Challenging
BEHAVIOUR
foundation

making a difference
to the lives of people with
severe learning disabilities

A Report to the NICE Guideline Development Group

Adults, young people and children with learning disabilities who display behaviour described as challenging: Family perspectives

The brief

The Guideline Development Group (GDG) for the NICE Guidelines on 'Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges' approached the Challenging Behaviour Foundation (CBF) to organise, and facilitate, two focus group events for family carers. The aim of the focus group events were to ensure that the voice of family carers of adults, young people and children with learning disabilities who display behaviour described as challenging would be fed into the consultation process about what needs to be included in the Guidelines.

The GDG wanted the focus group events to address four specific questions from a family carer perspective.

1. Access to assessment: What is the experience of families accessing services for children, young people and adults with learning disabilities who display behaviour described as challenging?

2. Medication: What is the experience of the use of medication for children, young people and adults with learning disabilities who display behaviour described as challenging and their families?

3. Behavioural interventions: What support is given to families when involved in behavioural programmes and do they help children, young people and adults with learning disabilities who display behaviour described as challenging in the long term?

4. Transition between services: What is the experience of transitioning between services e.g. child and adult services, into residential services

They also wanted the families to tell them if there were any other issues that they felt needed highlighting for consideration by GDG.

Background information on The Challenging Behaviour Foundation

The Challenging Behaviour Foundation (CBF) is a charity for adults and children with severe learning disabilities who display behaviour described as challenging and those who support them. The CBF makes a difference to the lives of children and adults across the UK through collecting and sharing information, providing support for families and driving change in policy. Our vision is for all individuals with severe learning disabilities who display behaviour described as challenging to have the same life opportunities as everyone else and, with the right support, to live full and active lives in their community. Our mission is to improve understanding of challenging behaviour, empower families with information and support, and help others to provide better services and more opportunities to children and adults with severe learning disabilities who display behaviour described as challenging.

The focus group workshops: Who came?

Application process and trying to get a balance between children, adolescence and adults

The two focus groups were designed to be as representative as possible and endeavored to find a balance between the experiences of family carers' of children and young people and the family carers' of adults. We sent out an open invitation to our networks (consisting in more than 500 family carers) which included an application questionnaire asking about the specific challenging behaviours they had experienced and what the family carers thought they could bring to the group. After this application process we invited eighteen family members to the focus groups and in total seventeen attended and contributed.

We divided the family carers across the two focus groups by the age of their family member with a learning disability who display behaviour described as challenging: One group was attended by the family carers of adults, and the other group by the family carers of children and young people.

In the adults group, the age of the family member with a learning disability ranged from 18-37 and in the other group the age ranged from 7-21. Traditionally, the majority of family carers are mothers and our groups reflected this, but we also heard from two fathers, one sibling and an auntie. In our groups we also had a variety of living arrangements, including family members who lived at home, had been in Assessment and Treatment Units (ATUs), had experienced respite care and who were in supported living (and some individuals who had been in all four).

The focus group workshops: Methodology on the day

The workshops started at 11am and finished at 4pm to allow families to get there from across the country. The families worked in small groups and addressed each question in turn recording their discussion on flip chart paper. They then came together as a larger group to discuss their key issues and concerns and this information was also recorded. The same method was used to generate and record the 'Any Other Issues' concerns. Finally, each participant was asked to write out on a piece of paper his or her individual ***key***

priority statement for the GDG. All the information was then typed up and used as the basis for this report.

Issues arising from questions addressed at the workshops

Q1. Access to assessments: What are the experiences of families accessing services for children, young people and adults with learning disabilities who display behaviour described as challenging?

- Introductory comment
- Assessment needs to start early
- Assessment has to lead to outcomes
- Who is doing the assessment?
- Assessment needs to be person centred and joined up
- Diagnostic overshadowing
- Attitudes to families

Introductory comment

The families participating in the workshops said they found it hard to get to grips with this question, as **‘**assessment’ is a complex topic that is relevant to all the other questions and issues they are being consulted on.

- The use of medication
- The best sorts of intervention, care and support for their family member
- The experience of supporting someone as they age or their needs change

The families feel that the key questions around the assessment process are often not always clear to them.

- Who is doing the assessment?
- Why is the assessment being done?
- How is the assessment being done?
- Who is involved in the assessment?
- What are the outcomes of the assessment?
- Who is monitoring and reviewing these outcomes?

Assessment is a dynamic ongoing process that needs to be regularly reviewed and updated. **Assessment needs to be seen as part of a whole life approach to support across a person’s life cycle.**

Assessment needs to start early

Families said that they thought assessment should start early and been seen as part of a preventative strategy and should help them:

- Understand the issues and needs of their child
- Plan how to meet them
- Nip behaviour in the bud *before* it becomes a problem.

‘There is a black hole in assessing the needs of our children between the ages of 2 – 5. You cannot start early enough’

‘Sam got diagnosed way too late because nobody listened’

Getting the right assessment at the right time in the life cycle can help prevent problems developing.

‘We need to be proactively planning for life to prevent problems developing. Everything is so short term and narrow in focus.’

‘Sometimes I feel that professional aspirations are so low for my son!’

Families recognise they are in for the long haul and throughout life there are key transitional points that are critical to plan for, manage and get right. Having access to good quality assessment and planning will be important to them all.

- Being told – getting a diagnosis
- Getting the right early intervention support
- Making choices about school
- Making a smooth transition between childhood through adolescence into adulthood
- Moving into your own home
- Making a successful transition into old age and later life

Many of these critical points or transition can put stress on the family. It is important they get:

- The right information at the right time in an appropriate and accessible format to help to make the right choices and plan;
- Receive support in their own right – perhaps a short break or access to Family Advocacy.

Assessment has to lead to outcomes

The overarching message of the family carers taking part in both the workshops is that **assessment should always lead to something**- an outcome, and too frequently this does not happen.

‘Assessments do not produce action plans or guidance. The behavior specialist came in and did an assessment, discussed it with the staff team but never followed it up to see if it had been implemented and it wasn’t! What a waste of time that was!’

‘Professionals doing the assessment often have no idea of the capabilities of those implementing the recommendations.’

*‘The assessment wasn’t bad but there was f*** all available afterwards.’*

‘It’s all very well having an assessment but frankly the services are not there’!

The key question for families is why do an assessment if it does not lead to something? Why assess someone for a service if it is not there? Families suggest that the only justification for doing so is if the individual assessments are collated and used at a strategic level to evidence unmet needs to local commissioners? Families are not convinced this happens.

'One of the lessons from the fallout from Winterbourne View is that there simply aren't local services to meet the needs of people with learning disabilities and challenge behaviour. This simply isn't good enough. We need local services to meet our children's needs!'

Who is doing the assessment?

Families are concerned about what they perceive as the lack of expertise of the professionals doing assessment across the board. From local teachers, medical practitioners, CAMHS staff and even 'experts' in Tier 4 services. This relates to the professional frameworks and tools they are using to assess.

'The explanatory frameworks that professionals use to determine how they 'see a problem' and therefore how they respond to it! This is crucial in terms of how they assess 'what is wrong with our son and what they can do to 'treat' him'.'

'Explanations are important because they determine the solutions sought by professionals.'

'Are we talking about the same child here? The assessment from the psychiatrist painted a completely different picture of June compared to her school report! How do we begin to make sense of that?'

These issues clearly have implications for the interventions that are then recommended and it is easy to see how one professional might advocate medication and another positive behavioral support. Families feel that because of the perceived power differential between professions the doctor or psychiatrists' solution to use medication can win out in the first instance.

Assessments need to be person centred and joined up!

There is a real concern that assessments are not person centred and individualised. One brother pointed out that often: '*Practitioners use generic sentences in assessments, in plans and even prescribing favourite drugs.'*

One of the implications of this professional 'bias' in assessments is that they are not person centred or holistic. They do not see the whole child or adult in the round as an individual and in context.

'There is a lack of joined up, holistic person centred assessments.'

'The tools they use are not person centred. I don't think they see Peter as a person in the round he is just a cluster of labels to them.'

‘They start assessing really early but they never put any of it together.’

This, not *‘putting it together’,* has implications for the individual and their family but also for range of professionals who are working with them. Unless there is a formal Multi- disciplinary team in a local area it will difficult to support effective inter-professional working and therefore a proper integrated care plan. Once again the family will be left informally holding the coordination role between services.

Diagnostic overshadowing

A factor that families feel contributes to the lack of person centred assessment and the ability of people to really ‘see’ their child/ adult was caused by ‘diagnostic overshadowing’.

Many of the families discussed the implications of this in relation to accessing good physical health treatment for their child/adult

‘Their label means other things about them get missed, (such as health needs), there are some many assumptions’.

‘It’s about seeing the individual regardless of what they are or what their label is’.

But it also operated in other ways when one ‘label’ overshadowed others, for example around ‘autism’.

‘The minute Autism is mentioned we are sent on a different pathway. When it comes to autism and learning disability there is a lack of recognition of the specific issues. Applied Behavioural Analysis (ABA) is rejected in the ‘autism world’. There is a lot of evidence of person centred approaches to understand (assess) the person. This could be seen as another form of ‘diagnostic overshadowing’.

Attitudes to families

‘The culture of anti-family is absolutely rife!’

‘You don’t start off as an aggressive forceful person….your experiences shape you!’

The families told us that they often feel *‘under the spotlight’* when they meet professionals, and they feel that they are being assessed themselves, but this is never explicitly stated. They often feel that they are not listened to and judged to be part of the problem rather than partners in working to find the best solution for their family member.

As a result of this wariness of families they might find that their input into the assessment process is either not sought or not valued.

This issue of ‘*valuing families’* permeated all discussion topics and is discussed more fully in the section **Any Other Issues.**

Question 2: Medication: What is the experience of the use of medication for children, young people and adults with learning disabilities who display behaviour described as challenging and their families?

- Introductory comment
- Medication as the default option
- Lack of information
- Misuse of medication
- Evaluating outcomes
- CAMHS

Introductory comment

‘Medication is the most widely used intervention to manage behaviour that challenges. Although it may be effective for some people, it is considered by most processionals to be overused and there is a danger that it may simply sedate the person and lead to polypharmacy’.

The families that participated in both workshops share the same concerns as the professionals highlighted in the Scoping document for these guidelines.

‘It all goes back to the importance of assessment. You need a good one before prescribing; that looks at everything else first; medication should be the last resort!’

One Mum during the Children’s workshop said;

‘If used correctly medication can be very beneficial. Risperidone helped my son focus more clearly and allowed him to enjoy a better quality of life day to day.’

But she also noted that;

‘There were some bad side effects: weight gain, headaches and sickness’.

Medication as the default option

The families participating in both workshops are concerned that medication is frequently the only sort of intervention offered to their family member.

‘We need behavioural interventions not chemical coshing’.

‘There should be behavioural understanding before medication is prescribed’.

‘My daughter was offered Risperidone at 15 years old. On reading the research I questioned why it was being offered when there were no positive results for females. I asked for therapy and not medication. I was told there is not enough money so it was medication or nothing. I chose nothing.’

Discussed below are the areas that most concerned the families attending the two workshops.

Lack of information

'It is difficult to challenge the psychiatrists or help make an informed decision if you don't have the right information.'

The families said they are not being offered enough information about the medications that are being prescribed for their family member. This includes issues like:

- Potential side effects
- Interaction (poly-pharmacy) with any other drugs being prescribed
- Interaction with any home based remedies the person might take for a cold or a headache.

The families felt that NICE could play a role in offering advice and guidance on poly-pharmacy and managing side effects to other professionals (especially GP's) as well as families.

Misuse of medication

Families are aware that there are already Good Practice Guidelines. Families asked why these guidelines are not more widely used and were concerned that no one analyses or monitors the prescribing trends in this area. Families wondered if this should be included in CQC's role as Regulator.

There was a very strong view that '*Antipsychotics should never be used for challenging behaviour unless there is an underlying mental health problem'.*

Evaluating the outcome of the medication: Problems with approaches to gathering evidence

Families are concerned that no one knows how to effectively measure the outcomes of medication.

- How can you evaluate the efficacy of the medication if more than one medication is prescribed or if medication is used alongside a behavioural approach?
- How do you disaggregate and evaluate the component parts of an intervention that involved prescribing more than one drug?

'My daughter was given three medications changes in one month so it is difficult to separate out what effect they had on her'.

Many families felt that the routine observational monitoring and recording of their family member on a day-to-day basis is not valued or validated as evidence by professionals. Yet it could give greater insight into the lived experience of the person on a medication regime.

The question of evidence comes up again in the section on **Any Other Business.**

CAMHS were singled out for criticism in the children and young people workshop

Families in the children's workshop said there is a perception that CAMHS only dealt in medication.

'CAMHS are doling out Ritalin like smarties.'

'CAMHS need to be more than just drug pushers'.

The feeling was that Ritalin has some very bad side effects so assessment about whether to use it had to be extensive and thorough. There is a concern that local CAMHS services lacked the sort of expertise that is needed to do this properly. This is also felt to be true in relation to the prescribing of melatonin.

There was a consensus that there should be a minimum of a mandatory annual review of medication and this should involve a blood test to review medication levels and physical functioning. This consensus links to a strong feeling that there should be more information provided to GP's and a better link between primary care and specialist prescribers should be developed (as mentioned above).

Families would also like NICE to recommend and encourage more flexibility in how medication is administered. Many young people find it hard to swallow tablets and liquid options should be considered as a reasonable adjustment.

Question 3: Behavioural Interventions: What support is given to families when involved in behavioural programmes and do they help children, young people and adults with learning disabilities who display behaviour described as challenging in the long run?

- Introductory comment
- Access to Positive Behavioural Support
- Lack of expertise
- Person Centred Approaches and the use of person centred tools
- Working in partnership with Families
- Health interventions

Introductory comment

After medication, behavioural interventions were identified as the second most widely used approach for supporting and managing the needs of children, young people and adults with learning disabilities who display behaviour described as challenging. The families participating in the workshops are unanimously positive about this approach. However, they are concerned that there is not enough Positive Behavioural Support (PBS) (or ABA) on offer and available in all areas.

They are also concerned that some services think they are offering PBS (CAMHS and other providers were mentioned) but were not providing the '*real deal*'.

'Behavioural interventions are only as good as the people delivering them'.

Access to Positive Behavioural Support

All the families are concerned over the issue of *equity of access* to positive behavioural interventions both in terms of information and availability in their local area. The families of the children's' group also feel strongly that access to PBS (and ABA) should be part of a proactive early preventative strategy.

'I cannot imagine what our life would be like now if we hadn't found out about ABA early on. It has made such a difference to all our lives!'

This same mum also said that she felt lucky to have been told about ABA from another parent, and when services refused to pay for the assessment, that they were fortunate to have the money to pay for her son's assessment.

'I think it is very unfair that we were able to get the assessment and ABA support he needed just because we could pay. What about families that don't have the money? They are being denied an opportunity to put something in place that could potentially make a huge difference because it prevents behaviours developing that are difficult to change once they are established.'

The issue of accessing information about interventions that could help their family member came up in both workshops. Many of the families attending were *proactive* in seeking out information but said they still found it hard.

Some of the families get their information via new forms of media but the majority said they still '*find out things from talking to other families'*.

There was recognition that more isolated families, or families with lack of access to the Internet were disadvantaged.

Running alongside the issue of information and the difficulty of accessing it is the question of the *availability* of PBS assessment and support in local areas.

'CAMHS say they offer behavioural support but they don't really. It is just a tick box approach.'

Lack of expertise

The families identified lack of expertise in PBS as one of the main factors in limiting availability.

'People think they are doing it but are not.'

'I was proactive and given the tools, took them into school but they weren't received gratefully. They thought I telling them how to do their job!'

It was noted with concern that recent free PBS training on offer to special schools did not have a good take up rate. On the other end of the spectrum, families raised their concerns about some providers in the adult world who were '*doing their own thing'*.

'There needs to be greater consistency in terms of approaches adopted. National guidance in approaches that have a solid evidence base. A Register of qualified practitioners'.

'These behavioural interventions are only as good as the people delivering them'.

Staff development and workforce issues are a big concern for families. *'Consistency and expertise are needed'.* Yet the families' experience is often the opposite.

'PBS - functional assessment / implementation/ consistency / real challenge for care staff and also exhausted families / need monitoring and support by professional team'.

'Inconsistently applied interventions, staff changes, monitoring & supervision is flimsy. He's been looked after by hundreds of people. We're always battling against the staff that do what they think.'

'Three previous interventions failed – there's no regard given to tools, there's arrogance - he was left in a filthy room.'

Families recognise that some of these workforce issues are related to wider context of recruiting and retaining care staff in the current social and health care market. This issue is picked up again in **Any Other Issues.**

‘We don’t pay them enough. They can get more working stacking shelves in a supermarket. If we don’t value them how can we expect them to value our children’.

Person-centred approaches and person-centred tools

‘Families are naturally person centred - how could we not be – we are talking about my son’.

The lack of a person centred approach to assessment and interventions is a big issue for families. The workshop participants feel the lack of person centred *assessments* leads inevitably to care and support intervention plans that are not individualised.

‘One size does not fit all’

It is therefore important that practitioners use some of the excellent person centred tools that are currently available. Their lack of knowledge is indicative of the concern over expertise discussed above. Families flagged up the value of using:

- Communication passports
- Mood charts
- Videos
- Essential Life Style planning

There are also more practical concerns about: the ability and capacity of systems to respond quickly, how plans will be funded, and also, how to monitor the effectiveness of their implementation.

‘Care plans are delayed getting signed off and often not accurate.’

‘Don’t have the time to keep these plans up to date.’

‘Interventions should be based on a functional assessment of the individual and co-produced with families and as part of the persons Person Centred Plan’.

‘A person centred plan needs to be fully implemented and regularly reviewed as a ‘living document’.’

Working in partnership with families

Families want to be involved in designing, co-producing and delivering care and support for their family member. This is obvious if the child or adult lives at home but is also be relevant for those who are living away from home in residential care, supported living, ATU or hospital setting.

‘There needs to be a package of care which recognises that the family play a central part. This care and support should be based on PBS’.

All families need to be informed, equipped and supported to take an active role in finding the best way to support their individual child or adult with a learning disability who display behaviour described as challenging.

‘Bugger all support is given to families- we are not informed or equipped to deal with the things that confront us. We are just left to manage on our own’.

‘A family’s ability to fulfil any intervention very much depends on how tired/ stressed they are, as well as the appropriate skills being shown’.

‘Its sink or swim. Some of us manage to swim but a lot of families sink! It puts so much pressure on a marriage. Families need more respite. It makes it so much easy to cope and stay positive’.

The families also highlighted the fact that they were concerned about working within the law in terms of any interventions they were involved in; particularly in relation to restraint and the new Deprivation of Liberties Safeguarding Guidance. In general they said that they felt it was important as to have an understanding of both the Mental Capacity Act and Mental Health Act as their family member reached adulthood.

Physical health interventions

All the families described the difficulties they encountered trying to access good health care (including dentistry) for their family member. *‘It is simply a nightmare’* one Mum said. The issues that were raised ranged from ‘diagnostic overshadowing’ to lack of reasonable adjustments to accommodate the specific needs of the person. For those with an adult family member the issue about choice and decision-making is seen as essential and more information is needed for both families and practitioners.

‘The care workers wanted to refer him to the behavioural psychologist because he couldn’t control his bowels. In the end he was given a diagnosis of Ulcerative Colitis but it took us two years to persuade the people it was a physical not a behavioural problem’.

Many of the families attending the workshops had children, young people or adults with complex health needs as well as having a learning disability and displaying behaviour described as challenging.

‘There is no sense of coordination. None of the departments seems to speak to each other.’

'I spent hours filling in my boys 'My Hospital Passport' all the useful points about his care, needs, phobias, etc.- yet one no looks at it! It needs to be used by professionals'.

One Dad in the workshop had a list of suggestions about what needed to happen to improve the experience of getting better health care:

- Training for all NHS staff in making reasonable adjustments: mental capacity act, appointments, access, care, communication
- Training for GPs in the use of the mental capacity Act, reasonable adjustments, annual health checks and proactive care planning
- Annual Health Checks to be made a compulsory part of the GP contract rather than optional (enhanced)
- At least one LD liaison nurse in every hospital
- All hospitals to have a team of staff trained in challenging behaviour and appropriate interventions. (Could include restraint training)
- Effective and proactive healthcare planning and screening including a care passport.
- Help to maintain health and communication passports and family support plans are a brilliant idea too
- Easy read documentation and appointment letters
- Community LD teams to stop discharging clients. They have a duty of care therefore should maintain an interest/file
- Commissioning which enables everyone with a chronic condition to have access to appropriate proactive care irrespective of the condition
- Medical staff to be made to treat carers as equal partners unless there is a very good reason why they cannot.

Question 4: Transition between services: What are the experiences of transitioning or moving between services (E.g. Child to adult services, or into residential services)?

- Introductory comment
- Good practice – planning for transitions
- Chaotic and unplanned transitions
- Critical transitions identified
- Good and bad transitions

The families attending the workshop acknowledged that going through any sort of transition can be a difficult experience for anyone.

'We all make many transitions in our lives, some we have a choice over, some we do not. The context of the transition can make a difference to the way we experience it'

Individuals with learning disabilities whose behaviour challenges experience a number of major *life* transitions: moving from childhood to adulthood, leaving home, facing the death of loved ones. However, as one Mum pointed out, smaller everyday challenges can be a challenge as well!

'Transitions between shifts in a unit can be problematic if not properly thought out, planned and well executed'!

Good practice: Planning for transitions

All good transitions involve preparation, planning and execution of an action plan that everyone has signed up to, whatever the transition is.

'Obviously we need as much information to make the right choices and make the right decision'.

Families are clear that preparation and planning always needs to involve the person, (even if they lack capacity), and their family.

'I wish they would listen to my son! I wish they would listen to me!'

Even if the child, young person or adult with a learning disability who displays behaviour described as challenging cannot communicate using verbal communication, it is essential to find other ways of finding what their preferences would be as they make a change in their life.

This should involve using a range of person centred tools to find out *what is important to the person* as well as *what is important for them!* Also *mapping* the person's key relationships likes and dislikes, as well as developing a Communication Passport.

'The tools are there, we just need to know about them to use them'.

This reinforces the point made by families in relation to earlier questions that '*one size does not fit all'* and planning with people has to be person centred way in partnership with the person and their family. The families at the workshop told us that this was not always as straightforward or easy!

'There is a lot of great information out there now to help you prepare and plan for the time your child moves into adulthood. The sad thing is that where we lived it was all left to the last minute and we were told that when he left school his only choice was the local college but when we talked to the college they made it clear that they couldn't cope with Josh and he ended up sitting at home with me! He got bored and things went from bad to worse and he ended up being placed in a home miles away'.

Chaotic and unplanned transitions

The families said they thought that children, young people and adults with learning disabilities who display behaviour described as challenging are particularly vulnerable to experiencing chaotic transitions. They attribute this to the lack of expertise in local services to enable the needs of people with more complex needs to be met. This relates back to the issue of local capacity:

'It's all very well having an assessment but frankly the services are not there'!

'The staff just didn't have the expertise to meet her needs and she had to move!'

Critical transitions identified

In the workshop families identified the transitions that had been critical for them or they anticipated being critical for them. These included:

- Moving into education
- Making a decision about 52 week residential school
- Moving from children to adult services
- Leaving the family home
- Moving into a residential service
- Moving to a different placement in an emergency as a result of placement breakdown
- Being admitted into an ATU or hospital in a crisis – under a MHA Section.
- Moving into a supported living arrangement

Good and bad practice identified

Families shared their good and bad experiences of transition but it has to be acknowledged that the bad experiences heavily outnumbered the good. The good practice examples demonstrated that when an investment was made in giving time to preparing and planning the transition, it worked well.
Transition between services

‘The new staff team worked with Kay in her old environment for four months before supporting her to move to her new home. We (my daughter and myself) were involved in recruiting the new staff team. Videos of the interview questions were sent to Kay.’

‘She had no real preparation when she left her school (52 week residential) and was sent to a private hospital. None of her records from school were transferred and her teaching staff had no input into the admission and assessment process. As family we were told we should not come and see her for a few weeks as it might unsettle her. When we eventually got to see her she had turned in to a ‘wild animal’. It was beyond distressing to see her. It took us ages to get her case reviewed by the Mental Health Tribunal. The experience was appalling!’

Families said they feel that many children, young people and adults with learning disabilities who display behaviour described as challenging are on a pathway that can lead to mental services and institutional care because they fall at the hurdle of each life transitions they make. This happens because of a lack of understanding of their specific needs and a lack of planning on the part of local commissioners and providers. This results in a lack of local services that are designed, equipped or have the capacity to meet their individual needs.

‘They are round pegs and we try to fit them into square holes and it just doesn’t work!’

‘The only way I have been able to keep him out of a locked facility is to take a personal budget and develop a support service around him, which I manage. He has a good life but it comes at a cost and the cost is me!’

Any other issues: NICE scope

Introductory comment

Family carers often relish the opportunity to come together and discuss the issues that face them in their quest to get the right support for their family member with a learning disability who display behaviour described as challenging. The families that participated in the NICE workshops were no different.

The opportunity to discuss 'any other issues' generated much discussion, some of which was clearly outside the remit of the NICE Guideline scope. This included the political situation, the funding crisis, (particularly in Social Care) and the challenge of implementing *national* policy, including the NICE Guidelines in local areas when there is a move away from centralism to localism. Some of these concerns are reflected in the **individual priority statements** in the appendix.

It is interesting that the Scope included some issues that we weren't explicitly asked to address but did come up in the *Any other Issues* section, for example *workforce* issues. The workshops did not directly address the question of: *Interventions – that would help the family*. Short breaks and respite were mentioned and information (addressed below) but on the whole the families' focus was on getting the right support for their family member with a learning disability who display behaviour described as challenging. Reinforcing the point often made by family carers; ***if you get it right for them, you get it right for us!***

Any other issues: Not covered explicitly in relation to the other questions

Valuing families

For the majority of children and adults with learning disabilities and behaviour described as challenging their families offer not only love and concern but also a continuous and caring relationship throughout their life. Families hold the child's or adult's history and know them the best.

Yet the families at the workshop said they didn't feel valued by professionals and often felt that they were being assessed and labelled, as 'good' or 'difficult', overprotective or having 'unrealistic expectations'. .

'I think they see us as the problem. They certainly don't see us as partners or involve us in their assessment or decision-making.'

Whilst this was also true for the families of children, the families of adults felt it most acutely.

'Don't lock us out' was the unanimous opinion. '*See us as partners. Value what we have to offer'.*

Families frequently hold the coordination role for their family member - which links to the lack of 'joining up' in services discussed below. It is really important that they are involved in all aspects of the process of finding the right way to ensure that their family member is supported to live a good quality of life.

This involves embedding in all services (from childrens and adults) a culture of partnership working with families and co-producing:

- Person centred assessment
- Care and support plans

And involving families in:

- The monitoring and evaluation plans
- Reviews.

The families feel that this needs to be reflected in the guidance that is produced by NICE as an integral part of establishing person centred and integrated care for the child, young person or adult with learning disabilities who display behaviour described as challenging. It also reinforces the need for local services as it is logistically much easier to involve families in this way if their family member is closer to home.

Access to information

The empowering role of providing good information to families at the right time, in the right place and in a format that is appropriate and accessible, cannot be underestimated, and is a prerequisite for enabling families to be fully valued partners as described above.

'If you don't go looking for it, it won't come looking for you'.

'A lot of the time getting information is like being a private detective – what's wrong? What could have caused it? Having someone else to talk to helps.'

'We just didn't know where to get help or what was available. No one seemed able to tell us'

Families require information throughout the different ages and stages of life. The families participating in the workshops highlighted:

- Understanding learning disabilities and challenging behaviour
- What PBS approaches have to offer
- The pros and cons of a range of medications
- What does good support look like?
- What is person centred planning?
- What to expect from providers?
- Understanding the welfare benefit system
- Understanding the legal framework – children
- Understanding the legal framework – adults

- Understanding the MCA and the MHA – decision making and rights etc.
- Understanding the processes of admission to an ATU and what to expect, including the role of the family in assessment and treatment plans and the statutory rights of the person and the family.

All providers of care and support at whatever life stage need to invest in producing clear information about what they do and how they work and how they involve families.

‘The system is a mystery to us – we just don’t know how it works, what questions to ask. What we can expect to happen!’

Workforce issue

As highlighted in Question 3 - **care and support plans are only as good as the people that deliver them.** This is a major area of concern for families. Building relationships with professionals and the staff that support their family member is vital. An essential part of this is continuity.

‘They know him and they know us. We have worked at our relationship over the years and we trust them to do the best for our daughter’.

Where there is high staff turnover it is difficult to build trust; important information about how to support the person gets lost as there is no sense of history.

Although outside of the scope of the NICE guidelines families feel strongly that the issue of developing a better paid, more highly valued workforce needs to be a priority.

Staff development issues for this workforce are also a priority across the range of services and including clinicians, teachers as well as support of care staff. This includes emphasising a value driven approach as well as improving knowledge and awareness of the specific issues facing children, young people and adults with learning disabilities who display behaviour described as challenging. It also needs to focus on developing skills (in areas like PBS).

‘Staff development is different from training. We want the people, who support our family member to really understand them, build a relationship with them and engage them in meaningful, purposeful, care. You can’t do that unless you build a relationship’.

One member of the workshop who is both a Mum and a qualified psychiatric nurse also emphasised the role of practice leadership, whilst other families are keen to stress the importance of developing a workforce where there is a culture of transparency and openness rather than defensiveness and secrecy.

Integrated care and joined up working

Families told us they frequently experience the health and social care system as fragmented and nothing seems to join up.

‘There is a lack of integrated / joined up support – each service assumes you only see (or need to see) them.’

In practice this means families are often the bridge between a range of services and find themselves playing an important coordination role. This role is frequently not recognised or valued and puts added layers of frustration and stress on their relationship with services.

To enhance integrated care involves thinking about care and health pathways from the person’s perspective. Services and the different professional groups within them need to pay more attention to shared working and creating structures that coordinate information, interventions and evaluation and review into a single process.

Developing a range different ways of collecting and recording evidence

Families understand the need for robust, evidence-based practice as a way of ensuring good person centred outcomes for their family member. However during the workshops, families expressed a concern about how NICE would define what constituted ‘evidence’. There was a real fear that there would be a bias towards ‘hard’ quantitative data, which might be easier to develop around medication, than ‘softer’ ethnographic or experiential qualitative data.

Families were also concerned that the routine, observational, everyday changes they record would not be valued or validated. The implications for NICE is the need to have a more flexible approach to evidence and to invest in evaluating a range of different ways of collecting and recording evidence of what works.

‘It is really crucial that the research that’s being done in these areas such as need for medication and challenging behaviour is not always based on number crunching research studies alone. Basing an understanding of a subject only on these studies gives one a very narrow understanding of what is happening’.

Access to advocacy

Families often feel that they have to take on the role of advocate to get the best out of services on behalf of their family member: especially, but not exclusively, if they do not communicate verbally. Families who take on an advocacy role often find themselves as labelled as ‘difficult’. This does not help build good working relationships,

‘It does feel lonely and isolating fighting with services all the time. I get depressed.’

For this reason many of the families told us they would welcome having greater access to *Family Advocacy: f*amily advocates that could/can work alongside them and support them to both get the best for their family member and wider family needs. Despite the need there is very little of this sort of advocacy available to families.

There is also an issue of availability for families trying to access Independent Advocacy services for their family member. This is particularly important if the person is placed out of area in either a residential setting or an ATU or hospital. The mental health system is often a new and difficult system for families to navigate and the role of a good quality advocate is vital in reassuring families that their family members best interests are being looked after!

Personal Budgets

Some families manage a Personal Budget/Direct Payment for their son or daughter. Others are considering Personal Health Budgets. The management of these budgets and becoming an employee is something that they say they need much more information and support with.

'It does give you more choice and control but it is not always easy to manage. You have to recruit staff with the right values, induct them and train them up.'

'It feels like a minefield! Employee rights – employer responsibilities – all I want is good people supporting him to live well in the community - I never thought I would be managing rotas.'

In conclusion: Making change happen!

The workshops provided an opportunity for families to have their say about the range of issues that are important from their perspective and experience. However there was concern about whether, as a result of the new guidelines, their experience would change!

'We have so many policy documents telling us what should happen! We have a lot of good practice published that tells us what can happen and yet nothing changes where we live'.

The families at the workshops asked the question *what difference will these NICE Guidelines make'?* What support will be put in place to implement them? Who will monitor and evaluate the outcomes?

'We have policy; we have research – what are the barriers to implementation?'

Making change happen is the challenge we *all* face!

Appendix

At the end of each session families were asked "*If you had one key message to send to the guideline development group what would it be?"*. These statements have been transcribed below and highlight key themes that arose during the days' discussions. These themes have been underlined. They demonstrate how different people highlighted similar issues as the main priority.

1. *Involve and listen to families at every opportunity and level.*
2. *High quality positive behavioural support and ABA needs to be readily accessible as a local service in all parts of the country for adults and children with learning disability who display behaviour described as challenging.*
3. *That the correct expertise is available (Tizard, PBS, ABA, Dr Santosh, CBF, MENCAP, NAS, Improving Lives Review). The correct expertise has to be involved in the joint commissioning, CQC, training, NICE guidance and mental health act development, education. Including 'experts by experience' (families).*
4. *Person centred assessment, planning & treatment. Basically everything should, needs & must be person centred.*
5. *ABA overseen by BCBA – available on the state for all, not just the rich.*
6. *More qualified carers in all areas. More caring in the caring community (we've got the funds but can't find the expertise).*
7. *A strong accountable implementation programme to make the guideline a reality.*
8. *Why has it taken so long to realise these people need guidance – put words into action. Make a difference to our young people's lives "Give her a life not just an existence".*
9. *Always listen to the parents who are best placed to know their young person and tell them what you know regarding available provision.*
10. *ATU's must have closer monitoring with specific research on the use of physical and chemical restraint. The Mental Health Act allows our most vulnerable people to be abused in health care settings and it would not be allowed in any other health care settings. You need to give local areas greater expertise in regard to service requirements in their locality. Without this they cannot bring people 'home'.*

11. *Four pleas:*

    - *Please treat parents and carers as equal partners*
    - *Please make sure staff have adequate training so they can advocate for their patients effectively*
    - *Please make sure commissioning is responsive to individual needs and not just for the masses*
    - *Please remember that every patient has a right to have their needs met*

12. *I think it is essential that a functional assessment carried out by someone with a qualification in ABA underpins behaviour support plans & that they are monitored & amended when necessary. Early intervention is key.–There needs to be increased knowledge amongst all professionals in Health & Social Care.*

13. *It's important that carers are well paid & fully qualified to care for our child/young person/adult.*

14. *Assessors start blind, they don't know the person, and the tools are not fit for purpose (how are tools tested?). They're not joined up through assessment, action & evaluation. (This needs to change).*

15. *Communication needs to be tested against understanding - people are individuals. With challenging behaviour the devil is in the 'minute' detail.*

    Qualitative data tells you what you need to do differently, numbers don't.

16. *It's crucial that the research that is being done in these areas (such as need for medication and challenging behaviours) is not always based on numbers alone. Basing an understanding of a subject only on these studies gives a very narrow understanding of what is happening.*

17. *How skilled are people? What power do they have, what skills do they have? What constituency are they representing? People should be involved & included. Are they engaged? What is the impact?*