



Kent Academic Repository

Wodehouse, G. and McGill, Peter (2009) *Support for family carers of children and young people with developmental disabilities and challenging behaviour: What stops it being helpful?* *Journal of Intellectual Disability Research*, 53 (7). pp. 644-653. ISSN 0964-2633.

Downloaded from

<https://kar.kent.ac.uk/20883/> The University of Kent's Academic Repository KAR

The version of record is available from

<https://doi.org/10.1111/j.1365-2788.2009.01163.x>

This document version

Author's Accepted Manuscript

DOI for this version

Licence for this version

CC BY-NC (Attribution-NonCommercial)

Additional information

Versions of research works

Versions of Record

If this version is the version of record, it is the same as the published version available on the publisher's web site. Cite as the published version.

Author Accepted Manuscripts

If this document is identified as the Author Accepted Manuscript it is the version after peer review but before type setting, copy editing or publisher branding. Cite as Surname, Initial. (Year) 'Title of article'. To be published in *Title of Journal*, Volume and issue numbers [peer-reviewed accepted version]. Available at: DOI or URL (Accessed: date).

Enquiries

If you have questions about this document contact ResearchSupport@kent.ac.uk. Please include the URL of the record in KAR. If you believe that your, or a third party's rights have been compromised through this document please see our [Take Down policy](https://www.kent.ac.uk/guides/kar-the-kent-academic-repository#policies) (available from <https://www.kent.ac.uk/guides/kar-the-kent-academic-repository#policies>).



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

Journal:	<i>Journal of Intellectual Disability Research</i>
Manuscript ID:	JIDR-05-2008-0071-MH.R2
Manuscript Type:	Mental Health
Keywords:	Intellectual Disability, Family carers, Challenging behaviour, Support



Review

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Running head: *Support for family carers*

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

Gemma Wodehouse and Peter McGill*

Tizard Centre, University of Kent, UK

*Requests for reprints should be addressed to Peter McGill, Tizard Centre, University of Kent, Canterbury, Kent CT2 7LZ, UK (e-mail: P.McGill@kent.ac.uk).

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).

1
2
3 A partnership approach is likely to result in greater behavioural change, as well as be
4
5 viewed as valued and empowering by families (Luchshyn et al, 2002).
6
7

8 Communication and joint working between various services and families appear vital,
9
10 and consideration should be given to family life. Qureshi (1993) reported that parents
11
12 viewed professionals as helpful if they demonstrated respect for the parent and their
13
14 knowledge regarding their child. Unfortunately, 73% of parents in past research have
15
16 reported the need to fight for partnership, and lack of professional sensitivity to the
17
18 family situation was identified as a key factor inhibiting partnership in 38% (Knox,
19
20 Parmenter, Atkinson & Yazbeck, 2000). Similarly, general family support research
21
22 has identified the provision of sufficient information, listening to parents and working
23
24 in equal partnership as key professional attributes (e.g. Prezant & Marshak, 2006).
25
26
27
28
29
30
31

32 While much, then, is known about the characteristics of effective family support, the
33
34 reality for the families of children who display challenging behaviour appears rather
35
36 different. Kiernan and Alborz (1996) reported that most families received no
37
38 professional behaviour management support over a five-year period, despite
39
40 persistence of the young person's behaviour. Turnbull and Ruef (1996) emphasised
41
42 the isolation experienced by families, with often only periodic input received. More
43
44 recently, McGill, Papachristoforou & Cooper (2006) found that almost a third of
45
46 families in their sample reported receiving no psychological support and over 40% no
47
48 help with their child's communication.
49
50
51
52
53
54

55 Even when support is received, it may not be perceived as helpful. Qureshi (1993)
56
57 found that 61% of families that had received support reported it as not useful. McGill
58
59 et al (2006b) found that many families that had received support found it unhelpful or
60

1
2
3 were dissatisfied. For example, 71% of families had received psychological support
4
5 but only 38% of these found it helpful and, overall, 66% of the sample was
6
7
8 dissatisfied with the psychological advice received regarding challenging behaviour.
9

10
11
12 Why is support found so frequently unhelpful? Qureshi (1993) noted the difficulties
13
14 families experienced implementing interventions within daily life and feeling that
15
16 professionals failed to understand their situation. Other factors identified include
17
18 parent-professional conflict regarding the child's control over behaviour (Qureshi,
19
20 1993), families wanting professionals to identify environmental factors that predict
21
22 behaviour rather than blaming the child or family (Turnbull & Ruef, 1996), and the
23
24 perception that professionals lack understanding of the reasons for challenging
25
26 behaviour, as well as expertise regarding behaviour management and autism (McGill
27
28 et al, 2006b).
29
30
31
32
33

34
35
36 Given the problems of behaviour support services, it might be hoped that at least
37
38 services could provide families with respite/short breaks, to reduce stress levels and
39
40 renew energy. Unfortunately, many families do not receive short breaks as often as
41
42 they would like (McGill et al, 2006a), or in a form perceived as suitable or
43
44 consistently reliable (Qureshi, 1993). Additionally, it may be questionable whether
45
46 these services are truly providing 'respite' as some parents have reported being asked
47
48 to 'stay on the end of the phone' or collect their child early due to difficulties in
49
50 behaviour management (Qureshi, 1993). McGill et al (2006a, b) found that between a
51
52 quarter and a third of families reported that their child was excluded from respite,
53
54
55
56
57
58 with challenging behaviour often being a key factor in this.
59
60

1
2
3 Research on the support received by families caring for a child who exhibits
4
5 challenging behaviour has been limited. The present qualitative study aims to provide
6
7 a more detailed account of the issues within this area, increasing understanding of the
8
9 barriers to more effective support provision. Without understanding these factors,
10
11 simple advocacy for increasing the amount of family support services will be of
12
13 limited value. This study, therefore, asks two related questions:
14
15

- 16
17 • What problems do parents identify in the support they have received?
- 18
19 • How could that support have been more helpful?
- 20
21
- 22
23
- 24

25 **Method**

26 Participants and recruitment

27
28 Ethical approval was obtained from the Departmental Research Ethics Committee.
29
30 The interviewer was regularly supervised by the second author (a chartered clinical
31
32 psychologist), giving the opportunity for any emerging ethical issues to be discussed.
33
34 Parents were recruited via magazine advertisements, a school's email list, and a
35
36 carers' association. Participants were included who had specifically experienced
37
38 problems with the professional support received regarding their child's behaviour.
39
40 This was a self-selected, purposive sample.
41
42
43
44
45
46
47

48
49 Demographic details and information on the child's challenging behaviour were
50
51 gathered via short questionnaires, adapted from McGill et al (2006a). Severity of
52
53 various behaviours was rated on a 6-point rating scale by parents (0 = not present, 5 =
54
55 serious problem).
56
57
58
59
60

1
2
3 Thirteen mothers of fourteen children aged between 7 and 17 (average age was 9.9)
4 were recruited (including the two pilots). All participants had White British origin
5
6
7
8 except for one with Anglo/North African background. All spoke English as their first
9
10
11 language. Mothers' average age was 38.7 years (range: 33-44). Most mothers lived
12
13 with a partner (10/13), and many also had one or more other children in addition to
14
15 the child who exhibited challenging behaviour (8/13).
16
17

18 19 20 Child characteristics

21
22 Ten were male. Diagnoses included autistic spectrum disorder (9/14), Rett Syndrome
23
24 (2/14), Angelman Syndrome (1/14), autistic spectrum disorder/ Rett Syndrome (1/14),
25
26 and no diagnosis (1/14). Ten were reported as having at least one additional
27
28 impairment, with three having a visual impairment, six a physical impairment, and
29
30 eight a persistent medical problem.
31
32
33

34
35
36 Children were described as exhibiting an average of 10.6 different challenging
37
38 behaviours (range: 6-12). Of behaviours viewed as a serious problem, aggression and
39
40 social disruption were commonest, each occurring in half the children.
41
42
43

44 45 Services received

46
47 Most children lived in the parental home (10/13). The remaining children had lived at
48
49 home in the past but now attended residential school. Almost all children attended
50
51 schools for children with severe learning difficulties, with two receiving a mainstream
52
53 education. Most mothers were currently in receipt of respite or had received this prior
54
55 to their child beginning residential education (10/13). Respite took the form of
56
57 overnight stays, or more frequent (weekly, fortnightly) breaks for a few hours.
58
59
60

1
2
3
4
5
6 Most families (11/13) had received specialist challenging behaviour input for their
7
8 child, from a mixture of psychologists, nurse specialists, challenging behaviour
9
10 “teams” and child/adolescent mental health services.
11

12
13
14
15 Despite it not specifically being explored during interviews, all participants reported
16
17 gathering information informally, by speaking to other parents and/or carrying out
18
19 their own research (books, the internet, enrolling on courses). Many parents were
20
21 members of a local parent support charity. One parent, not part of this, specifically
22
23 commented on her isolation and her desire to be in touch with similar parents.
24
25
26
27
28

29 Interview Schedule

30
31 A semi-structured schedule was devised following a review of themes in relevant past
32
33 research. This included the following areas:
34

- 35 - Types of professionals seen
- 36
- 37 - Type of support/advice offered, (e.g. medication, psychological, etc).
- 38
- 39 - Perceived benefits and issues in relation to this support, (e.g. ease of
40
41 implementation, effectiveness, parental control, consistency across settings).
42
43
- 44 - Partnership with professionals – information and communication, (e.g.
45
46 agreement with professional views, equal partnership, ease of contact,
47
48 information sharing, communication)
49
- 50 - Respite availability and effectiveness
- 51
- 52 - Consistency and coordination of professional views
53
54
55
56
57
58
59
60

1
2
3 Two pilot interviews confirmed the general appropriateness of the schedule.
4
5 However, two alterations were made. To increase the interview's focus on
6
7 challenging behaviour support issues (vs. more general support), subsequent
8
9 interviews initially requested parents to give details of the challenging behaviours
10
11 shown by their child and when support was first received in relation to these.
12
13 Additionally, a final question was included regarding how past support/future services
14
15 could be improved. As no substantial changes were made to the interview schedule,
16
17 pilot interviews were included within the main analysis.
18
19
20
21
22
23
24

25 The Interview

26
27 Interviews were conducted by the first author (a psychology graduate) as part of a
28
29 postgraduate research project. Most participants were telephoned in advance to make
30
31 arrangements for the interview and further discuss the nature of the research.
32
33 Interviews took place within participants' own homes. Interview length varied
34
35 between 31 and 68 minutes (mean: 46). Interviews were tape-recorded and
36
37 transcribed.
38
39
40
41
42

43 Analysis

44
45 Transcripts were analysed using Interpretative Phenomenological Analysis (IPA)
46
47 (Smith, Jarman & Osborn, 1999). The analysis was conducted as follows:
48
49

- 50 - The first transcript was read. Upon reading a second time, notes were made in
51
52 the left-hand margin to summarise the data, highlight points of interest, and
53
54 make preliminary interpretations.
55
56
- 57 - The transcript was read a third time, emerging themes using key words being
58
59 noted in the right-hand margin.
60

- 1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
- 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

41
42
43
44
45
46
47

The following safeguards were adopted to maximise the validity of conclusions reached:

- 48
49
50
51
52
53
54
55
56
57
58
59
60
- 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.

- 1
2
3
4 - Pilot interview transcripts were shown to the second author and feedback
5
6 acknowledged before proceeding with the main interview sample. In general,
7
8 feedback was consistent with that noted in the reflective diary.
9
10
11 - One interview transcript was independently analysed, and the extent of
12
13 agreement with the primary researcher evaluated. There was agreement across
14
15 all of the main themes and 69% of the sub-themes. In two cases, sub-themes
16
17 relating to positive support experience were identified by the main researcher
18
19 but not in the reliability check, possibly due to the research focus on support
20
21 issues and reservations. Excluding these, percentage agreement was 76%.
22
23 The other discrepancies related to sub-themes being identified by one reader
24
25 only (in 6 cases), or by both but categorised differently (in one case).
26
27
28
29 - A copy of the results section was sent to participants, allowing them the
30
31 opportunity to comment on the extent that apparent themes reflected their
32
33 experience.
34
35
36
37
38

39 Results

40
41 The key themes that emerged from analysis are described below and illustrated in
42
43 Figure 1.
44

45
46
47
48 Figure 1 about here
49
50
51
52

53 General service provision

54
55 Despite the interview schedule's focus on challenging behaviour support, parents
56
57 commented frequently about issues of general service provision. Many parental
58
59 experiences concerning their child's behaviour occurred within the context of contact
60

1
2
3 with schools, GPs or social workers. Often, parents did not experience a clear divide
4
5 between challenging behaviour support and more general support issues.
6
7

8
9
10 All participants reported difficulty accessing good services. This included issues such
11
12 as delays in provision, a crisis management approach within support allocation,
13
14 having to fight for or chase services, difficulty contacting services, poor coordination,
15
16 high staff turnover, and lack of speech and language therapy.
17

18
19
20
21
22 'I get very, very annoyed that things have to get to the point that you're ready
23
24 to kill your child...until you get to that point you don't get any help really'
25
26
27 (P7)
28

29
30
31
32 Poor information provision was highlighted by almost all participants (12/13), leading
33
34 to parents having to find out information for themselves, and many placing greater
35
36 reliance on informal sources, (e.g. other parents, the internet). A small number felt
37
38 that services were selective in the information which they shared:
39

40
41
42
43 'comes down to money again...that's part of why they don't tell you about
44
45 these services' (P2)
46
47
48
49

50
51 Most (11/13) reported issues related to respite provision. The most prevalent theme
52
53 was receipt of insufficient respite. Nearly half experienced restricted availability,
54
55 with smaller numbers viewing provision as unsuitable or unreliable.
56
57
58
59
60

1
2
3 'When you get a doctor's note saying "please give her more hours"...feel
4
5 they're waiting for you to crash' (P10)
6
7
8
9

10 Almost all faced partnership and communication problems when working with
11 professionals. Approximately half expressed concern over the lack of communication
12 and joint working that occurred between school and home. A small number felt
13 excluded from reports and meetings. Many felt they were not always listened to or
14 consulted, their account of challenging behaviour not believed or taken seriously and
15 that professionals lacked sympathy towards their situation. A small number of parents
16 felt blamed for their child's behaviour.
17
18
19
20
21
22
23
24
25
26
27
28

29 'you give up after a while, when someone's not actually listening' (P8)
30
31
32
33

34 'It's only when other people are seeing the same behaviour as you are...that
35 the ball starts rolling' (P7)
36
37
38
39
40

41 Challenging behaviour specific themes 42 43 44 45

46 *Ineffective strategies* 47

48 Almost all (12/13) found professionally suggested strategies for managing behaviour
49 to be ineffective. Many felt that professionals were unable to provide interventions to
50 reduce their child's challenging behaviour, and this included both direct behaviour
51 support, and to a lesser extent that provided to the child at school:
52
53
54
55
56
57
58
59
60

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

‘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)

1
2
3 Although approximately half reported being offered pharmacological interventions,
4
5 these were not viewed positively, medication being seen as ineffective, disliked or
6
7 causing undesirable side-effects:
8
9

10
11
12 'I wanted him to learn how to behave or learn ways of asking through...other
13
14 interventions where he learns it rather than being drugged up...didn't find it
15
16 greatly changed anything' (P10)
17
18

19
20
21
22 *Lack of expertise*
23

24 Mothers frequently (11/13) expressed a negative view of professionals. They
25
26 perceived professionals as lacking knowledge, understanding or expertise in either the
27
28 complexities of autism, or about challenging behaviour:
29
30
31

32
33
34 'It's a lack of understanding. It's having mental tick boxes in their heads of
35
36 autistic traits that don't actually have any bearing, or fit in at all with what
37
38 your son's like' (P7)
39
40
41

42
43
44 'I think the people that I meet have, you know, done a half-day course and
45
46 read half a book, and I think I know much more, which is really frightening'
47
48 (P13)
49
50

51
52
53 These concerns related to many generic support professionals, including occupational
54
55 therapists, social workers, paediatricians and general practitioners. However a few
56
57 mothers also reported issues concerning more specialist services, providing direct
58
59 behaviour support to families:
60

1
2
3
4
5
6 'I phoned up the office and I said "I don't think I need her anymore". Which
7
8 was a lie but it was easier to say that than to say "I'm sorry I think she's totally
9
10 incompetent and hasn't got a clue' (P8)
11
12

13
14
15 A similar number reported a lack of expertise within the school setting:
16
17

18
19
20 'I was told "we are the experts, but we're never seen one as bad as this". So in
21
22 a way he's a learning curve for others coming up behind him' (P5)
23
24

25
26
27 *Insufficient specialist services*
28

29 Most (11/13) had received some form of behaviour management support from
30
31 professionals, other than the prescription of medication. Despite this, many
32
33 participants (9/13) felt there were insufficient specialist services available.
34

35
36 Approximately half perceived direct behaviour support as limited and rationed:
37
38

39
40
41 'I'm studying psychology now...I thought I'm not getting help from anywhere
42
43 else so I'll have to do it myself' (P1)
44
45

46
47
48 'We're not actively involved with them at the moment...there aren't any, what
49
50 they would call priority issues, and there's so many families being referred to
51
52 them...unless I'm basically in danger of being hurt they won't be deemed
53
54 important' (P4)
55
56
57
58
59
60

1
2
3 This theme was further highlighted by a few parents who indicated a desire to receive
4 more training, with some expressing an interest in restraint training:
5
6
7

8
9
10 'for parents to get the kind of training that a classroom assistant gets for a
11 start, SCIP training or whatever. We seem to not be trusted with this sort of
12 information...yet we're having to live with it' (P6)
13
14
15
16
17

18
19 Although no clear preference was highlighted as to the training format that would
20 have been most beneficial, one parent specifically reported her satisfaction with
21 regular, in-home support to put strategies in place. Additionally, some parents felt
22 that a group training course with other parents would be beneficial.
23
24
25
26
27
28

29
30 As well as the need for direct behaviour support, a small number highlighted their
31 need for more general emotional support:
32
33
34
35
36
37

38 'There's nothing from school...or any other professionals...There's no "oh
39 how are you doing?"' (P1)
40
41
42
43
44
45

46 The value of regular, reliable, continuous support was expressed by approximately
47 half:
48
49
50

51
52 'They don't sort of leave you, and I think that's critical, is the follow up...just
53 being there...not so you can whinge but to say, you know, "he's doing this,
54 what can I do"?' (P7)
55
56
57
58
59
60

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

1
2
3 backgrounds, especially those who do not have English as their first language.
4
5
6 Thirdly, as a phenomenological study, the intent was to gain parents' personal
7
8 perceptions of support, not objective evidence of the actual level or kind of support
9
10 offered. Future research, investigating the perspective of professionals working with
11
12 these families would be of value. Finally, this study deliberately sought to look at
13
14 difficulties families experienced in their attainment of behaviour support, and, as
15
16 such, did not specifically investigate experiences of helpful support. Future studies
17
18 might usefully address this question.
19
20
21
22
23

24
25 Participants identified three main issues. First, they reported many problems with
26
27 generic service provision, both services such as schools and GPs and "generic"
28
29 children's or disability services. Second, they struggled to obtain adequate access to
30
31 more specialist provision (i.e. help focused on their child's challenging behaviour).
32
33
34 Third, when such provision was accessed it was not very specialist, often leaving
35
36 them no better off. We consider these issues below.
37
38
39
40

41
42 Given participants' emphasis on experiences related to generic disability support
43
44 services, such as schools, respite and social services, it is apparent that these families
45
46 test mainstream services. The limited nature of generic support services has
47
48 previously been acknowledged (Beresford, 1995) and it is likely that if these services
49
50 are already struggling to cope with demand, this situation may be further accentuated
51
52 by the additional needs of children with challenging behaviour. More competent
53
54 generic services would allow lower levels of challenging behaviour to be effectively
55
56 dealt with and escalation of behaviour minimised. This would prevent more specialist
57
58
59
60

1
2
3 services being overwhelmed by demand, allowing them to focus on more extreme
4
5 cases of challenging behaviour (cf. Department of Health, 2007).
6
7
8
9

10 Parents continue to struggle to access both generic and more specialist services, with
11
12 delays, difficulties contacting services, a crisis management approach, poor
13
14 coordination, and support discontinuity due to high staff turnover being apparent.
15
16 Insufficient respite, as well as access to and coordination of community services,
17
18 appear to be ongoing issues. Families report a lack of the regular, reliable and
19
20 continuous support they value.
21
22
23
24
25
26

27 Many mothers described “fighting” for the restricted services available. Possible
28
29 inequalities in service access have been noted by McGill et al (2006b), who suggested
30
31 that articulate, middle class families may attain better support. The risks involved in
32
33 not working more preventatively with families are high, given that decisions are often
34
35 made to place children in residential provision in response to a crisis (Mental Health
36
37 Foundation, 1997, p35), and, currently, many children and young adults end up in
38
39 residential placements, often far from the family home (e.g., McGill et al, 2006a).
40
41 Within the families in the present research, four children were either already
42
43 attending, or about to begin residential education due to behaviour concerns. Not
44
45 intervening early makes it more likely that families reach a stage of crisis, and then
46
47 require more complex and expensive interventions (HM Treasury/Department for
48
49 Education and Skills, 2007).
50
51
52
53
54
55
56
57

58 One consequence of the struggle for access to all types of information and support is a
59
60 heavy reliance on informal sources such as friends and family (cf., McGill et al,

1
2
3 2006b). This was apparent in the present research. McConachie (1994) suggested
4 that professionals should support and work with such informal support networks and,
5 given the limited nature of services, the facilitation of these may alleviate some of the
6 difficulties resulting from service shortfalls. Such an approach might also be argued
7 more fundamentally. Perhaps some of the challenges faced by families are such that
8 publicly organised services, however high quality, cannot hope to meet them fully. A
9 “self-help” focus on family training, advocacy and family-to-family support might
10 achieve more.
11
12
13
14
15
16
17
18
19
20
21

22
23
24 Previous research (McGill et al, 2006b; Qureshi, 1993) has suggested that specialist
25 challenging behaviour support is often viewed as unhelpful. Participants in the
26 current study identified a number of issues mediating perceived unhelpfulness. Most
27 mothers felt that some professionals lacked expertise, within the areas of challenging
28 behaviour and/or autism (cf, McGill et al, 2006a, 2006b). Many professionals were
29 unable to suggest effective strategies to alleviate challenging behaviour or had little to
30 add to what parents were already doing. Additionally, many parents disagreed with
31 suggested interventions, viewing them as inappropriate or impossible to put into
32 practice. Concern has been expressed regarding the extent that professionally
33 suggested interventions are evidence-based (McGill et al, 2006b) or are contextually
34 appropriate (Lucyshyn et al, 2002). Given the apparent issues around professional
35 expertise, it is perhaps unsurprising that some educational and respite services were
36 unable to cope with challenging behaviour and, consequently, excluded the child. This
37 results in increased demands on families.
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3 A need for behaviour management training was expressed by some, including
4
5 physical restraint. In the absence of effective behaviour support, families may be
6
7 forced to use these reactive strategies. Frustration was expressed that school staff
8
9 received more adequate training, despite parents spending the most time with their
10
11 child. It seems difficult to justify this failure to train parents, given the injury that
12
13 may result from the use of inappropriate, unplanned physical interventions (Allen et
14
15 al, 2006).
16
17
18
19

20
21
22 It seems vital that professionals adopt a family-centred focus, and work in partnership
23
24 with parents, if interventions are to be accepted by families, effective, and consistently
25
26 applied across different settings (Lucyshyn et al, 2002). Past research has
27
28 demonstrated the value of professionals taking on board parental knowledge (e.g.,
29
30 Prezant & Marshak, 2006). However, many mothers in the present study reported that
31
32 their views were not always considered. Effective joint working might also increase
33
34 the likelihood that suggested interventions suit the needs of the family and take due
35
36 account of family routines (Qureshi, 1993; Turnbull and Ruef, 1996). Other issues
37
38 within working relationships were also reported, with professionals failing to
39
40 understand parents' situation, not taking their account of challenging behaviour
41
42 seriously, and seeming to blame parents for their child's behaviour (cf. Qureshi, 1993;
43
44 Turnbull and Ruef, 1996).
45
46
47
48
49

50
51
52 Some of the barriers to better support might be addressed by adoption of an approach
53
54 such as 'Team Around the Child' (Limbrick, 2005). In this, a small number of key
55
56 professionals work in an individualised and coordinated manner, providing regular
57
58 therapeutic contact, centred on the needs and aspirations of the child and family.
59
60

1
2
3 There is a strong emphasis on partnership working, both between professionals and
4 families and amongst different professionals, to ensure coherence, collaboration and
5 respect. A key worker takes the lead in ensuring that interventions effectively fit
6 together, as well as ensuring that families have access to appropriate services and
7 sufficient information. Even if such a system was possible, however, the importance
8 of also facilitating self- and mutual help, of supporting families as “expert carers”
9 (Allen, 2000), should not be forgotten.
10
11
12
13
14
15
16
17
18
19
20
21

22 **Acknowledgments**

23
24 We are grateful to the family carers who participated in this study.
25
26
27
28

29 **References**

- 30
31 Allen, D. (2000) Negotiating the role of expert carers on an adult hospital ward.
32 *Sociology of Health and Illness* 22, 149-171.
33
34
35
36
37
38 Allen, D., Hawkins, S. & Cooper, V. (2006). Parents’ use of physical interventions in
39 the management of their children’s severe challenging behaviour. *Journal of Applied*
40 *Research in Intellectual Disabilities*, 19, 356-363.
41
42
43
44
45
46
47
48 Beresford, B. (1995). *Expert opinion: A national survey of parents caring for a*
49 *severely disabled child*. Bristol: The Policy Press.
50
51
52
53
54
55 Department of Health (2007, revised edition) *Services for people with learning*
56 *disabilities and challenging behaviour or mental health needs: Report of a project*
57 *group*. (Chairman: Prof J.L. Mansell). London: Department of Health.
58
59
60

1
2
3
4
5
6 Emerson, E. (2001, 2nd Ed.). *Challenging behaviour: Analysis and intervention in*
7
8 *people with severe intellectual disabilities*. Cambridge: Cambridge University Press.
9

10
11
12 Hastings, R.P. (2002). Parental stress and behaviour problems of children with
13
14 developmental disability. *Journal of Intellectual and Developmental Disability*, 27,
15
16 149-160.
17
18

19
20
21
22 HM Treasury/Department for Education and Skills (2007). *Aiming high for disabled*
23
24 *children: Better support for families*. London: HMSO.
25
26

27
28
29 Kiernan, C. & Alborz, A. (1996). Persistence and change in the challenging and
30
31 problem behaviours of young adults with intellectual disability in the family home.
32
33 *Journal of Applied Research in Intellectual Disabilities*, 9, 181-193.
34
35

36
37
38 Knox, M., Parmenter, T.R., Atkinson, N. & Yazbeck, M. (2000). Family control:
39
40 The views of families who have a child with intellectual disability. *Journal of*
41
42 *Applied Research in Intellectual Disabilities*, 13, 17-28.
43
44
45

46
47
48 Limbrick, P. (2005). Principles and practice that define the Team-Around-the-Child
49
50 (TAC) approach and their relationship to accepted good practice.
51
52 <http://www.icwhatsnew.com/bulletin/articles/TAC.pdf>. Accessed 26/03/2007.
53
54
55

1
2
3 Lucyshyn, J.M, Dunlap, G & Albin, R.W. (Eds.) (2002) *Families and positive*
4 *behavior support: Addressing problem behavior in family contexts*. Baltimore: Paul
5
6
7
8 H Brookes.

9
10
11
12 McConachie, H. (1994). Implications of a model of stress and coping for services to
13 families of young disabled children. *Child: Care, Health and Development*, 20, 37-
14
15
16
17
18 46.

19
20
21
22 McGill, P., Tennyson, A. & Cooper, V. (2006a). Parents of children with learning
23 disabilities and challenging behaviour who attend 52-week residential schools: Their
24 perceptions of services received and expectations of the future. *British Journal of*
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
Social Work, 36, 597-616.

34 McGill, P., Papachristoforou, E. & Cooper, V. (2006b). Support for family carers of
35 children and young people with developmental disabilities and challenging behaviour.
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
Child: Care, Health and Development, 32, 159-165.

44 McIntyre, L.L., Blacher, J. & Baker, B.L. (2002). Behaviour/mental health problems
45 in young adults with intellectual disability: the impact on families. *Journal of*
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
Intellectual Disability Research, 46, 239-249.

53 Mental Health Foundation (1997) *Don't forget us: Children with learning disabilities*
54
55
56
57
58
59
60
and severe challenging behaviour. London: Mental Health Foundation.

1
2
3 Prezant, F.P. & Marshak, L. (2006). Helpful actions seen through the eyes of parents
4 of children with disabilities. *Disability and Society*, 21, 31-45.
5
6
7

8
9
10 Qureshi (1993). Impact on families: Young adults with learning disability who show
11 challenging behaviour. In C. Kiernan (Ed.) *Research to practice? Implications of*
12 *research on the challenging behaviour of people with learning disabilities* Clevedon:
13 BILD.
14
15
16
17
18

19
20
21
22 Redmond, B. & Richardson, V. (2003). Just getting on with it: Exploring the service
23 needs of mothers who care for young children with severe/profound and life-
24 threatening intellectual disability. *Journal of Applied Research in Intellectual*
25 *Disabilities*, 16, 205-218.
26
27
28
29
30
31

32
33
34 Smith, J.A., Jarman, M. & Osborn, M. (1999). Doing interpretative
35 phenomenological analysis. In M. Murray & K. Chamberlain (Eds.) *Qualitative*
36 *health psychology: Theories and methods*. London: Sage.
37
38
39
40
41

42
43 Turnbull, A.P. & Ruef, M. (1996). Family perspectives on problem behaviour.
44 *Mental Retardation*, 34, 280-293.
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47

Figure 1 Key themes from interviews

For Peer Review

