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Support for family carers of children and young people with developmental disabilities and challenging behaviour: What stops it being helpful?

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Support for family carers of children and young people with developmental disabilities and challenging behaviour: What stops it being helpful?

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Abstract

Background
Many family carers find the support they receive in respect of their child’s challenging behaviour unhelpful. This study sought to identify carer perceptions of the ways in which support is unhelpful and how it could be more helpful.

Methods
Thirteen mothers, caring for a child with intellectual disability and challenging behaviour, were interviewed. Parental perceptions and concerns regarding support received were investigated. Transcribed interviews were analysed using interpretive phenomenological analysis.

Results
Parents reported problems with generic disability services including accessing good services, obtaining relevant information, working relationships with professionals, and issues with respite provision. Concerns were also expressed about challenging behaviour specific provision including ineffective strategies being suggested, an apparent lack of expertise, insufficient input and their child’s exclusion from services.

Conclusions
More preventative approaches, more widespread adoption of effective behaviour management and improved partnership between professionals and families appear needed. Increasing family support may be ineffective if not accompanied by greater insight into the factors related to effectiveness and recognition of the role of informal support.
Introduction

In an average area of 250,000 people there will be approximately 25 children with a developmental disability (mostly living with their families) exhibiting at least one form of serious challenging behaviour (Mental Health Foundation, 1997). Challenging behaviour is associated with a range of family difficulties, including high stress levels (e.g. Hastings, 2002) and quality of life restrictions (e.g. Emerson, 2001). Such difficulties, combined with inadequate family support, contribute to children being placed in residential schools (McGill, Tennyson & Cooper, 2006) and young adults in out-of-home placements (McIntyre, Blacher & Baker, 2002).

Inadequate family support has been reported commonly by the families of people with intellectual disabilities. Obtaining helpful information can be ‘difficult’ and ‘haphazard’, (Redmond & Richardson, 2003) and parents often have to fight for support or cope with long delays before its provision (Beresford, 1995). For the families of children who display challenging behaviour, effective, proactive behaviour support provision is particularly important, given the high percentage of families resorting to reactive, physical interventions without having received appropriate training (Allen, Hawkins & Cooper, 2006). Best practice guidelines indicate that such reactive strategies should only be used within a constructional context (Emerson, 2001) such as that associated with Positive Behaviour Support where professionals work in partnership with families to formulate individualized interventions, based on functional assessment of behaviour, to improve the quality of life of both the child and the family (Lucyshyn, Dunlap & Albin, 2002).
A partnership approach is likely to result in greater behavioural change, as well as be viewed as valued and empowering by families (Luchshyn et al., 2002).

Communication and joint working between various services and families appear vital, and consideration should be given to family life. Qureshi (1993) reported that parents viewed professionals as helpful if they demonstrated respect for the parent and their knowledge regarding their child. Unfortunately, 73% of parents in past research have reported the need to fight for partnership, and lack of professional sensitivity to the family situation was identified as a key factor inhibiting partnership in 38% (Knox, Parmenter, Atkinson & Yazbeck, 2000). Similarly, general family support research has identified the provision of sufficient information, listening to parents and working in equal partnership as key professional attributes (e.g. Prezant & Marshak, 2006).

While much, then, is known about the characteristics of effective family support, the reality for the families of children who display challenging behaviour appears rather different. Kiernan and Alborz (1996) reported that most families received no professional behaviour management support over a five-year period, despite persistence of the young person’s behaviour. Turnbull and Ruef (1996) emphasised the isolation experienced by families, with often only periodic input received. More recently, McGill, Papachristoforou & Cooper (2006) found that almost a third of families in their sample reported receiving no psychological support and over 40% no help with their child’s communication.

Even when support is received, it may not be perceived as helpful. Qureshi (1993) found that 61% of families that had received support reported it as not useful. McGill et al (2006b) found that many families that had received support found it unhelpful or
were dissatisfied. For example, 71% of families had received psychological support but only 38% of these found it helpful and, overall, 66% of the sample was dissatisfied with the psychological advice received regarding challenging behaviour.

Why is support found so frequently unhelpful? Qureshi (1993) noted the difficulties families experienced implementing interventions within daily life and feeling that professionals failed to understand their situation. Other factors identified include parent-professional conflict regarding the child’s control over behaviour (Qureshi, 1993), families wanting professionals to identify environmental factors that predict behaviour rather than blaming the child or family (Turnbull & Ruef, 1996), and the perception that professionals lack understanding of the reasons for challenging behaviour, as well as expertise regarding behaviour management and autism (McGill et al, 2006b).

Given the problems of behaviour support services, it might be hoped that at least services could provide families with respite/short breaks, to reduce stress levels and renew energy. Unfortunately, many families do not receive short breaks as often as they would like (McGill et al, 2006a), or in a form perceived as suitable or consistently reliable (Qureshi, 1993). Additionally, it may be questionable whether these services are truly providing ‘respite’ as some parents have reported being asked to ‘stay on the end of the phone’ or collect their child early due to difficulties in behaviour management (Qureshi, 1993). McGill et al (2006a, b) found that between a quarter and a third of families reported that their child was excluded from respite, with challenging behaviour often being a key factor in this.
Research on the support received by families caring for a child who exhibits challenging behaviour has been limited. The present qualitative study aims to provide a more detailed account of the issues within this area, increasing understanding of the barriers to more effective support provision. Without understanding these factors, simple advocacy for increasing the amount of family support services will be of limited value. This study, therefore, asks two related questions:

- What problems do parents identify in the support they have received?
- How could that support have been more helpful?

Method

Participants and recruitment

Ethical approval was obtained from the Departmental Research Ethics Committee. The interviewer was regularly supervised by the second author (a chartered clinical psychologist), giving the opportunity for any emerging ethical issues to be discussed. Parents were recruited via magazine advertisements, a school’s email list, and a carers’ association. Participants were included who had specifically experienced problems with the professional support received regarding their child’s behaviour. This was a self-selected, purposive sample.

Demographic details and information on the child’s challenging behaviour were gathered via short questionnaires, adapted from McGill et al (2006a). Severity of various behaviours was rated on a 6-point rating scale by parents (0 = not present, 5 = serious problem).
Thirteen mothers of fourteen children aged between 7 and 17 (average age was 9.9) were recruited (including the two pilots). All participants had White British origin except for one with Anglo/North African background. All spoke English as their first language. Mothers’ average age was 38.7 years (range: 33-44). Most mothers lived with a partner (10/13), and many also had one or more other children in addition to the child who exhibited challenging behaviour (8/13).

Child characteristics

Ten were male. Diagnoses included autistic spectrum disorder (9/14), Rett Syndrome (2/14), Angelman Syndrome (1/14), autistic spectrum disorder/ Rett Syndrome (1/14), and no diagnosis (1/14). Ten were reported as having at least one additional impairment, with three having a visual impairment, six a physical impairment, and eight a persistent medical problem.

Children were described as exhibiting an average of 10.6 different challenging behaviours (range: 6-12). Of behaviours viewed as a serious problem, aggression and social disruption were commonest, each occurring in half the children.

Services received

Most children lived in the parental home (10/13). The remaining children had lived at home in the past but now attended residential school. Almost all children attended schools for children with severe learning difficulties, with two receiving a mainstream education. Most mothers were currently in receipt of respite or had received this prior to their child beginning residential education (10/13). Respite took the form of overnight stays, or more frequent (weekly, fortnightly) breaks for a few hours.
Most families (11/13) had received specialist challenging behaviour input for their child, from a mixture of psychologists, nurse specialists, challenging behaviour “teams” and child/adolescent mental health services.

Despite it not specifically being explored during interviews, all participants reported gathering information informally, by speaking to other parents and/or carrying out their own research (books, the internet, enrolling on courses). Many parents were members of a local parent support charity. One parent, not part of this, specifically commented on her isolation and her desire to be in touch with similar parents.

Interview Schedule

A semi-structured schedule was devised following a review of themes in relevant past research. This included the following areas:

- Types of professionals seen
- Type of support/advice offered, (e.g. medication, psychological, etc).
- Perceived benefits and issues in relation to this support, (e.g. ease of implementation, effectiveness, parental control, consistency across settings).
- Partnership with professionals – information and communication, (e.g. agreement with professional views, equal partnership, ease of contact, information sharing, communication)
- Respite availability and effectiveness
- Consistency and coordination of professional views
Two pilot interviews confirmed the general appropriateness of the schedule. However, two alterations were made. To increase the interview’s focus on challenging behaviour support issues (vs. more general support), subsequent interviews initially requested parents to give details of the challenging behaviours shown by their child and when support was first received in relation to these. Additionally, a final question was included regarding how past support/future services could be improved. As no substantial changes were made to the interview schedule, pilot interviews were included within the main analysis.

The Interview

Interviews were conducted by the first author (a psychology graduate) as part of a postgraduate research project. Most participants were telephoned in advance to make arrangements for the interview and further discuss the nature of the research. Interviews took place within participants’ own homes. Interview length varied between 31 and 68 minutes (mean: 46). Interviews were tape-recorded and transcribed.

Analysis

Transcripts were analysed using Interpretative Phenomenological Analysis (IPA) (Smith, Jarman & Osborn, 1999). The analysis was conducted as follows:

- The first transcript was read. Upon reading a second time, notes were made in the left-hand margin to summarise the data, highlight points of interest, and make preliminary interpretations.
- The transcript was read a third time, emerging themes using key words being noted in the right-hand margin.
- Themes from the right-hand margin were copied to a separate page, and clustered together into related themes.
- A page of main themes and sub-themes was formed for each of the interviews.
- An additional step was added to the suggested method in order to more effectively summarise each of the sub-themes, and where appropriate merge very similar themes together. Extracts from the transcript, as well as where the section could be found, were added alongside each of the themes.
- A master table was produced. This included main and sub themes across participants so that comparisons could be made across interviews and a broader picture illustrated. At this stage some theme categories were merged into broader themes.
- Additionally, at this stage, sub themes were deleted where they were supported by limited evidence or did not fit well with the broader thematic structure.
- To facilitate clearer presentation, a diagrammatic version of the master table was created.

Validity

The following safeguards were adopted to maximise the validity of conclusions reached:
- A reflective diary allowed the researcher to make general comments about the interview experience, noting examples where she may have influenced the interviewee’s account. This ensured that attention was persistently paid to this area, and that continued attempts were made to improve interviewing method.
- Pilot interview transcripts were shown to the second author and feedback acknowledged before proceeding with the main interview sample. In general, feedback was consistent with that noted in the reflective diary.

- One interview transcript was independently analysed, and the extent of agreement with the primary researcher evaluated. There was agreement across all of the main themes and 69% of the sub-themes. In two cases, sub-themes relating to positive support experience were identified by the main researcher but not in the reliability check, possibly due to the research focus on support issues and reservations. Excluding these, percentage agreement was 76%. The other discrepancies related to sub-themes being identified by one reader only (in 6 cases), or by both but categorised differently (in one case).

- A copy of the results section was sent to participants, allowing them the opportunity to comment on the extent that apparent themes reflected their experience.

Results

The key themes that emerged from analysis are described below and illustrated in Figure 1.

Figure 1 about here

General service provision

Despite the interview schedule’s focus on challenging behaviour support, parents commented frequently about issues of general service provision. Many parental experiences concerning their child’s behaviour occurred within the context of contact
with schools, GPs or social workers. Often, parents did not experience a clear divide between challenging behaviour support and more general support issues.

All participants reported difficulty accessing good services. This included issues such as delays in provision, a crisis management approach within support allocation, having to fight for or chase services, difficulty contacting services, poor coordination, high staff turnover, and lack of speech and language therapy.

‘I get very, very annoyed that things have to get to the point that you’re ready to kill your child...until you get to that point you don’t get any help really’

(P7)

Poor information provision was highlighted by almost all participants (12/13), leading to parents having to find out information for themselves, and many placing greater reliance on informal sources, (e.g. other parents, the internet). A small number felt that services were selective in the information which they shared:

‘comes down to money again...that’s part of why they don’t tell you about these services’ (P2)

Most (11/13) reported issues related to respite provision. The most prevalent theme was receipt of insufficient respite. Nearly half experienced restricted availability, with smaller numbers viewing provision as unsuitable or unreliable.
‘When you get a doctor’s note saying “please give her more hours”…feel they’re waiting for you to crash’ (P10)

Almost all faced partnership and communication problems when working with professionals. Approximately half expressed concern over the lack of communication and joint working that occurred between school and home. A small number felt excluded from reports and meetings. Many felt they were not always listened to or consulted, their account of challenging behaviour not believed or taken seriously and that professionals lacked sympathy towards their situation. A small number of parents felt blamed for their child’s behaviour.

‘you give up after a while, when someone’s not actually listening’ (P8)

‘It’s only when other people are seeing the same behaviour as you are…that the ball starts rolling’ (P7)

**Challenging behaviour specific themes**

**Ineffective strategies**

Almost all (12/13) found professionally suggested strategies for managing behaviour to be ineffective. Many felt that professionals were unable to provide interventions to reduce their child’s challenging behaviour, and this included both direct behaviour support, and to a lesser extent that provided to the child at school:
‘They were sort of saying, “well yeah you’re doing the right, just keep doing what you’re doing”…they sort of didn’t really come up with any’ (P3)

‘He was the youngest child in his county to go to boarding school because of his behaviour…quite a few years on the school hasn’t managed to tackle the behaviour’ (P5)

Approximately half disagreed with suggested strategies, which they perceived as unlikely to be effective or felt to be inappropriate:

‘They felt that they were trying to give us ideas that would help the situation…But I just felt it would just inflame the situation’ (P3)

A similar number experienced difficulty implementing strategies, either because practical assistance was required as mothers were alone, or because obstacles within family life had not been considered, (e.g. type of family, siblings).

‘I’ve got two children and I’ve got this to do, and there’s still the washing and the ironing and shopping to do, and it’s said without taking into account how people really…live their lives’ (P9)

‘You come and live my life for a day and see how you would put that intervention in, if it’s actually applicable and appropriate’ (P12)
Although approximately half reported being offered pharmacological interventions, these were not viewed positively, medication being seen as ineffective, disliked or causing undesirable side-effects:

‘I wanted him to learn how to behave or learn ways of asking through…other interventions where he learns it rather than being drugged up…didn’t find it greatly changed anything’ (P10)

Lack of expertise

Mothers frequently (11/13) expressed a negative view of professionals. They perceived professionals as lacking knowledge, understanding or expertise in either the complexities of autism, or about challenging behaviour:

‘It’s a lack of understanding. It’s having mental tick boxes in their heads of autistic traits that don’t actually have any bearing, or fit in at all with what your son’s like’ (P7)

‘I think the people that I meet have, you know, done a half-day course and read half a book, and I think I know much more, which is really frightening’ (P13)

These concerns related to many generic support professionals, including occupational therapists, social workers, paediatricians and general practitioners. However a few mothers also reported issues concerning more specialist services, providing direct behaviour support to families:
‘I phoned up the office and I said “I don’t think I need her anymore”. Which was a lie but it was easier to say that than to say “I’m sorry I think she’s totally incompetent and hasn’t got a clue’ (P8)

A similar number reported a lack of expertise within the school setting:

‘I was told “we are the experts, but we’re never seen one as bad as this”. So in a way he’s a learning curve for others coming up behind him’ (P5)

**Insufficient specialist services**

Most (11/13) had received some form of behaviour management support from professionals, other than the prescription of medication. Despite this, many participants (9/13) felt there were insufficient specialist services available.

Approximately half perceived direct behaviour support as limited and rationed:

‘I’m studying psychology now…I thought I’m not getting help from anywhere else so I’ll have to do it myself’ (P1)

‘We’re not actively involved with them at the moment…there aren’t any, what they would call priority issues, and there’s so many families being referred to them…unless I’m basically in danger of being hurt they won’t be deemed important’ (P4)
This theme was further highlighted by a few parents who indicated a desire to receive more training, with some expressing an interest in restraint training:

‘for parents to get the kind of training that a classroom assistant gets for a start, SCIP training or whatever. We seem to not be trusted with this sort of information…yet we’re having to live with it’ (P6)

Although no clear preference was highlighted as to the training format that would have been most beneficial, one parent specifically reported her satisfaction with regular, in-home support to put strategies in place. Additionally, some parents felt that a group training course with other parents would be beneficial.

As well as the need for direct behaviour support, a small number highlighted their need for more general emotional support:

‘There’s nothing from school…or any other professionals…There’s no “oh how are you doing?”’ (P1)

The value of regular, reliable, continuous support was expressed by approximately half:

‘They don’t sort of leave you, and I think that’s critical, is the follow up…just being there…not so you can whinge but to say, you know, “he’s doing this, what can I do”? ’ (P7)
Exclusion

Exclusion was reported by approximately half (6/13). This referred both to exclusion from school, and to a lesser degree from respite services:

‘The SLD School were phoning saying “can you come and pick him up? We can’t cope.” I just think yeah it’s me on my own here, you’ve got a whole team of people’ (P5)

‘Once we were at the cinema and we were rung just before the film ended and we had to…go and pick him up’ (respite; P10)

Discussion

Before the implications of the results are discussed, the study’s limitations should be acknowledged. Firstly, given the nature of the sample, findings should be generalised with care. Participants may not be representative of other families who have experienced difficulty regarding the support received with their child’s challenging behaviour. Participants, for example, may be more assertive about their needs, and, therefore, both more critical and in a better position than other less assertive parents. Given some participants belonged to a parent support charity focused on challenging behaviour, their children may have exhibited more severe challenging behaviour. It is possible that parental views on support effectiveness and availability may vary with both the child’s age and the level of challenging behaviour displayed. It may have been useful to have had a more standardized measure of the challenging behaviour displayed. Secondly, the situation for white British citizens (12/13 of the present study’s participants) may not be representative of that of those from minority ethnic
backgrounds, especially those who do not have English as their first language.

Thirdly, as a phenomenological study, the intent was to gain parents’ personal perceptions of support, not objective evidence of the actual level or kind of support offered. Future research, investigating the perspective of professionals working with these families would be of value. Finally, this study deliberately sought to look at difficulties families experienced in their attainment of behaviour support, and, as such, did not specifically investigate experiences of helpful support. Future studies might usefully address this question.

Participants identified three main issues. First, they reported many problems with generic service provision, both services such as schools and GPs and “generic” children’s or disability services. Second, they struggled to obtain adequate access to more specialist provision (i.e. help focused on their child’s challenging behaviour). Third, when such provision was accessed it was not very specialist, often leaving them no better off. We consider these issues below.

Given participants’ emphasis on experiences related to generic disability support services, such as schools, respite and social services, it is apparent that these families test mainstream services. The limited nature of generic support services has previously been acknowledged (Beresford, 1995) and it is likely that if these services are already struggling to cope with demand, this situation may be further accentuated by the additional needs of children with challenging behaviour. More competent generic services would allow lower levels of challenging behaviour to be effectively dealt with and escalation of behaviour minimised. This would prevent more specialist
services being overwhelmed by demand, allowing them to focus on more extreme cases of challenging behaviour (cf. Department of Health, 2007).

Parents continue to struggle to access both generic and more specialist services, with delays, difficulties contacting services, a crisis management approach, poor coordination, and support discontinuity due to high staff turnover being apparent. Insufficient respite, as well as access to and coordination of community services, appear to be ongoing issues. Families report a lack of the regular, reliable and continuous support they value.

Many mothers described “fighting” for the restricted services available. Possible inequalities in service access have been noted by McGill et al (2006b), who suggested that articulate, middle class families may attain better support. The risks involved in not working more preventatively with families are high, given that decisions are often made to place children in residential provision in response to a crisis (Mental Health Foundation, 1997, p35), and, currently, many children and young adults end up in residential placements, often far from the family home (e.g., McGill et al, 2006a). Within the families in the present research, four children were either already attending, or about to begin residential education due to behaviour concerns. Not intervening early makes it more likely that families reach a stage of crisis, and then require more complex and expensive interventions (HM Treasury/Department for Education and Skills, 2007).

One consequence of the struggle for access to all types of information and support is a heavy reliance on informal sources such as friends and family (cf., McGill et al,
This was apparent in the present research. McConachie (1994) suggested that professionals should support and work with such informal support networks and, given the limited nature of services, the facilitation of these may alleviate some of the difficulties resulting from service shortfalls. Such an approach might also be argued more fundamentally. Perhaps some of the challenges faced by families are such that publicly organised services, however high quality, cannot hope to meet them fully. A “self-help” focus on family training, advocacy and family-to-family support might achieve more.

Previous research (McGill et al, 2006b; Qureshi, 1993) has suggested that specialist challenging behaviour support is often viewed as unhelpful. Participants in the current study identified a number of issues mediating perceived unhelpfulness. Most mothers felt that some professionals lacked expertise, within the areas of challenging behaviour and/or autism (cf, McGill et al, 2006a, 2006b). Many professionals were unable to suggest effective strategies to alleviate challenging behaviour or had little to add to what parents were already doing. Additionally, many parents disagreed with suggested interventions, viewing them as inappropriate or impossible to put into practice. Concern has been expressed regarding the extent that professionally suggested interventions are evidence-based (McGill et al, 2006b) or are contextually appropriate (Lucyshyn et al, 2002). Given the apparent issues around professional expertise, it is perhaps unsurprising that some educational and respite services were unable to cope with challenging behaviour and, consequently, excluded the child. This results in increased demands on families.
A need for behaviour management training was expressed by some, including physical restraint. In the absence of effective behaviour support, families may be forced to use these reactive strategies. Frustration was expressed that school staff received more adequate training, despite parents spending the most time with their child. It seems difficult to justify this failure to train parents, given the injury that may result from the use of inappropriate, unplanned physical interventions (Allen et al., 2006).

It seems vital that professionals adopt a family-centred focus, and work in partnership with parents, if interventions are to be accepted by families, effective, and consistently applied across different settings (Lucyshyn et al., 2002). Past research has demonstrated the value of professionals taking on board parental knowledge (e.g., Prezant & Marshak, 2006). However, many mothers in the present study reported that their views were not always considered. Effective joint working might also increase the likelihood that suggested interventions suit the needs of the family and take due account of family routines (Qureshi, 1993; Turnbull and Ruef, 1996). Other issues within working relationships were also reported, with professionals failing to understand parents’ situation, not taking their account of challenging behaviour seriously, and seeming to blame parents for their child’s behaviour (cf. Qureshi, 1993; Turnbull and Ruef, 1996).

Some of the barriers to better support might be addressed by adoption of an approach such as ‘Team Around the Child’ (Limbrick, 2005). In this, a small number of key professionals work in an individualised and coordinated manner, providing regular therapeutic contact, centred on the needs and aspirations of the child and family.
There is a strong emphasis on partnership working, both between professionals and families and amongst different professionals, to ensure coherence, collaboration and respect. A key worker takes the lead in ensuring that interventions effectively fit together, as well as ensuring that families have access to appropriate services and sufficient information. Even if such a system was possible, however, the importance of also facilitating self- and mutual help, of supporting families as “expert carers” (Allen, 2000), should not be forgotten.

Acknowledgments

We are grateful to the family carers who participated in this study.

References


Figure 1 Key themes from interviews
- **Exclusion**
  - From school
  - From respite

- **Lack of expertise**
  - Lack of knowledge, understanding, expertise of autism or challenging behaviour (generic and specialist support)
  - Lack of knowledge or expertise (school)

- **Insufficient specialist services**
  - Limited and rationed behaviour support
  - More parent training needed (physical restraint)
  - More emotional support needed
  - Regular, reliable, continuous support valued

- **Mothers’ perceptions of problems with behaviour support**

- **Ineffective strategies**
  - Professionals unable to provide effective interventions
  - Parental disagreement with suggestions
  - Difficulties implementing strategies due to obstacles within family life or need for practical assistance.
  - Medication disliked

- **General service provision**
  - **Difficulties accessing good services**: delays, crisis management approach, having to fight for or chase services, difficulty contacting, poor coordination, high staff turnover, lack of speech and language therapy.
  - **Poor information provision**: Parents having to find out for themselves, greater reliance on informal sources.
  - **Problems with respite/short break provision**: Insufficient amount, restricted availability, provision unsuitable or unreliable.
  - **Partnership and communication problems**: Lack of communication and joint working, excluded from reports and meetings, not listened to or consulted, not believed or taken seriously, professional lacked sympathy, parent felt blamed for the behaviour,