted qualitative and quantitative work with hard-to-reach groups, particularly with a view to understanding differences between the cohorts described above. Further research is also necessary to make sense of the mechanisms by which hard-to-reach factors impact upon different elements of the help-seeking process and with the increasing emphasis on alternative pathways to care via schools, Children's Centres and the voluntary sector, research looking at how families perceive and interact with these would also be of value.

The findings presented in this review emphasise the importance of taking a holistic approach to service provision for hard-to-reach families, and this would be facilitated by improving links between adult and child mental health services and between the statutory and non-statutory sector. At a macro-level, the provision of information to parents about normal child development and mental health, problems to look out for, and what to do should they have any concerns, may help with problem perception and recognition. Finally, clinicians need to be mindful that hard-to-reach families are likely to have had negative experiences of accessing support in the past and open discussion about these and what needs to be done differently may help to build trust.

¹ Bussing et al. (2003) reports that two thirds of parents indicated that they did not have a need for mental health services despite their child meeting diagnostic criteria for ADHD.

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**HARD-TO REACH PARENTS' UNDERSTANDING OF SUPPORT SERVICES FOR
THEIR CHILDREN AND OF HOW THEY MADE CONTACT WITH A VOLUNTARY
SECTOR ORGANISATION: AN INTERPRETATIVE PHENOMENOLOGICAL
ANALYSIS**

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ABSTRACT

Many of the risk factors for children developing psychological problems are the same as those that make families hard-to-reach but little is currently known about the help-seeking process undertaken by this group.

The aim of this piece of research is to investigate hard-to-reach parents' experiences of accessing social and emotional support for their children and in particular, the circumstances and decision-making process leading-up to them engaging with a voluntary sector organisation.

Eight parents accessing one such organisation in the West Midlands, United Kingdom were interviewed individually and transcripts were analysed using Interpretative Phenomenological Analysis.

Three main themes are reported: Power and disempowerment, Ambivalence about support and coping, and Drawing upon internal and external resources to survive. Being in a disempowered position and feeling controlled contributed to parents having an ambivalent relationship with services. Positive experiences of engaging with services were related to the ability of service staff to make parents feel valued.

Findings suggest that hard-to-reach families may be more likely to engage with services that offer a holistic and flexible approach and whose staff convey warmth and unconditional regard. Further research with specific hard-to-reach groups and those who remain hard-to-reach for even the most flexible and inclusive services is recommended.

INTRODUCTION

In this section a definition of help-seeking is provided and the applicability of existing help-seeking models to hard-to-reach families is explored. Models of care for the hard-to-reach are summarised and the service accessed by participants in the current study is described. Finally the gaps in research leading to the development of this project are highlighted.

Help-seeking

Help-seeking is a process of translating psychological distress into the 'interpersonal domain' of seeking help (Rickwood, Deane, Wilson & Ciarrochi, 2005) and it has been identified as an area in need of further research in the academic literature (Bogart, Bird, Walt, Delahanty & Figler, 2004; Segal, Hodges & Hardiman, 2002). There is a greater prevalence of children with mental health difficulties than those who receive services (Feehan, Stanton, McGee & Silva, 1990; Haines, McMunn, Nazroo & Kelly, 2003), suggesting there are differences in the way families perceive difficulties and seek help for them.

There are numerous models of help-seeking but this paper will focus on those describing or explaining the process undertaken by parents concerned about the mental health of their child(ren). Models vary in their structure and focus, with some being stage-based and taking parental recognition of the child's distress as a starting point (Logan & King, 2001; Srebnik, Cauce & Baydar, 1996; Zwaanswijk, van der Ende, Verhaak, Bensing & Verhulst, 2005), and others viewing help-seeking as a fluid and dynamic process with values and beliefs playing a key role (Biddle, Donovan, Sharp & Gunnell, 2007; Costello, Pescosolido, Angold & Burns, 1998). In

contrast to this more systemic approach, Morrissey-Kane and Prinz (1999) focus specifically on the parental attributional process suggesting that parents will be poorly motivated to engage in treatment if they attribute their child's problems to factors they cannot control.

Parents may also present a barrier to receiving help if they fail to recognise that a problem exists, do not consider that it is related to mental health difficulties, perceive that there is no need for treatment, or take no action to address it (Haines et al., 2003; McKay & Bannon, 2004; Sayal, 2006; Srebnik et al., 1996). Conflict or disorganisation in the family can impact on service use, as can the age and gender of the child, sociocultural factors such as stigma and coping styles, and logistical issues such as time, transport, financial constraints and waiting lists (Feehan et al., 1990; McKay & Bannon, 2004; Srebnik et al., 1996). There is strong evidence to suggest that the level of stress experienced by parents and the burden this places upon them is pivotal in determining whether or not treatment for a child will be sought (Bussing et al., 2003; Morrissey-Kane & Prinz, 1999) but factors that contribute to parents feeling overwhelmed by their child's difficulties can also make it difficult for them to seek help.

Who are the 'hard-to-reach'?

Hard-to-reach families are those faced with multiple psychosocial risk factors such that any resilience they have to individual factors is overwhelmed (Fonagy & Higgitt, 2007; Vostanis, 2007). The sheer number of difficulties they face, negative beliefs about services, or practical constraints, can mean that they are unable or unwilling to seek or accept professional help (Hutchings & Lane, 2005; Wilson & Refson, 2007).

Unfortunately, many of the factors which make it hard for families to access help are the same as those that increase the risk of children developing mental health problems and include poverty, poor housing, little or no parental qualifications, living in a single-parent or reconstituted family, enduring poor physical health, poor peer and family relationships, witnessing domestic violence, and having parents with mental health problems or who misuse substances (British Medical Association (BMA), 2006; Department for Education & Skills (DfES), 2003; Hutchings & Lane, 2005; Jensen, Bloedau & Davis, 1990; Rutter, 1987).

Little is currently known about the mechanisms by which hard-to-reach factors impact upon the help-seeking process. In their epidemiological study looking at predictors of parental consultation for child psychological difficulties, Haines et al. (2003) found that female gender, being from a manual social class, and being on a low income meant parents were less likely to seek help, even after controlling for the presence of psychological difficulties in their child. The authors propose that difficulties taking time off work, previous negative experiences of using health services, low expectations of services, and poor quality services may explain the association between low social class and income, and lower rates of consultation (Haines et al., 2003).

Wilson and Refson (2007) posit that reluctance to seek help may be because of the practical challenges of attending appointments such as transport, childcare arrangements and money, or because of intrapsychic factors such as suspicion of services, fear of negative appraisals, or a belief that family difficulties should not be discussed outside of the family. Vostanis (2007) argues that vulnerable children are not well served by traditional service structures due to the multiplicity of their needs, parents' difficulties in advocating for them and lack of stable home living

arrangements. Clearly, the role of hard-to-reach factors in help-seeking is dynamic and complex but initiatives designed to meet the needs of this group remain under-researched.

Models of care for the hard-to-reach

Although there is a strong evidence base for many of the psychological interventions designed to address the mental health needs of children (Carr, 2000; Wolpert, et al., 2006), hard-to-reach families can be reluctant to engage with statutory services or are unable to attend consistently enough for interventions to be effective (Social Exclusion Task Force, 2007). Parenting programmes are another efficacious way of treating children's emotional and behavioural problems but although some have successfully engaged and retained hard-to-reach families (Hutchings & Lane, 2005), improvements in parent-child relationships are not always sustained (Webster-Stratton & Hammond, 1990).

In considering models of care for hard-to-reach families, issues of engagement and retention must be a priority. Research in this area is in its infancy but Statham's (2004) review of the evidence for the effectiveness of services targeting children in special circumstances (those at risk of achieving poorer outcomes but less likely to receive services), found that being allowed to discuss issues that matter to them and perceiving that the service is being of help increases the likelihood of services being accessed. It is also important that families feel respected and not stigmatised and that services are based in welcoming and attractive locations.

Snell-Johns, Mendez and Smith (2004) also focused on underserved families in their review of studies that examined strategies designed to overcome access barriers,

decrease attrition and facilitate change. They report that providing home-based services, using multiple family therapy groups (MFT)² and facilitating self-directed treatment have empirical support for being effective with a range of families. With regard to improving access to services, findings were inconclusive although addressing childcare and transport issues and providing financial incentives showed some promise. There was also evidence to suggest that for parenting training to be effective, parents may need support with their own distress and for any marital difficulties. Two further reviews on engaging families with child mental health services did not focus specifically on the hard-to-reach but found that addressing needs at a variety of levels by taking an ecological approach to service delivery is vital (McKay & Bannon, 2004; Staudt, 2003).

In the UK, school-based projects are increasingly being used as a way to provide these kinds of ecological services to vulnerable families in a non-stigmatising way (Masia-Warner et al., 2005; Reddy & Richardson, 2006; Statham, 2004; Wolpert, 2007). There is currently very little empirical evidence with regard to these projects and significant variation between schools in terms of the sorts of services being offered (Department for Children, Schools & Families (DfCSF), 2010a). Many are provided by the voluntary sector which is considered well-placed to provide support in a non-stigmatising and accessible way (DfCSF, 2010b; Social Exclusion Task Force, 2007; Wolpert, 2007). This study focuses on one such organisation in an effort to address research gaps highlighted in the reviews above; specifically, parents'

² Groups including children, parents and a facilitator and taking a problem focused approach to help families connect with one another, learn new skills, and receive feedback from multiple sources (McKay et al., 1995; O'Shea & Phelps, 1985).

experiences of engaging with services, their expectations of support, and their relationships with service staff (McKay & Bannon, 2004; Staudt, 2003).

Malachi Community Trust

Malachi Community Trust (MCT) is a voluntary sector organisation working in schools and Children's Centres across the West Midlands to offer family support and counselling to children and families in disadvantaged neighbourhoods. The service evolved in response to a realisation by the CEO that family breakdown can have a profound effect on children, a fact supported by the literature and one of the issues that can contribute to a family being hard-to-reach (Fonagy & Higgit, 2007; Webster-Stratton, 1998).

Classroom-based music, dance and theatre projects enable children to explore issues such as family conflict and separation, violence, crime, bullying and truancy in an engaging and non-stigmatising way. Drama work with children has been found to improve: emotional expression and awareness (Moneta & Rousseau, 2008); confidence, team working and decision-making (Salmon, Orme, Kimberlee, Jones & Murphy, 2005; Starkey & Orme, 2001); peer relationships and social skills (Amatruda, 2006; Daykin, Orme, Evans, Salmon, McEachran & Brain, 2008); classroom behaviour and self-efficacy (Amatruda, 2006) and conflict resolution skills (Zachariah & Moreno, 2006).

Where individual children are identified by staff as being in particular need, trained staff can offer additional support, individually to the child, to the child's family, or both. This may take the form of individual person-centred counselling, advocacy, or help with practical matters such as housing and benefits. MCT also runs groups which

provide the opportunity to explore parenting strategies, as well as other issues pertinent to those attending. Guided by individual need and informed by psychological theories of attachment, risk and resilience, the service aims to improve parents' capacity to reflect and problem-solve, enhance the parent-child relationship, and support access to education.

In addition to those children and families identified during the class-based projects, families can also self-refer or be referred by school staff or external agencies. Many of the families who access MCT are either not accessing CAMHS or are finding that the services offered by CAMHS are not fully meeting their needs. Given the increasing role of the voluntary sector in providing support to vulnerable families, it would seem important to find out how parents made the decision to access help for their children from MCT, and how this compares to their experiences of accessing other types of formal and informal support for their family.

Gaps in knowledge

Although much has been written about the risk factors for children developing psychological problems and the characteristics of families less likely to access mainstream mental health services, little is currently known about how such risk factors impact upon the help-seeking process. Much of the existing literature in this area has focused on barriers to care and has looked almost exclusively at help-seeking as it relates to statutory services. The voluntary sector is taking a greater role in providing services to families with complex ecological needs but how families link-in with such services and how this experience relates to the other ways they seek support is poorly understood.

Malachi Community Trust is one of a growing number of voluntary sector organisations working with hard-to-reach children and families using a flexible and holistic approach in close partnership with schools. Gaining parents' perspectives of engaging with this service, their experiences of seeking help from other formal and informal sources, and their beliefs about support for psychological and emotional issues will bring an important new perspective to the existing help-seeking literature. Specifically, the aims of the research were to:

Aims

- Explore hard-to-reach parents' understanding of what MCT as a voluntary sector organisation does and their experiences of engaging with the service.
- Explore hard-to-reach parents' prior experiences of seeking or accepting help for themselves and their children and how this compares with their experiences of engaging with MCT.

DESIGN & METHODOLOGY

A qualitative research design was chosen for this study in part because the nature of inquiry is exploratory and also because it was felt that a qualitative methodology would provide more scope for participants to express themselves openly. Participants were drawn from a marginalised sector of society and the issues of interest are complex and poorly understood, making a qualitative approach the most appropriate way of addressing the research aims (Social Exclusion Task Force, 2008; Willig, 2007).

Ethics approval was received from the School of Psychology Research Ethics Committee for the University of Birmingham on 17th December 2007 (see Appendix II) and interviews commenced in March 2008. The final interview was conducted in December 2008.

Sampling and participants

A total of 10 individuals were interviewed. The first interview was conducted with a mother who had been working with MCT for some time and was used to determine how effective the questions were at eliciting relevant information and get a sense of what the interview process was like for participants. Data from the second interview was also excluded from analysis as it transpired that the participant, though pregnant, was not already a parent. However, in response to this interview, the wording of some of the questions was made more concrete and additional prompts were added as the participant seemed unsure of how to respond to broad, abstract questions. Given the narrow scope of this study, the depth of the interviews, and recommendations in IPA literature (Smith, Jarman & Osborn, 1999; Smith, 2004), it

was decided that 8 interviews would achieve the right balance between providing rich and varied data, and not producing so much information that the identification of themes became unmanageable.

Eligible parents were those who had self-referred or agreed to a referral to MCT and had had no more than three individual sessions with MCT staff. By interviewing parents shortly after engaging with the service, it was hoped that their recollection of the decision-making process surrounding initial contact would be clearer and less influenced by the service they were receiving. Given the multiple challenges faced by individuals using the service, MCT staff were free to use their clinical judgement in deciding whether or not to invite parents to participate in the research. Parents were not informed about the study if: a) they were in crisis; b) they had a history of aggression towards professionals; or c) there was a risk they would be put-off from engaging with MCT by participation in the research. Individuals who required translation services were also excluded as there is evidence to suggest that translation can be problematic in phenomenological research designs (Twinn, 1997).

At the time of the research, MCT was organised geographically into two key areas, Birmingham East and North and Birmingham South; participants were drawn from both of these areas. A summary of key characteristics of the 8 interviewees is provided in Table 6.

Table 6: *Key Characteristics of Participants*

Pseudonym	Gender	Source of referral	Help sought or offered	Focus of intervention
Tina	F	SureStart	Offered	Mother
Lisa	F	School	Offered	Child
Abby	F	School	Sought	Mother
Rachael	F	Social Services	Offered	Mother
Sharon	F	School	Sought	Mother
Eileen	F	School	Offered	Mother & child
Ali	M	School	Offered	Father & child
Derek	M	Self	Sought	Father

All parents interviewed were either the primary caregiver or shared equal custody of their child(ren) with an ex-partner. They were aged between 23 and 47 and had between one and four children ranging in age from 2 to 17. Two of the participants had a child with a diagnosis of attention deficit hyperactivity disorder and / or autism. Although more detailed information about participants was not requested due to concerns that this could compromise engagement with MCT, many participants spontaneously shared information during the interview that illustrates the multiple stressors they faced.

All the participants alluded to being on a low income and experiencing poor housing, either currently or in the recent past. Only two were currently living with a partner and all but one of the participants had experienced mental health problems, Two had experienced social services involvement when they themselves were children, two

had been victims of domestic violence, at least one had misused drugs and alcohol, one had significant physical health difficulties, and one had a history of offending.

Interview schedule

Questions were developed with a view to achieving the aims described above and were modified in response to explicit and implicit feedback gathered during the pilot interviews. In particular, it was found that participants found very open or abstract questions difficult and the use of more concrete prompts were necessary to facilitate engagement. A copy of the interview schedule can be viewed in Appendix III.

Data collection

After liaison with research and clinical staff, the following recruitment process was agreed:

1. All parents meeting an MCT staff member for initial assessment were considered regarding their suitability for inclusion (a checklist regarding the research requirements was provided to MCT staff and staff were also encouraged to use their clinical judgement; see Appendix IV).
2. Any eligible parents were provided with a copy of the Participant Information Sheet (see Appendix V) by MCT staff. Interviews were either arranged at this time in consultation with the researcher or potential participants were asked if the researcher could call them to answer any questions and arrange an interview.
3. Prior to commencing interviews, the Participant Information Sheet was reviewed and written consent obtained (see Appendix VI).

Interviews took place either at Malachi's offices, the child's school, or the participant's home, depending upon participant preference and room availability. Interviews lasted between 36 and 72 minutes and were recorded digitally to enable transcription and analysis. Half of the interviews were transcribed by the author, the other half were transcribed by a professional transcription service and then checked for accuracy against the original recordings by the author.

Analysis

The qualitative method used for this study is Interpretative Phenomenological Analysis (IPA); an approach derived from a branch of philosophy called phenomenology (Smith, 2004). IPA was judged appropriate for this study because it provides space for individuals to share their perspectives and experiences without imposing existing theoretical assumptions upon the data (Reid, Flowers & Larkin, 2005). Given the paucity of research on hard-to-reach groups and voluntary sector services, this was considered particularly important.

IPA also takes a structured and systematic approach to analysis and acknowledges the influence of the researcher's beliefs and preconceptions, ultimately helping to protect the validity of the findings (Willig, 2007). The aim of this study was to gain a rich understanding of participants' experiences, not to develop a theory to explain the data and thus IPA was chosen in preference over Grounded Theory. The analysis of interview data using IPA comprised the following steps:

1. Transcribed interviews were read and descriptions of the participants' perspectives were summarised in the left-hand margin of the page.

2. Each interview was re-read and inferences were made about the meaning of the participants' experiences and any concerns and conflicts. Interpretive coding was noted in the right-hand margin of the page.
3. Individually for the first four transcripts, emergent themes identified during stage 2 were listed and paper copies of these were physically moved around in an effort to identify connections and patterns within the data.
4. This resulted in four tables of emerging themes for each of the first four transcripts. Once again, paper copies were manipulated in order to identify patterns and connections across the four individuals. A preliminary framework for making sense of the experiences of these four participants was created. Analysis was progressed to this level before proceeding to integration of interpretative data from the remaining 4 transcripts to aid with management of the very large quantities of data.
5. Interpretative data from the remaining 4 transcripts was added to the preliminary framework developed during stage 4. During this process, new themes were created and existing themes revised to ensure that the explanation of participants' experiences continued to reflect what was said during the interviews.

Credibility and validity

The following procedures were followed to maximise the trustworthiness of findings and to minimise researcher bias:

1. Interviews were recorded to reduce inaccuracies.
2. Negative case analysis was employed as theories developed. This involved actively searching for quotes or emergent themes that contradicted higher

level themes and revising or refining these to ensure that they encapsulated as many of the participants' experiences as possible.

3. Data was interpreted whilst keeping reflexivity firmly in mind. In addition, during the development of emerging themes, interpretations were checked by colleagues with experience of IPA but no direct involvement in the research to check that links between these and the data were clear.
4. An audit trail was kept from the transcripts themselves, through each stage of coding, to the creation of a table illustrating links between quotes and main themes (an extract of this can be seen in Appendix VII).
5. A research diary was maintained describing exactly what was done and my thoughts and impressions throughout the process. Emerging themes were cross checked for congruence with these initial impressions.
6. Preliminary themes were reviewed by clinical and academic research supervisors to ensure that they were based on participants' responses and were not unduly affected by researcher bias.
7. During the integration of interpretative data from the final four participants, themes that were suspected of having strayed too far from participants' experiences were re-worked by going back to the transcripts and manually sorting phenomenological and interpretative items. This led either to the creation of new themes or the refinement of existing themes.

IPA acknowledges the biases and preferences that the researcher will bring to the analysis and it is important to be as transparent as possible about these so that the reader can make sense of the data with this in mind (Reid, Flowers & Larkin, 2005). I chose to undertake this project after being supervised by a clinical psychologist with

strong links to MCT and learning more about the work they do. I have previously worked in the voluntary sector and have a strong belief in the contributions such services can make to improving mental health and well-being in hard-to-reach groups. I also believe that as a society, we have a duty to reduce social exclusion and that intervening early with vulnerable children is one important way to achieve this.

When approaching the interviews, I was conscious that participants may be unsure of my role and affiliations. This became evident in one or two of the interviews when participants had to be reminded that I was not employed by MCT or any other organisation with influence over their lives. Whilst participants could be reassured that I had no actual power over them, as a trainee Clinical Psychologist attending University I occupy a powerful position in society and this may have influenced the extent to which participants felt able to engage with me. In terms of interpretation of data, as a mother to two young children, I will have made sense of participants' experiences within the context of my own experiences of parenting.

Clinical supervision for this project was provided by the clinical psychologist referred to above plus two academic supervisors, one of whom has a clinical interest in child and adolescent mental health and one with a strong background in IPA and prior experience of supervising research carried out with MCT.

FINDINGS

Three main themes emerged from the analysis and a summary of these and the sub-themes and minor themes comprising them are presented below in Table 7. The main theme of 'Power and disempowerment' could be viewed as the context within which the remaining two themes sit as these issues provide some explanation for both the positive and negative experiences of coping and support described by participants. This section will use direct quotes to explore the themes presented below keeping in mind both the individual and shared experiences of participants.

Table 7. *Main Themes, Sub-Themes and Minor Themes Derived from Analysis*

Main theme: Power and disempowerment	
Sub-themes	Minor themes
Being in control vs being out of control	Being controlled Being in control Feeling out of control
Occupying a disempowered position	Feeling worthless and inadequate Being in a disempowered position Fear of being judged Being afraid of rejection Feeling fearful and unsafe Wanting approval / validation Being uncertain and unsure Feeling trapped The impact of depression
Main theme: Ambivalence about support and coping	
Ambivalent relationships with services	Mismatch between needs and services Being unwilling or unable to trust services Services don't really care Feeling hard-done-by Services as another demand on resources Feeling ambivalent Experiencing benefits
Coping as a strength vs needing support as a weakness	Using positive coping strategies Escape as an alternative means of coping Needing support is a weakness
Main theme: Drawing upon internal and external resources to survive	
The experience of seeking and receiving help from Malachi	Being pushed and pulled towards support Feeling Malachi could be trusted The impact of referral Understanding of MCT and expectations of involvement
Feeling valued and valuable	Fears and apprehensions Feeling connected to others Feeling valued Feeling safe Being parented Feeling empowered
Being a survivor	Retaining hope Survival and self-preservation Being an experienced service user Being self-reliant and confident Moving on from the past

Main theme: Power and disempowerment

All participants described situations in which they had been in a disempowered position and of positive experiences where they had been able to wield more power and control over their circumstances.

Being in control vs being out of control

Participants shared experiences of being controlled in personal relationships and by services. Abby described feeling controlled by her young son '*I felt like he was ruling the roost with me*' (Abby, line 62) whilst Tina made reference throughout the interview to her partner's attempts to control her:

'It caused an argument when I said [the house is in] Northfield, he says, 'ah no, don't accept it', and we were trying, me and my support worker were trying to erm argue, 'I have to accept it'. And he says 'oh no, we'll get you another private', like, he'll phone a contact...' (Tina, line 505)

Although these experiences differ in that Tina had actually been physically assaulted by her partner whilst Abby was feeling controlled by her 5 year-old son, the lack of self-worth shared by these women may underpin their difficulties with asserting themselves. Whilst this could be understood from a feminist perspective, the experience of being controlled was not unique to the female participants. Derek described the controlling relationship he has with his brother:

'And then he gets all arsy and defensive and starts - he hasn't got a [pause]. He's not an aggressive person but he can - you know when he's getting there, and it's best just to leave him and walk away. Coz I mean he's never got aggressive, the most he'll do is just mouth off and swear and shout and I'm just like, I ain't bothering with yah, 'coz where I'd always kind of tip toe round him, you know make sure I didn't say the wrong things, which is what I've always done.' (Derek, line 494).

A lack of certainty and belief in oneself and one's decisions was common to most of the participants leading to many experiences of feeling out of control. Sometimes there was a conscious awareness of this, as described by Eileen and Abby:

'It, it was going round and round and round in a circle, not getting anywhere.'
(Eileen, line 751).

'So I don't, I don't know. But then you could do that about everything couldn't you. Sit here questioning everything that you've done...' (Abby, line 189).

At other times, a sense of being out of control was conveyed by difficulties articulating their experiences:

'I feel really, really low, I feel - oh I don't know - I don't know what I'm doing - I don't know, I wanted to go to the doctors but I couldn't even get up and phone the doctors' (Abby, line 378).

For Derek and Ali, a lack of control over thoughts and feelings led to a desire to regain some control, either by getting away or using physical force:

'I was all ready to leave, it was getting to the point where I was going to leave or punch someone, because we had a supervisor who couldn't manage...' (Derek, line 94).

'Yeah, well with mine [situation] like what flipped me was what did happen to my children 'cause nobody would tell me anything, not even the police 'cause they thought I was going to do something...' (Ali, line 58).

All the participants also described being controlled by services, either implicitly due to a lack of choice or consultation, or explicitly because of the statutory powers being exercised by the service.

'And that was erm, sitting there, doing a test and they - the woman's going, 'Oh yeah, you're gonna need this or you don't need this' (Abby, line 479).

She asked Social Services, just for help, like with money to get them nappies, and they came and said, 'look, you're not the proper mother, we have to take them' (Tina, line 434).

Unsurprisingly perhaps, many of the participants highly valued situations in which they had felt able to take control, and services or professionals who had offered choices were spoken of warmly:

'I mean when Barry phoned to make the arrangements for the first meeting he was 'I understand you work at the school, are you comfortable coming to the school or do you want to meet somewhere else?'" (Derek, line 863).

'Its much more relaxing, 'well, if you'd like to do this you can or, if you don't want to yet, then you can come back when you're ready to and we can have a look again'.' (Rachael, line 694).

It seemed that where 'being controlled' was a disempowering and infantilising experience, being given control conveyed a sense of respect which in turn allowed participants to believe they had some value.

Occupying a disempowered position

Many of the experiences of being controlled described by participants are underpinned by the minor themes illustrated in this section. Although some of these could be considered intra-psychic, for example, feeling worthless and inadequate and the impact of depression, these were commonly played out in the interactions participants had in their personal lives and with service providers. For example, Tina felt uncomfortable in her dealings with professionals, feeling that she would not be able to understand what was being discussed:

'I don't want them thinking, 'well, she's here on a, with a solicitor and she aint' got a clue what I'm on about'" (Tina, line 733).

This pessimistic assessment of ability was shared by Ali who was unsure whether he was going to be deemed a good enough father to retain custody of his children:

'And I thought 'Oh God they're going to take them away from me 'cause I ain't done good enough' and then they all just stood up and clapped me and I - And I looked at him as if to say well what's wrong?' (Ali, line 172).

This lack of self-esteem seems to imbue interactions with a fear of being judged and a fear of rejection which is sometimes reinforced by past experiences with professionals. Tina for example had been left feeling hurt and angry when she had been judged as not really being in need of support:

'I would never come if I could, if I knew that I could sort something out myself, it's like taking advantage or something, I don't do that.' (Tina, line 359).

'If you know someone so well, like a one-on-one, you would know how they are and you know that if they're using you or something.' (Tina, line 784).

A fear of being rejected may have fuelled Derek, Eileen and Abby's tendency to minimise their distress, put others first and avoid conflict. Abby and Derek had both had counselling in the past and seemed used-to reflecting directly on their style of interacting with people and the consequences this had on their lives:

'And I'm, you know I, I won't say a bad word about anyone. I, I just want to get, I'm happy to be getting on with everyone. I don't like conflict, that's why I bite me lip and bottle it up so much.' (Derek, line 141).

'I've kept a lot of stuff to myself, and tried not to hurt people and think, oh, I don't want to upset them, but now I think, I'm in the mind well its upsetting me so...' (Abby, line 357).

This disempowered position was exacerbated for half of the parents I interviewed by their experiences of depression. Difficulties with motivation, concentration and memory, and feelings of hopelessness make it hard to deal assertively with people

and situations. For Rachael, these symptoms seemed layered over the top of an external locus of control, leaving her feeling that she had no real influence over her life. She seemed to occupy a position of passivity, perhaps to protect herself from being hurt by failure and disappointment:

'Whatever, whatever happens happens, you can't change it so why bother trying.' (Rachael, line 257).

Derek illustrates that just as mental health problems can impact upon one's ability to take action, being in a disempowered position can in turn affect one's mental health:

'We had yet another round of redundancies at work and it was about the sixth one in three years, so I hit a low because I weren't sure if I had a job, Christmas coming up, things at home were getting... [refers to relationship difficulties]' (Derek, line 165).

Some participants felt patronised, bullied and insulted by the services they accessed yet there was a sense of there being no choice but to put up with this treatment and in some instances, even to feel grateful:

'I know it's serious but she doesn't help me sometimes the way she talks to me. Because she's quite like, not abrupt but like um [slight pause], I don't know. You know, I know what he's like, no one needs to tell me...' (Eileen, line 125).

'Manager rang me yesterday from Social Services and eh she said 'That's the way that social worker is, but she is really trying to bend over backwards for yah''. (Sharon, line 737).

In other cases, the sense of powerlessness was more implicit and came about because of a lack of information or a failure to communicate openly about the support being provided:

'So I'm still struggling and still trying to find out the different agencies I can go to for help with Charlie.' (Sharon, line 603).

'But I didn't know until the other day that they've stopped that, so if I want to carry on that statement I've got to pursue it. They only told me that the other day, I didn't know.' (Eileen, line 655).

One important exception to this picture of disempowerment is that of Lisa who, despite having a significant physical disability, did not take on the rhetoric of powerlessness and who seemed able to take control of her relationship with services. Her assertive stance was also reflected in the interview itself where I found myself feeling 'on the back foot' and somewhat unsure of myself. Whilst one could argue from a psychodynamic perspective that this was an example of transference, I wonder whether an equally valid interpretation might be derived from the very significant life events she had experienced from a relatively early age:

'I was eighteen and diagnosed tumour in my spine, and every operation and everything has been my decision and I think well if I can't do it myself, then no-one else is gonna do it for me, because it's me that's got to get over it.' (Lisa, line 790)

Rather than be subjugated by the many procedures she had been through and the limitations her ongoing health problems imposed, Lisa seemed able to use these experiences as proof of her strength and resilience. This coupled with a supportive husband and family meant her contribution to this theme was minimal.

Main theme: Ambivalence about support and coping

All the participants had at least some experience of using mental health or social care services for themselves or their children prior to engaging with Malachi. These

experiences were mixed, as were participants' views of accessing external support and what this might mean about their ability to cope.

Ambivalent relationships with services

Most participants seemed to feel that the services on offer often did not meet their needs or were not to be trusted. This seemed to stem either from a feeling that services were actively hostile, or that what they provided was ineffective. It seemed that accessing services can be experienced as another demand upon resources although in some cases, this had been compensated for by the benefits experienced.

For Derek, what he had been offered in the past simply wasn't enough and he felt that the limits imposed upon counselling sessions had impeded his progress:

'I've got to try and remember that for a week, and I go in and we talk about something completely different and then right at the end, I remember what we were talking about it, get back on it "Sorry, we'll carry on next week". And then after seven weeks, I don't feel like--, I accomplished bits, you know... and seven weeks went flying by and I don't feel like I really sorted anything out, apart from tiny little pieces' (Derek, line 612).

For Sharon, it was the type of support that was inappropriate and there's a sense that she almost feels fobbed off by what was offered to her:

'Um they got me some grants for fencing I need but it's, it was all about give me money for fencing and give me money--. I didn't want the money for things like that, I just wanted more support, for Charlie.' (Sharon, line 632).

In some cases, parents felt actively snubbed or criticised by services, 'so Social Services are trying at the moment, I feel, to make me feel like I'm a bad mum...' (Sharon, line 427) and possibly in response to this, participants were sometimes disparaging of the interventions on offer. At times there was a specific complaint

about a discreet element of service provision but often a sense of scepticism was conveyed to me via the language used. Eileen for example was able to name several issues that she felt were indicative of poor care for her son but also seemed to want to distance herself from the explanations offered for his difficulties by health professionals:

'Um but like I said the doctors and the school don't seem to get that involved together. Like I said when I've been to the Mar -, eh Allens Croft now 'Have you heard from the school?' 'No.' When I've seen the school, 'Have you heard from Allens Croft?' 'No.' (Eileen, line 666).

'And they reckon he'll go all back to the beginning and he's got to think about it again.' (Eileen, line 894).

All but one of the parents I spoke to seemed to feel that services did not really care about them or their child. This seemed particularly apparent for Sharon, Eileen and Lisa whose children all had special needs and who had significant experience of dealing with Social Services and CAMHS:

'He, he sits there and he listens and he listens and he jots things down and at the end of the appointment 'There's your prescription. See you in a month's time'. I think I've just sat there, I've had a good moan, he's jotted it down, he's never attended all the meetings at the school, respite, he's just sent a report. I think really though professionals that are involved in children, I know they're busy, should, on these important meetings, go to 'em. You know, but half of 'em don't. (Sharon, line 956).

'Eh sorry, made the appointment for September, got a letter it was changed to late in September. Then got another letter and they've changed it now from September to November so it's been changed twice this time. Touch wood it won't be changed again.' (Eileen, line 699).

Here it appears that for Sharon the role of her son's psychiatrist is too limited and his focus on managing symptomatology and medication is perceived as a lack of real care. For Eileen, this feeling that services and professionals are not really committed to her and her family as individuals is conveyed by administrative errors with her appointments.

However, disappointment and frustration with inadequate care was often juxtaposed with a very real fear that children could be removed if services became more involved, *'I don't want him taken away, I just want the help and support I should be getting, so.'* (Sharon, line 782). This fear was echoed by Eileen who seemed to be treading a fine line between alerting services to how difficult it is to cope with her son's behaviour and giving them cause to remove him:

'Because I think that if I told all the truth they'd take him off me, 'cause if they thought I wasn't stable or I couldn't cope or we shouted at him or me and his dad had had a row or, you know...' (Eileen, line 1178).

Negotiating these kinds of issues meant that for some of the parents interviewed, accessing support was experienced as an additional demand upon their resources. Rachael in particular viewed Social Services involvement as *'just one more thing you don't really need'* (Rachael, line 367) and *'just one more stress to go through and then it'll be over with...'* (Rachael, line 420). Although Rachael's views could be partly explained by Social Services becoming involved after her child had a fall, this sense of there being an emotional and psychological cost associated with accessing support was also echoed by parents who had voluntarily sought help:

'That's when I come to the school, admitted what I'd done and said I wanted help, so.' (Sharon, line 165).

'It's vulnerability. You're sitting there. I actually thought, oh, you go to see a counsellor because there's something wrong with your head.' (Derek, line 585).

'You know, each one thinking, god, I don't know what this one's gonna be like, walking down the path, taking each step...' (Abby, line 508).

For Sharon, there seemed to some trepidation in admitting she is having difficulties which is perhaps explained by Derek's use of the term 'vulnerability'. Abby too talked about how hard it is to share personal experiences with a stranger and how, to make that kind of emotional investment, you need to be sure that you will not be let down:

'That's why I was so, hesitant about going to counselling again because I thought well I don't want to be in the middle and then just dropped...' (Abby, line 643).

Despite these reservations, the benefits that many parents derived from accessing support made it worthwhile. In particular, participants talked about experiencing 'relief' suggesting that the opportunity to talk to someone about their difficulties was cathartic:

'And I don't know why but I felt a lot better for doing it, I swear to God it took a lot off of my -, it took a lot of weight off me. Maybe that's what I needed to do for a long time like.' (Ali, line 527).

'I just bottle it up and then just come in once a week just to get it off my chest. No matter what it's to do with and I, I walk out and I feel fine again.' (Derek, line 134).

For Abby, the chance to talk and explore her thinking with someone removed from her situation allowed her to come to a realisation about the cause of some of her distress *'This one time I hit on, I kept having this recurring dream and that's what it*

was.’ (Abby, line 603), whilst for Sharon, active support and guidance from a counsellor helped her to make sense of her experiences and feel more empowered:

‘So I sit and think, it’s like Rebecca makes me sit and think about the consequences, she draws diagrams, she’ll show you like ‘How did you feel here? What did you do? Then what happened?’ and it’s like she showed me last week how it goes round in a vicious circle but now I can sort of like go from the top of the diagram half way round and it doesn’t carry on all the way round.’ (Sharon, line 240).

Most parents had actively chosen to make contact with Malachi or to accept a referral being made by a third party suggesting that for these parents, there have been enough positive experiences to make engaging with another service a risk worth taking.

Coping as a strength vs needing support as a weakness

All but one of the participants illustrated the use of positive coping strategies, even if they were not always consciously aware of doing so. Lisa talked explicitly about the way she copes with her health problems and about her mum’s role in teaching her how to re-frame her situation in a way that makes it easier to bear:

‘And erm, my mum like, she goes, ‘Well Lisa, there’s nothing you can do about it, you’ve just got to get on with it’ and she’s, ‘you’re not the only one in the world’, which I’m not, so you just get on with it then. I mean there’s people worse off than me so -. And I always look at it that way, there’s always children that are dying of cancer, and I can always turn round and say I’ve had a life, they haven’t. (Lisa, line 884).

Lisa also talked about focusing on the here-and-now, being solution-focused, and accepting things that cannot be changed. Five of the other parents overtly acknowledge their strengths and achievements during the interview, and in addition

to this being a way of boosting self-efficacy, it may also have been borne of a desire to demonstrate their competence to me:

'Because I think, I don't know whether you picked up, I probably still do it [use positive parenting strategies], without thinking.' (Eileen, line 851).

'I've picked myself up and realised how low things were and I've got back up again and just keep kicking it.' (Sharon, line 233).

'I found it hard at first like but with help like from people like I've got there so. And like I say like, with my own problems as well.' (Ali, line 46).

Many of the achievements described by parents came about after engagement with services, yet there was a general sense from over half of those interviewed that needing support is somehow shameful. Rachael was keen to assert that Malachi's involvement was primarily for her son's benefit, despite alluding to suffering from depression herself, *'Its more how to, playing with Harry and interact with Harry properly and well than anything else.'* (Rachael, line 572). Sometimes this sense of shame and failure was fuelled by others' reactions to seeking help:

'I had post-natal depression with Emily but never dealt with it because you felt, well I felt like I couldn't deal with it because you know, 'What's wrong with you?' type of thing with the family and different things I didn't feel I could go, go for help.' (Abby, line 300).

'She [mum] pulled a bit of a face when I said I was going for the first one and she was 'Why?'' (Derek, line 518).

For the two male participants, reaching out for help seemed particularly difficult because of the negative connotations this had for their masculinity:

'But um like I say I couldn't ask my friends for that sort of help 'cause we weren't like that and they might think I'd, 'oh he's going soft'...' (Ali, line 548).

'It's that whole male thing, um I mean it was hard. Work forced me to go to counselling, the last time I went...' (Derek, line 150).

Main theme: Drawing upon internal and external resources to survive

There was a strong sense from all the participants of having been through a lot and of this informing a critical approach to accessing services. In addition, it seemed that there was some kind of synergy between the power and control missing from some parents' lives and the types of interactions with services that left people feeling valued.

The experience of seeking and receiving help from Malachi

Participants made contact with Malachi via a variety of routes but the general sense across all eight parents was of being both pushed and pulled towards accessing support. For Abby, her distress seemed to cross an internal tipping point that prompted her to reach out to school staff for support, *'I was crying, and I thought, this is no good. And that's when I got in touch'* (Abby, line 51). Sharon had been coping alone with a child with special needs and struggling with depression for many years but an escalation in her distress led her to seek help from a member of staff she knew at her child's school:

'I wasn't desperate to speak to anybody at that point anyway, it was just the start of my depression, then it built up worse...' (Sharon, line 46).

For Ali, it was concerns he and the school staff had about his ability to control his anger that prompted Malachi staff to offer some one-to-one support. Without the close relationship he enjoyed with the school head, this intensification of Ali's anger may not have been picked-up:

'And it was only like when I was starting to get flexed again, like flexed up ready to do something, which I was going to regret, is that I was told like Neil'd see me...' (Ali, line 672).

The trigger for Derek was the breakdown of his relationship and specifically, a hope that seeking support might prompt a reconciliation:

'I was finding it hard. Since -. With the breakup I was just finding it harder and harder to cope. I was getting very short with people, finding it -, finding it difficult to cope. You, even the, the least stressful of situations um.' (Derek, line 127).

'Well, back then, there was still the chance that the marriage, you know was getting back together, um you know she'd been on and on and I thought well it's one thing she wants me to do, and I suppose deep down it was a large part that did it, just out of the chance of us getting back together. Knowing full well I needed it, but now I wish I'd done it a lot earlier, before, even before the marriage got in that state. You know, we probably wouldn't have got to where we were.' (Derek, line 244).

Although all the parents interviewed had concerns about their children, these were not always what prompted them to seek or accept support. For Eileen and Lisa, it was their child's school that initiated a referral to Malachi and this was done without consultation. Lisa responded somewhat angrily to this, *'cus it'd been put through the school, so I never knew anything about it.'* (Lisa, line 19) whilst Eileen felt relieved and quickly made links between her son's difficulties and the impact on her capacity to cope:

'Maybe it's because they can see I'm not coping too well when I pick him up, when they keep telling me he's done this, he's done that, he's done the other. Um maybe they can see I'm getting stressed, I'm getting angry, I'm getting upset. Maybe they can't handle Jarrod so they're at the end of the tether so

they think oh God we'll get Malachi in. I do, I don't really know really, you know. Um I don't know.' (Eileen, line 571).

Feeling able to trust Malachi was important to most of the parents interviewed and for some parents, this sense of the organisation and its staff being trustworthy seemed to evolve in part from being familiar with the service:

'I'd seen her a couple, cus I'd came down a couple of times for the Stay and Play, and they'd told me about the cooking course, I'd done that, I came to the cooking course, so I saw them a few times...' (Abby, line 41).

'It's just passing in the corridor and chatting. And, yeah word of mouth really.' (Derek, line 76).

'Cause I was asking a few, 'cause there is a few single parents here like being in really bad relationships and I was, a few of them said 'Have you talked to them?' I said 'Well the kids talk to them' I said 'But I thought it was only for the children'. They said 'No it's for the adults as well if you ever feel you'd like to talk' I said 'Well I never knew that'.' (Ali, line 276).

Knowing a bit about Malachi did not dispel participants' trepidation at meeting staff for the first time however and parents spoke about feeling nervous, scared of being judged and unsure of what to expect:

'It was cus I was like, really nervous, like how they gonna be, who they gonna be like, yeah...[what were your worries?]. Dunno, was like, judging you after they'd read your file, or just seeing me, who I am... just that really, that's what I was scared of.' (Tina, line 46).

'Oh I was very nervous but as soon as I met her she made me feel at ease straight away, it li -, as if I'd known her like for years.' (Sharon, line 105).

For Abby, the process of engagement with Malachi was empowering and very different from the many other experiences she had had of accessing support from a

variety of different sources *'I feel a bit more in control, because it's like off my own back.'* (Abby, line 459).

Feeling valued and valuable

Although none of the parents interviewed had had more than three one-to-one sessions with Malachi staff, Abby was not the only parent who already seemed to be deriving benefits from their contact with the service. It seemed that for some participants, just knowing that there was someone there to support them was an empowering experience that gave them the confidence to make changes to their lives:

'But now if something just comes to upset me I tell 'em. And that's just going -, you know why should I always have to suffer for other people? I mean that's come out through sessions, just talking about it. So it's giving me more confidence.' (Derek, line 502).

'Um, but then like I started talking to people like and now I've calmed down. When I start to lose it I know I can phone people and I can sit and talk and I'm okay now so I don't lose it like I used to.' (Ali, line 51).

In some instances, participants almost seemed to feel parented by Malachi and I wondered whether this sense of being contained by staff could explain how they found the confidence to change unhelpful patterns and become more assertive despite interventions being in their very early stages:

'You know like if I ever get like depressed or get down or stuff like that I have, like I say I phone eh the school up to see if Neil's in, if not I will phone him on his mobile and if he can't answer the mobile like I'll leave him a message. And I've got to admit, within an hour or two he phones me back, eh and we just talk on the phone like and I feel alright then like.' (Ali, line 300).

'I know if I need a pick me up session I can pop in coz they're always here. If it, I mean if it's, I mean Barry says if it's really bad give him a ring. Yeah I can always speak to Barry.' (Derek, line 637).

Another compelling experience shared by parents was of Malachi staff being able to get things done. Not only did this seem important from a practical perspective (and is indicative of the lack of power many participants seemed to feel) but it also seemed to convey to parents that they were valued, and worthy of efforts being made on their behalf:

'So any, any problem, any anything, they're willing, if they don't know anything about it, they're gonna look for me, so that's good.' (Tina, line 116).

'I don't know what, you know Neil done but -. I don't know what strings he pulled or anything like but within three weeks they offered me this three bedroom house, the biggest -, well the biggest house on the road. Like um, um he's got me furniture, he's helped me out with everything.' (Ali, line 157).

This sense of value and worth communicated to parents by Malachi staff seemed to mean a great deal and may help to explain why participants were so positive about engaging with Malachi relative to their experiences of accessing other services. Feeling worthless and inadequate and being afraid of rejection were common experiences for participants and the ability of Malachi staff to address these needs meant that parents quickly made a connection with staff. Being accepted and valued were not experiences that Ali seemed particularly familiar with and the unconditional regard conveyed to him by his worker had a powerful impact on him:

'They, looked at me and they used to sit me down like we are now and talk to me like a human being like instead of an ani -. Alright I admit I was an animal but they talked to me as a human being and that's what a lot of people never ever did.' (Ali, line 586).

For Abby, Sharon, and Tina, their value was signalled to them by the responsiveness of Malachi staff and the fact that they seemed to prioritise their needs:

'Say if it was a Friday, they were coming round on the Monday, they says, 'Is it alright on the Monday?' I thought that was good.' (Abby, line 247).

'She was asking really what I preferred, what I needed...' (Tina, line 79).

'I think they could see how low I was so it was just like given to me on a plate. I was quite lucky there, to get it so quick.' (Sharon, line 869).

Unfortunately, the intensity of these kinds of relationships meant that some participants had been very hurt when services they had accessed in the past were withdrawn. Tina, Rachael and Ali had formed close relationships with workers past and present which seemed more akin to a friendship than a client – worker relationship. It seemed important to them that they were valued over and above their status as a client:

'Sometimes I think she was crossing the boundaries because we became more like friends'. (Tina, line 343).

'Well she's still classed as a worker but she's a friend anyway...' (Rachael, line 519).

'Eh with Neil I class him as a friend now, a good friend now because of, he's, he's there for me if you understand what I mean, when I need him. Alright he, he ain't like, he can't get to me house like but he will stay on the phone and talk to me...' (Ali, line 514).

But then:

'At first you, you used to do this and you used to do that but then I felt I couldn't come to you anyway because, you'd say no...' (Tina, line 744).

'I know she did work as well but there were only certain times of the day she could come round and she missed a couple and then I've not heard from her since then, so I was like, ok, whatever.' (Rachael, line 537).

'Like I say he's a very good friend, well I hope he's a very good friend, now, instead of a, just a counsellor for me in a job like.' (Ali, line 530).

The sense of vulnerability, disappointment and hurt is palpable here, perhaps because those underlying feelings of worthlessness are easily re-awakened. Relationships with staff may hold particular significance for parents who do not feel connected with the wider community. Feeling lonely was not uncommon for the parents I spoke with and both Sharon and Eileen valued the companionship offered by attending parenting groups as much if not more than the strategies they learned:

'Yeah but I didn't mind doing it in a group because I, I met up with some people I used to know ... it was great. It was nice. It's like being back at school!' (Sharon, line 573).

'And it was a social thing. We'd have a cup of coffee and some biscuits and all that, and it's like ooh I'm looking forward to that you know 'cause like you're stuck in the house and you know...' (Eileen, line 784).

Friends, acquaintances and other parents also seemed to be an important source of information and expertise, particularly for Sharon and Eileen:

'And my mate who I keep talking about she told me about, she said 'Does Charlie do this? Does Charlie do that?' I went 'Yeah, yeah'. She says, 'Does he keep the eye contact?' I said, 'No'. He does now, but she told me about, eh, how she went through, um going to Dudley Road Hospital, they did the assessments over I think 12 weeks and that's what, that's what I did. I took her advice...' (Sharon, line 929).

'When I used to go to this class, like SENCO, there was some of the mums there, they were like really clued up...they're all up on it, what school's good, what school's bad...' (Eileen, line 963).

Unconditional regard, warmth and genuineness, responding to needs and going out of your way seemed to communicate to parents that they are valued and worthwhile, a belief that most participants did not seem to hold about themselves. Connecting with family, friends, other parents or workers also seemed to reduce self-blame and offer the sense that difficulties did not have to be managed alone.

Being a survivor

Some parents had considerable expertise as service users and thus were likely to approach new services having a fairly clear idea about what worked for them:

'I think it takes time to, with some professionals, to build a good relationship. With some it's straight away, so.' (Sharon, line 996).

'And I've had when they talk back to you, and then I've had different ones that ask questions. I've had them all I think.' (Abby, line 502).

'With counselling they can, they can help depending on what, where you got to. At the end of the day, within an organisation, some are just talking, some are art or playing or more relaxed talking...' (Rachael, line 582).

Lisa in particular appeared to be very self-reliant and confident about her abilities to cope and thus for her, things would need to be very bad before she would consider accessing support:

'I suppose Ryan would have to really, really, really regress that much that I really can't cope.' (Lisa, line 722).

'If he got physically violent and stuff like that then yeah, I would consider it...' (Lisa, line 742).

Lisa also seemed to use strategies during the interview to close down areas of discussion she was uncomfortable with and to take a very practical and pragmatic approach to her difficulties, and to support services:

'If Malachi aren't helping Ryan as much as I think they would then I'd say, 'well, can we end the services then'.' (Lisa, line 469).

'(Interviewer) So what were you feeling before Jeremy turned up? (Lisa) Nothing really.' (Lisa, line 396).

'(Interviewer) Have you ever thought, 'God, I really need some extra help?'
(Lisa) No (Interviewer) No? (Lisa) No never.' (Lisa, line 305).

This style of interacting may be related to Lisa's solution-focused style of problem solving and it is possible that an interview process that encouraged reflection on feelings and emotions was somewhat threatening. I also wonder how she might have felt about being interviewed by an able-bodied young woman and whether this resulted in her taking a particularly strong and assertive stance.

Despite experiences of ill-health, depression, violence and poverty, many of the participants remained hopeful about the future and were able to reflect on the improvements they had made to their lives. Ali conveyed powerfully the way his life had changed since getting custody of his children and had many aspirations for himself and his children:

'Like a lot of people say oh a leopard can't change it's spots but they can if you give 'em a chance. Like eh I mean if I can do it anybody can you know what I mean?' (Ali, line 573).

'Eh they done brilliant on the SATs the both of them so, well they passed their SATs so I'm well happy with it.' (Ali, line 622).

Derek had also made changes to the way he coped with his difficulties since engaging with Malachi and seemed to gain some comfort from understanding how they may have developed:

'Eh, the main thing I was, I always did in a session was just to vent off, get everything off me chest but now I'm actually doing it away from the sessions,

at that moment instead of storing it up until next Wednesday and say it all then.’ (Derek, line 510).

‘Where a lot of my insecurities have come from, coz I was never close to me dad. He was clos -, he was a lot closer to my two brothers because of sport. I didn’t like playing rugby and cricket I was an athl -, you know I was into athletics and basketball...’ (Derek, line 619).

All of the parents interviewed seemed to draw upon their own experiences of surviving adversity and positive and negative experiences of accessing support to cope with their current difficulties and make an informed choice about whether or not to engage with Malachi. Participants spoke positively about occasions when interactions with friends or professionals did not follow the more typically experienced script of being controlled and disempowered.

DISCUSSION

Summary of findings

The parents I spoke to during this study shared common experiences of being in a disempowered position and of feeling controlled by individuals and services. This contributed to them having an ambivalent relationship with services, often wanting more support, but also being reluctant to admit they needed help and wary of services becoming intrusive. Experiences of engaging with Malachi were very positive, possibly partly attributable to staffs' ability to make parents feel valued. Most of the participants seemed to feel worthless and inadequate and experiencing a genuine connection with others, whether other parents or health professionals, may help to counter this. The parents I spoke to had survived a great many challenges, both in their personal lives and while accessing support. Most retained a sense of hope and optimism about this most recent attempt to seek help for themselves and their families.

Experiences of feeling disempowered are not uncommon for hard-to-reach groups, indeed, in Anderson et al.'s (2006) study of lower income mothers, beliefs that clinicians have excessive power over their lives was identified as a barrier to receiving care. Deconstructing this sense of disempowerment further, it would seem that the parents in this study felt they would either be judged as inadequate and subjected to patronising and humiliating treatment by staff, or overlooked and controlled by services. In many cases these concerns were borne of previous negative experiences with service providers but there were also examples of parents finding it hard to assert themselves in their personal lives.

It seems likely that hard-to-reach families' sense of disempowerment is generated by

an interaction between intra-psychic issues such as low self-esteem and symptoms of depression, and the position they occupy in society. Individuals in lower social classes perceive the world as less controllable and are more likely to attribute personal and social outcomes externally (Kraus, Piff & Keltner, 2009) and many of the participants in the current study certainly seemed to display an external locus of control (Rotter, 1966, 1975). One could argue that this perception is at least in part grounded in reality; the parents I spoke to shared many examples of not being kept informed or given choices about key issues such as benefits, housing and healthcare.

These kinds of issues were only partly responsible for parents' somewhat ambivalent relationship with services. Similarly to previous research with hard-to-reach groups, feelings of scepticism and mistrust were prominent (Snell-Johns et al., 2004; Richardson, 2001). Accessing support was also another demand on limited resources and given some parents' experiences of cancelled appointments and long waiting lists, it is perhaps unsurprising that families sometimes deem the benefits of support as being insufficient to justify the efforts required to access it.

Needing support was felt to be a shameful experience for some of the parents, perhaps because of how they felt this might reflect on their parenting abilities. Indeed, Avis, Bulman and Leighton's (2007) qualitative study of factors affecting participation in Sure Start programmes found that parents were less likely to engage with the service if they perceived that it was for those who are failing as parents. However, there seemed to be something about the way Malachi staff engaged with parents that ameliorated this sense of shame and rapidly conveyed a sense of being valued and cared for.

Workers were quickly viewed as trustworthy by participants and they seemed to achieve this via a combination of prioritising parents' needs, offering choice and control, being accessible, and being prepared to help with any difficulty the individual brought to them. The reciprocal and respectful relationships with staff that parents described to me seemed to help counter their feelings of worthlessness and failure and were highly valued. The personality and trustworthiness of staff has been found to be an important factor in deciding whether or not to engage with services in previous research with the hard-to-reach (Gross, Julion & Fogg, 2001) and the current findings certainly seem to substantiate this.

Returning to the models of help-seeking summarised in the introduction to this paper, it seems that Costello et al.'s (1998) revised Network Episode Model (NEM) or Biddle et al.'s (2007) Cycle of Avoidance (COA) model are best able to account for the influence of parents' perceptions and beliefs about services and support on the help-seeking process. The NEM in particular acknowledges the many push and pull factors influencing the help-seeking process and is able to incorporate ideas of control and disempowerment, whether these evolve from intra-psychic characteristics or the social context individuals inhabit.

Clinical implications

These findings have several implications for policy makers, services and professionals working with hard-to-reach parents. Worries about children are just one of a myriad of concerns for this group and thus services will need to take a holistic approach and foster strong communication between one another to meet families' needs. Similar recommendations have been made in government and academic

publications (Social Exclusion Task Force, 2007; Wolpert, 2007) and some progress has been made but it seems unrealistic to expect parents to be able to engage more wholeheartedly with services when basic needs such as decent housing and an adequate income remain unmet (Wolpert, 2007).

Equally challenging is how to address inherent power disparities between services and the individuals who use them. Increased use of voluntary sector organisations has been recognised as one way of tackling this issue and the parents I spoke to certainly seemed more at ease engaging with Malachi than with services imbued with statutory powers. It is ironic that CAMHS services, for example, have no more power to initiate child protection proceedings than a voluntary sector service and yet they are perceived to be less 'safe'. Simple changes such as offering greater flexibility around appointment times and venue may be one way of placing more power and control with parents. Greater transparency about the rationale for treatment approaches may also be of help.

Other service qualities valued highly by service users such as being able to contact staff via mobile telephone and having ad hoc appointments would likely meet with significant resistance from CAMHS staff but open dialogue amongst professionals about their roles and the flexibility inherent in these would be valuable. Clinical Psychologists could take a leading role in challenging practices that are not inclusive and promoting those that are, including leading by example where appropriate (British Psychological Society, 2008). We may also have a role as consultants to voluntary sector organisations, helping to ensure that pressure to demonstrate their effectiveness does not result in the imposition of structures and procedures that alienate the hard-to-reach.

In terms of our clinical practice, Clinical Psychologists working with hard-to-reach families must be mindful of the powerful position we occupy. Service structures may limit the extent to which we can offer choice and flexibility but engaging families in open discussion about treatment options and how issues such as childcare, housing, poverty and relationship issues might impact on these is important. The experiences of parents in this study would suggest that feelings of being judged and de-valued are easily triggered. Endings in particular can be experienced as hurtful and rejecting. Paying particular attention to endings, and putting parents in control of these as far as possible, might be one way to manage this. Finally, it is worth remembering that many hard-to-reach parents are coping with enormous challenges on a daily basis; taking a strengths and resilience-based approach may help to tap into and reinforce existing resources.

Limitations of study and research implications

Whilst this study has gone some way to increasing our understanding of help-seeking by hard-to-reach parents, there are a number of limitations which must be borne in mind. Perhaps the most fundamental of these is the fact that those parents interviewed were not only engaging with Malachi but were also perceived by staff to be agreeable to participation in the research and thus may not be representative of the most excluded and marginalised families. In addition, concerns from Malachi staff about the impact of participation on engagement with their service meant I was unable to interview parents prior to their first appointment with a Malachi worker. Participants' experiences of meeting with Malachi staff are likely to have influenced their recollections of engaging with the service and in order to really capture parents' hopes, fears and expectations of the service, it would have been preferable to speak

to them earlier in the help-seeking process.

All the participants interviewed were white British and it cannot be assumed that the experiences shared with me reflect those of individuals from different ethnic or cultural backgrounds. Children from ethnic minority groups, those who are 'looked after', refugee and asylum seekers, children engaged in anti-social or offending behaviour, children who are abused, and those from travelling families are known to be at greater risk of developing psychological difficulties and are under-represented in mental health services (Coe, Gibson, Spencer & Stuttaford, 2007; Correa-Velez & Gifford, 2007; Statham, 2004; Wolpert, Lavis, Wistow & Foster, 2007). Studies targeting these groups individually are necessary because, while some experiences may be common across hard-to-reach groups, there are also likely to be many differences.

From a methodological perspective, although IPA was chosen in an attempt to give voice to a marginalised group, Willig (2007) cautions that the communication of thoughts, feelings and perceptions demanded by this approach can be difficult for individuals unused to expressing themselves in this way. The pilot interviews I undertook highlighted this issue and led to the addition of more prompts and less abstract terminology but I still found that some parents seemed uncomfortable talking about themselves and their experiences in the way IPA demands.

I must also draw the reader's attention back to my role as an interpreter of parents' experiences. It cannot be claimed that what is presented above *directly* represents participants' experiences. In particular, limits to the length of this paper and the focus on help-seeking meant that not all themes generated by participants' experiences

have been reported. The reader is encouraged to view the findings above in the context of other important experiences for participants, a list of which can be seen in Appendix VIII.

IPA seeks to describe a phenomenon rather than explain it and now that pertinent experiences for hard-to-reach parents have been identified, further research is necessary to develop explanations for these. Quantitative designs exploring the impact of locus of control, self-efficacy and stress on coping and help-seeking would be of interest, as would longitudinal designs that could follow parents through the help-seeking process. It would also be of value to explore children's experiences of the help-seeking process. Finally, innovative research designs may be necessary to capture the perspectives of families who remain hard-to-reach for even the most flexible and inclusive services.

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PUBLIC DOMAIN BRIEFING PAPER

**Help-seeking amongst hard-to-reach parents whose children have emotional
and behavioural problems: A review of the literature**

AND

**Hard-to reach parents' understanding of support services for their children and
of how they made contact with a voluntary sector organisation: An
Interpretative Phenomenological Analysis**

This paper comprises a summary of a literature review examining research undertaken on help-seeking for children's psychological and emotional problems amongst hard-to-reach families. Hard-to-reach families are those who face multiple stressors resulting in a greater risk of children developing mental health problems and a diminished ability to access help. This group are also the focus of an original piece of qualitative research summarised below which explored hard-to-reach families' experiences of seeking help from a voluntary sector organisation.

Literature review

Several empirical reviews of help-seeking for children with emotional and behavioural problems have been undertaken but none have focused specifically on hard-to-reach families, a group known to exhibit a greater number of risk factors for child mental health problems but who are underrepresented in mental health services.

Databases were searched to identify papers that focused on help-seeking by hard-to-reach parents published between 1987 and 2008. Twelve papers were identified and the reference lists of these were reviewed leading to a further 6 being included in the review. Papers were rated according to their degree of relevance to hard-to-reach groups.

Only six papers focused specifically on a hard-to-reach group and half of these were purely descriptive in nature. Five papers used a sample that included a significant percentage of hard-to-reach families or investigated those in need but not receiving care. Hard-to-reach families report that having different perceptions about the causes of distress to professionals (Anderson et al., 2006), fear and mistrust of professionals (Anderson et al., 2006; Keller & McDade, 2000; Richardson, 2001), practical issues

such as transport and childcare (Keller & McDade, 2000), having difficulties with discipline (Harrison, McKay & Bannon, 2004), and negative expectations about mental health care, including concerns about stigma (Richardson, 2001) can all impact negatively on help-seeking. Conversely, service or program location, the personality and trustworthiness of staff, and the relevance of the help being offered to parenting goals, facilitate engagement with services (Gross, Julion & Fogg, 2001).

Hard-to-reach factors such as poverty, multiple parental stressors and parental separation can act as barriers to receiving help directly, and because economic hardship impacts upon perceptions of need, stigma, treatment effectiveness and service accessibility (Bussing et al., 2003; Owens et al., 2002; Pavuluri, Luk & McGee, 1996). The 7 papers that had no specific focus on the hard-to-reach but used hard-to-reach factors as independent variables had little substantive to contribute to understanding help-seeking amongst this group.

Methodological issues included problematic definitions of service use and need, the use of clinical samples, lack of clarity about methods used to code qualitative data, reliance on parental self-report, failure to account for possible confounding factors and the use of unvalidated surveys. In undertaking research with the hard-to-reach, it is important to clearly define the particular cohort of hard-to-reach families of interest, both in terms of demographic characteristics, and subjective or objective need.

Costello, Pescosolido, Angold & Burns' (1998) Network Episode Model (NEM) of help-seeking is a useful way of making sense of these findings as it includes the influence of socioeconomic factors on social support systems (including family and peer-group beliefs and attitudes), illness factors, and the role of services. These findings would suggest that a holistic approach to service provision for hard-to-reach

families is important and that clinicians need to be mindful of the negative perceptions families are likely to have about services.

Research study

Little is currently known about the help-seeking process undertaken by hard-to-reach families although Wilson and Refson (2007) posit that practical challenges such as transport, childcare arrangements and money, and intrapsychic factors such as suspicion of services, fear of negative appraisals, or a belief that family difficulties are to be kept private could all have an influence. In the UK, school-based projects are increasingly being used as a way to provide holistic services to vulnerable families in a non-stigmatising way (Masia-Warner et al., 2005; Reddy & Richardson, 2006; Statham, 2004; Wolpert, 2007) and many are provided by the voluntary sector. This study focuses on one such organisation (Malachi Community Trust) to investigate hard-to-reach parents' experiences of accessing social and emotional support for their children and in particular, the circumstances and decision-making process leading-up to engagement with services.

Eight parents who had recently engaged with Malachi were interviewed individually and transcripts were analysed using Interpretative Phenomenological Analysis. This approach allows individuals to share their perspectives and experiences without imposing existing theoretical assumptions upon the data. It also takes a structured and systematic approach to analysis and acknowledges the influence of the researcher's beliefs and preconceptions, ultimately helping to protect the validity of the findings (Willig, 2007).

Three main themes emerged from the data: Power and disempowerment,

Ambivalence about support and coping, and Drawing upon internal and external resources to survive. Participants frequently felt themselves to be in a disempowered position in relationships with individuals and organisations, and this contributed to them having an ambivalent relationship with services. Parents also shared many negative experiences of engaging with services and felt a degree of shame and failure about having to ask for support. Experiences of engaging with Malachi were positive, possibly because the unconditional regard conveyed by Malachi staff helped to counter the feelings of worthlessness described by many participants.

These findings have several clinical implications. Worries about children are just one of a myriad of concerns for this group and thus services will need to take a holistic approach and foster strong communication between one another to meet families' needs. Mistrust of statutory services is harder to address but simple changes such as offering greater flexibility around appointment times and venue, and greater transparency about the rationale for treatment approaches may help parents to feel more in control.

Future research could use quantitative designs to explore the impact of locus of control, self-efficacy and stress on coping and help-seeking for this group, and longitudinal designs following parents through the help-seeking process would also be of value. Finally, innovative research designs may be necessary to capture the perspectives of families who remain hard-to-reach for even the most flexible and inclusive services.

Acknowledgements

I would like to thank all the participants who agreed to be interviewed for this study for taking the time to talk to me and share their experiences. I would also like to thank the staff of Malachi Community Trust for supporting the research and helping to organise interviews.

Thank-you to my research supervisors Dr. Michael Larkin and Dr. Heather Bennett for keeping me on track and providing excellent feedback. Special thanks to Dr. Stephanie Boyle for introducing me to Malachi and for her unwavering support.

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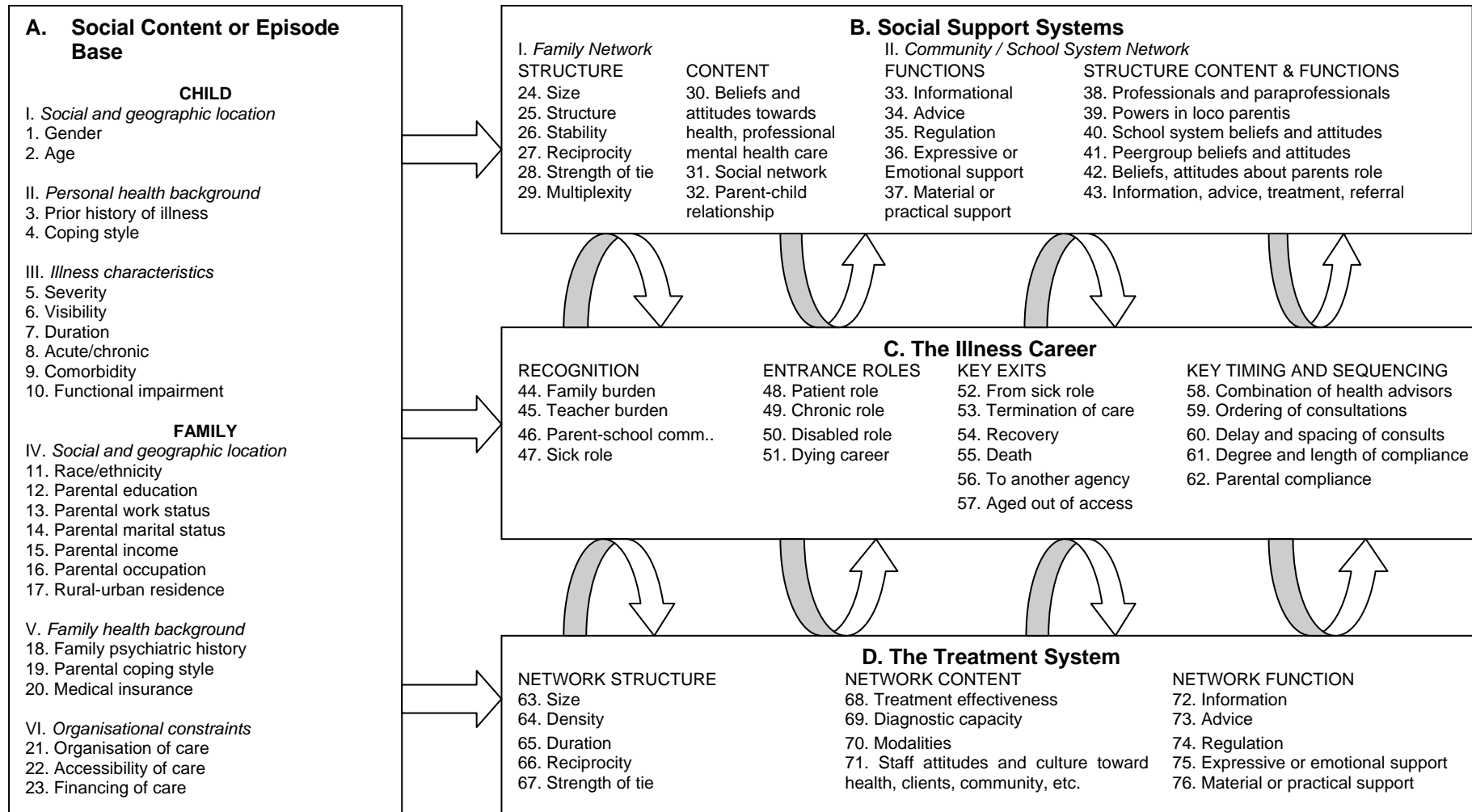
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APPENDIX I

Revised Network-Episode Model of access to care, adapted for children and adolescents (Costello Et Al., 1998).



APPENDIX II

Copy of ethical approval

App 28/07

December 17, 2007

Adele Freeman
Clinical Psychology Trainee
School of Psychology
University of Birmingham

UNIVERSITY OF
BIRMINGHAM

School of Psychology

Dear Adele,

Many thanks for your ethics application (received 16 November, 2007). Members of the School Research Ethics Committee have now had a chance to look at your proposal and have not raised any ethical concerns. I am therefore happy to grant your Chairman's action for approval. Please do bear in mind the following points as you conduct your study:

1. Ethical conduct of the study remains your responsibility. Once investigations begin unexpected issues can arise and you are encouraged to think again about the situation of your participants.
2. You are free to make modifications to your procedures, without further ethical review, so long as you remain confident that your new procedures do not raise any general ethical problems or particular violations of BPS guidelines.
3. If funding is provided by the ESRC then outside review is mandatory from January 1, 2006. A Birmingham wide REC has been created for this purpose and applications can now be accepted by the Chairperson, Suzanne Higgs. There is a dedicated website for submissions.

If you have any questions or further issues arising then do not hesitate to contact me. I wish you the best of luck with your research.

Yours sincerely,



Stuart Derbyshire
Chair: School Human Research Ethics Committee

Copies to: Dr Heather Bennett
Dr Gary Law
REC

APPENDIX III

Interview questions

Part 1: Introductory questions

1. Age?
2. How many children do you have and what ages they are?
3. Do any of them have any special needs / attend a special school?

Part 2: Interview proper

A. MCT – what it is and how is it accessed

1. How did you hear about Malachi?
2. What is your understanding of what they do?
3. What prompted you to contact Malachi / agree to a referral to Malachi?
4. Can you tell me some more about what was happening at this time?
5. How were you feeling?
6. What were you thinking?
7. What was going on for you and your family?
8. Could you describe the process of making contact with Malachi?
9. What did you think when you were told about the referral?
10. How did it feel?
11. What were your fears / what were you hoping for?

B. Services available for children and families and how they are accessed

1. What do you know about other services available to help families and children?
2. What has been your experience of getting help with this (or other problems) before?
3. Could you describe how x came to be involved with your family?
4. How did you feel at the time / what were you thinking?
5. What kinds of things did you take into account when deciding whether or not to get / accept help?
6. What kind of help were you expecting to get from x?
7. How did the help you actually got (if any) compare with this?
8. What sorts of things were / would be going on for you to make you decide to look for / accept, help / support?
9. How did / would you go about getting the support you wanted?
10. What did / does stop you?
11. What kinds of things did / do you consider before asking for / accepting help?
12. What is your understanding of getting help / support / counselling? Or What do you think about people getting help / support / counselling for them or their children? Or What sorts of people get help / support / counselling for themselves or their children?

C. Differences between MCT and other services (access and what's provided)

1. What was it about Malachi that helped you decide to contact them / ask for a referral / go back after the first meeting?
2. When deciding to seek help for your child from Malachi (or any other agencies you've had contact with), what kinds of things about the service are most important to you?
3. How does accessing support from Malachi compare with accessing support from other services?
4. Easier / more difficult / the same?

5. Is there anything else you think it would be helpful for me to know about?

APPENDIX IV

Malachi Community Trust checklist for inclusion

	Yes	No
1. Has the person worked with MCT before or had more than 3 individual sessions with a MCT worker?	<input type="checkbox"/>	<input type="checkbox"/>
2. Does the person need an interpreter?	<input type="checkbox"/>	<input type="checkbox"/>
3. Do they have a history of aggression against professionals / workers?	<input type="checkbox"/>	<input type="checkbox"/>
4. Do you consider they might be adversely affected by participating in the study?	<input type="checkbox"/>	<input type="checkbox"/>

If the answer is 'yes' to any of these questions, **do not** offer a Participant Information Sheet.

Otherwise, offer the person a Participant Information Sheet emphasising that the research is being carried out by a Birmingham University student and would involve them participating in a one-off 60 minute interview.

Ask if they would consent to being telephoned by the researcher. The purpose of this telephone call would be to answer any questions and arrange a time to conduct the interview if they are interested in participating.

If the person consents to a telephone call, please call Adele Freeman on 0788 216 xxxx with their contact details.

APPENDIX V



Participant Information Sheet

Parents' understanding of support services for their children and of how they made contact with Malachi

You are being invited to take part in a study about the support services available for children and how you came to make contact with Malachi. Please take time to read this information carefully and ask questions before you decide whether or not to take part.

I am asking you to participate because you recently met with a Malachi worker to talk about getting some support from them. My aim is to find out more about your experience of the services available to help children and their parents.

I am a student at the University of Birmingham and I am doing this research as part of a doctorate in Clinical Psychology.

What's involved?

If you decide to take part, we will arrange a time to meet, either at a local school or at the University of Birmingham – whichever is most convenient for you. During this meeting, I will ask you some questions about how you made the decision to seek help for your child, why you chose Malachi, and whether you thought about getting help from anywhere else. The meeting will take no more than 60 minutes and I will record (on an audio recorder) what we say. I may need to telephone you up to one month after the interview to clarify something you told me. You may also be invited to give me some feedback on the accuracy of my findings (either face-to-face or over the phone). You don't have to do this if you don't want to.

When all the parents who agreed to participate have been interviewed, the information collected will be put together and written-up. A summary of what we found will be sent to you.

What if I don't want to participate or I change my mind?

You do not have to take part and even if you do, you can withdraw at any time during the interview and for up to two weeks after the interview without giving a reason. If you decide not to take part, or to pull-out later on, this will not affect the support you receive from Malachi.

What are the pros and cons of participating?

We don't foresee that there are any disadvantages or risks of taking part but you may not get any direct benefit either. However, learning more about your experiences of getting support for your child/ren may help to improve access to services for other parents in the future.

If you want to talk to somebody about the way the research was carried out, contact numbers are provided below.

Will the information I provide be kept private?

The interview is recorded and then what you say is typed-up. Once this is done, the recording will be erased.

Your name will be stored separately from the typed interview and information related to the study will be kept in a locked cabinet that only the researcher and her supervisors have access to.

The final report will include some of your direct quotes, but no-one will be able to identify you as your name and any other information that could identify you will not be mentioned.

It is important for you to know that if you tell me something that suggests harm may come to you, your child or another person, I will have to tell my supervisor(s) and possibly report it to the relevant authorities to protect the safety of the individuals concerned.

Contact Details

Researcher:

Adele Freeman, School of Psychology, University of Birmingham, Edgbaston, Birmingham, B15 2TT.

Email: ADF603@bham.ac.uk



Supervisors:

Dr. Michael Larkin and Dr. Heather Bennett, School of Psychology, University of Birmingham, Edgbaston, Birmingham, B15 2TT. Telephone: 0121 414 7576

Email: larkinm@adf.bham.ac.uk; h.e.bennett@bham.ac.uk

Dr. Stephanie Boyle, Department of Clinical Psychology, 21-23 Birmingham Road, Sutton Coldfield, West Midlands, B72 1QA. Telephone: 0121 250 1560

Email: Stephanie.boyle@bch.nhs.uk

APPENDIX VI



Consent Form

Title: Parents' understanding of support services for their children and of how they made contact with a voluntary sector organisation: An Interpretive Phenomenological Analysis

Researcher: Adele Freeman

**Please initial
box**

I confirm that I have read and understand the information sheet for the above study. I have had the chance to think about it and ask questions and these have been answered satisfactorily.

I understand that it is up to me to decide whether or not I want to participate and that I can pull-out at any time during the interview and for up to two weeks after the interview without giving any reason. If I do decide to pull-out, this will not affect the support I receive from Malachi.

I understand that the interview I have with the researcher will be recorded and that this will be erased as soon as the interview is typed-up.

I also give permission for the researcher to use word-for-word quotes in the final report on the understanding that it will not be possible for other people to identify me from these.

I agree to take part in the above study.

Name _____ Signature _____ Date _____

Researcher _____ Signature _____ Date _____

Name of person _____ Signature _____ Date _____

taking consent (if different from researcher)

APPENDIX VII

Extract from table of themes

Main theme	Participants contributing to theme	Themes	Participants contributing to theme	Phenomenology	Key cross-references
Being in control vs being out of control	All	Being controlled	All	Decisions about support being made without explanation / consultation	<p>Eileen L660: I'm not sure. There's some terms that they don't do that now and I've got to pursue it.</p>
				Feeling controlled in relationships	<p>Tina L324: ...he understands that I need help, trying to help him. L338: ... 'as long as he's there to do his work that's alright by me'... L505: ...it caused an argument when I said Northfield... L507: ...he says, 'oh no, we'll get you another private', like, he'll phone a contact...</p> <p>Derek L494: And then he gets all arsy and defensive and starts / he hasn't got a-. He's not an aggressive person but he can--, you know when he's getting there, and it's best just to leave him and walk away. Coz I mean he's never got aggressive, the most he'll do is just mouth off and swear and shout and I'm just like, I ain't bothering with yah, 'coz where I'd always kind of tip toe round him, you know make sure I didn't say the wrong things, which is what I've always done.</p>
				Feeling imposed upon by services	<p>Abby L451:...and then they say, 'Oh yeah, you need</p>

	<p>a counsellor no you don't'. L479: And that was erm, sitting there, doing a test and they / the woman's going, 'Oh yeah, you're gonna need this or you don't need this'...</p> <p>Rachael L143: It's to help with general parenting skills so, to make you better parents. L152: ...what we should be doing. L192: It's the same with health visitors ...how quickly they should develop and if they don't develop such and such a skill by this time then she'd be worried that there's something wrong with them.</p> <p>Ali L442: Well I've, I've had to do anger management with them...</p>
Pressure is bad	<p>Rachael L206: if you push them too hard they won't like it and they'll just stop which seems silly.</p>
Objecting to interference	<p>Rachael L526: Just someone you can get on with and how doesn't try and tell you to do such and such or do something a certain way. L761: You could choose what you wanted to do and then they'd help you from there.</p>
Being told what to do is stressful	<p>Rachael L693: you will do this, you will do that, like Social Services. It's much more relaxing, 'well if you'd like to do this you can...'</p>
Medication as a means of control	<p>Lisa L725: Cus when we first got diagnosed, they said we can have drugs, and I went, 'no, I</p>

	<p>don't want drugs, I don't wanna drug him up.'</p> <p>L733: ...why give him drugs, he's a child.</p> <p>L793:... they wanted to give me anti-depressants and I went, 'no', cus if I can't get myself out of this depression, tables are not gonna do it cus its still gonna be there when you take me off them.</p> <p>Derek</p> <p>L89: Um I mean I've seen the difference when she's took a tablet and missed a tablet, you know...</p>
Feeling controlled by child	<p>Abby</p> <p>L50: I know they're all / they can get cheeky but he was really, really getting me upset...</p> <p>L62: ...I felt like he was ruling the roost with me...</p> <p>L78: ...trying me I always think he's doing, seeing how far he can push me all the time, I don't know why, I think he's just like, trying, trying me...</p> <p>L116:...you know what it is, he's always got an answer for everything, it doesn't matter if you tell him off, whatever, he'll always have to say something to you.</p> <p>L127: ...but I back down, he don't back down...</p>
Social services are interfering / intrusive	<p>Tina</p> <p>L435: ...asked Social Services, just for help, like with money to get them nappies, and they came and said, "look, you're not the proper mother..."</p> <p>Rachael</p> <p>L393: ...she was very sort of, mooching around everywhere...</p>

			<p>Sharon L393: ...they are quite nosey people. L400: ... from then on I had two nosey social workers come which I didn't like...</p>
		Feeling that life is on hold while Social Services are involved	<p>Sharon L412: ...um it would be nice to get on with my life again...</p>
		Power rests with Social Services	<p>Sharon L779: So when we have a meeting with her, Rebecca's going to read it out and say "This is a day with Sharon and Charlie" and make them realise how difficult it is...</p>
Being in control	Tina, Lisa, Rachael, Sharon, Derek	Malachi groups don't feel controlling	<p>Rachael L188: ...well its very relaxed in there as if um every kid's different but this is, there are the basic needs as to what they need so beyond that, um it's very relaxed.</p>
		Being able to access support from a range of sources	<p>Rachael L606: And then I moved and I got help through the organisation I moved through or with, and I got some help through the doctors when I moved up to Bradford so...</p>
		Being given choices	<p>Rachael L528: Someone who says well, 'Do this, this, this or this. This will make it easier for you so...' and leaves it to you to decide...</p> <p>Sharon L743: ...so it's down to me and then she'll come.</p> <p>Derek L863: I mean when Barry phoned to make the arrangements for the first meeting he was "I understand you work at the school, are you</p>

	comfortable coming to the school or do you want to meet somewhere else?"
Having an internal locus of control	Lisa L257: ... is there anything I can do to change that or help him?
Ownership over care / support provision	Tina L92: ...that's my CAF. So she's erm, she looked through my folders... Derek L99: I mean we have spoke about her coming back or at least going to see somebody but I mean that's for her to decide.
Being in control of endings	Tina L781: ...helping until that person in particular is confident...
Facilitation rather than instruction	Tina L727: I wanted erm help with, well support... Derek L519: ..."Because I just need somebody neutral, somebody who ain't going to sit and judge me or tell me what I should do or tell me what I should think; just someone to sit there and just let me vent off" L724: ...he says if you ever need the name of a good book, you know get in touch. Well not just him but anyone here.
Being in control of the rate of change is important	Rachael L694: ... 'well if you'd like to do this you can or if you don't want to yet, then you can come back when you're ready to and we can have a look again'.
Being dignified / in control of emotions	Tina L159: ...not going to retaliate, cus that just

			<p>makes them get a buzz off...</p> <p>L317: ...I wouldn't retaliate, I'd just say, well, you've got your own opinions of things, and carry on with my business.</p>
Feeling out of control	Tina, Abby, Sharon, Eileen, Ali, Derek	Feeling confused	<p>Abby</p> <p>L381: ...I feel / oh I don't know / I don't know what I'm doing / I don't know...</p> <p>Eileen</p> <p>L158: ...and I'm all confused because then I don't know how to sort of treat him because the teachers are saying this, do you know what I mean?</p>
		Feeling on the edge	<p>Tina</p> <p>L139: ...they are, they are hard at the moment; they are tough...</p> <p>L298: ...it's hard...</p> <p>Sharon</p> <p>L683: We get by, day to day.</p> <p>Derek</p> <p>L360: ...three or four weeks later I'll have another down moment, a bad night here, lots on, or argument with D, you know something small that sets it off, and eh I sit in me bedroom at night, I could pack my bag once everyone's asleep and go.</p>
		Feeling overwhelmed / frightened by strong emotions	<p>Tina</p> <p>L386: ...I'd be like, "oh, what do I do", you'd be there crying, oh erm, like that, I wouldn't know what to do.</p> <p>Derek</p> <p>L94: I was all ready to leave, it was getting to the point where I was going to leave or punch someone, because we had a supervisor who</p>

	couldn't man-manage... L701: my old gaffer at work who trained as a counsellor and then I think he said he lasted three months and he just couldn't cope with it. He's finding it harder and harder to switch off, listening to other people's problems, you know some of the stuff he heard he was taking home. It was stuck in his head and he couldn't get it out, so he jacked it in.
Questioning oneself	Abby L85...have I done something wrong with him, you know, have I let him have too much rein on everything... L169: ...its that, questioning myself again, did I / I didn't just leave him but questioning it? L189: So I don't, I don't know. But then you could do that about everything couldn't you. Sit here questioning everything that you've done, so that's er...
Feeling out of one's depth	Eileen L384: And I said "He won't stop on the mat", I said, "What do I do?"
Feeling trapped in circular thinking	Abby L170: ...did that have something to do with it but I couldn't have left Emily in the hospital by herself. Eileen L399: ...but then you would say well you're his mum, you're the one that sees him the most, maybe I do know him best. And so has he got ADHD or hasn't he, or is it some other illness that he's got, you know? L751: It, it was going round and round and

		round in a circle, not getting anywhere.
	Feeling that the need to talk is uncontrollable	Derek L435: ...once I got started I couldn't stop.
	Being impulsive	Sharon L241: ... makes me sit and think about the consequences...
	Wanting to retaliate / take revenge	Ali L60: 'cause they thought I was going to do something and it was only like when my oldest daughter was having to go onto camera and then I was having to sit in another room and listen to everything, it got me mad.
	Wanting security and a sense of ownership	Tina L509: ...getting a council, its yours... L519: ...I don't want to be in this situation so many years down the line.

APPENDIX VIII

Complete list of main themes and subthemes

Main themes	Subthemes
Being in control vs being out of control	Being controlled Being in control Feeling out of control
Occupying a disempowered position	Feeling worthless and inadequate Being in a disempowered position Fear of being judged Being afraid of rejection Feeling fearful and unsafe Wanting approval / validation Being uncertain and unsure Feeling trapped The impact of depression
Ambivalent relationships with services	Mismatch between needs and services Being unwilling or unable to trust services Services don't really care Services as another demand on resources Feeling ambivalent Experiencing benefits
Coping as a strength vs needing support as a weakness	Using positive coping strategies Needing support is a weakness
The experience of seeking and receiving help from Malachi	Being pushed and pulled towards support Feeling Malachi could be trusted The impact of referral Understanding of MCT and expectations of involvement Fears and apprehensions
Feeling valued and valuable	Feeling connected to others Feeling valued Feeling safe Being parented Feeling empowered
Being a survivor	Retaining hope Survival and self-preservation Being an experienced service user Being self-reliant and confident Moving on from the past
A male perspective on parenting and support*	Being ambivalent about strength and violence Career vs parenting Relationship with femininity Expectations of men
Challenges and rewards of being a parent*	Being scrutinised and judged

	Managing the demands of parenting Being aware of the responsibilities of being a parent Parenting as integral to one's identity and self-efficacy Parenting as an obstacle and barrier to self-fulfilment
Relationships as desirable yet painful*	Being separate and alone Feeling let down Having high expectations of relationships Friends can't be trusted
Living with children with behavioural problems (ADHD & autism)*	Day to day life is demanding and challenging The journey of awareness to diagnosis Personal and psychological impact on parents and families The parent-child relationship Trying to understand and make sense Trying to manage, fix and solve Not being understood or supported by services and wider community Fears and worries for children Experiences of seeking and receiving support Psychological impact of physical health problems** Experiences of drug / alcohol dependency** The psychological process of disclosure**

* Major themes not included in the paper in their entirety. However, as far as possible, experiences encapsulated within these themes have been included in the paper on the basis of their links to the 3 main superordinate themes.

** These subthemes were unique to single participants with limited relevance to help-seeking per se and were thus excluded from the write-up.