Findings from an online survey of family carer experience of the management of challenging behaviour in people with intellectual disabilities, with a focus on the use of psychotropic medication

ACCESSIBLE SUMMARY

- Family members often support people with intellectual disabilities who display challenging behaviour. Family carers should be listened to and included in important decisions.
- We asked family carers how professional services had helped their relative with challenging behaviour.
- Family carers said that the care of people with intellectual disabilities who display challenging behaviour can be improved. Family carers sometimes felt left out of decisions and said that they needed more information.
- Listening to parent carers' experiences can help to improve the services that are provided to people with intellectual disabilities and their families.

Keywords
Challenging behaviour; collaborative practice; family support; intellectual disability; mental health; psychopharmacology

ABSTRACT

Background

There is relatively little published data that report the experiences and views of family carers of people with intellectual disabilities who display challenging behaviour who are prescribed psychotropic medication.

Materials and methods

An online structured questionnaire was created by the Challenging Behaviour Foundation, a UK charity, and family carers of people with intellectual disability. Questions concerned the management of challenging behaviour and asked family carers about their experiences and views on the use of psychotropic medication. Responses were gathered between August and October 2016. Results are described using descriptive and inferential statistics and descriptive analysis of free-text comments.

Findings

Ninety-nine family carers completed the survey. Family carers reported gaps in the holistic and pro-active management of challenging behaviour. Whilst some felt involved in decisions around psychotropic medication prescribing, others described feeling marginalised and lacking information and influence. The decision to prescribe psychotropic medication evoked complex emotions in family carers and medication use was associated with mixed outcomes in those prescribed. Family carers identified areas of good practice and those areas where they believe improvements are needed.

Conclusions

Psychotropic medication should be only one option in a multi-modal approach to challenging behaviour but this may not always be reflected in current practice. Greater effort needs to be made to ensure that services are equipped to provide optimum care and to embed shared decision making into routine practice.

MANUSCRIPT

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Background

Challenging behaviour is a broad term used to describe problematic or socially unacceptable conduct including self-injury, aggression, and destruction of property (Emerson & Einfeld, 2011). The prevalence of challenging behaviour in people with intellectual disabilities is between 10 and 15 percent, with higher rates amongst boys and men, those with severe-profound intellectual disability, and those with co-morbid autism spectrum disorder (Emerson et al., 2001; McClintock, Hall, & Oliver, 2003). Individuals who display challenging behaviour face exclusion from community activities, are subject to restrictive interventions, and risk transfer to out-of-area residential placements or even admission to hospital. Caring for a person with intellectual disability who displays challenging behaviour is associated with chronic stress, physical and mental health problems, and social isolation (Baker et al., 2003; Davies & Honeyman, 2013; Maes, Broekman, Došen, & Nauts, 2003). Family carers often play a vital role in supporting people with intellectual disability across the lifespan and should be involved in care decisions (HM Government, 2011). However in previous research family carers have reported difficulties in accessing suitable information (Redmond & Richardson, 2003) and in partnership working with specialist services (Knox, 2000).

Improving the care and support offered to people with intellectual disabilities who display challenging behaviour and their carers is a national priority in the UK (Department of Health, 2012). Recent NICE guidelines for challenging behaviour emphasise holistic, multi-disciplinary assessment and formulation, and favour psychosocial and environmental interventions, such as positive behaviour support (National Institute for Health and Care Excellence, 2015). The use of psychotropic medication to support people with challenging behaviour is controversial and largely unsupported by research evidence (Deb, Sohanpal, Soni, Lentre, & Unwin, 2007;

Matson & Neal, 2009), although recent population-based studies indicate that this use continues to be widespread across regions (Sheehan et al., 2015; Lunsky et al., 2017). People with intellectual disabilities appear more sensitive to adverse side-effects of psychotropic medications (Arnold, 1993; Sheehan et al., 2017) and their use for challenging behaviour might detract from the provision of alternative modes of therapy.

In the UK, a national campaign, Stopping the Over-Medication of People with Learning Disabilities and/or Autism (STOMP), was established in 2016 to reduce the use of psychotropic drugs for challenging behaviour and promote the development and uptake of alternative interventions (https://www.england.nhs.uk/learning-disabilities/stomp/). The STOMP programme, led by the National Health Service in England, draws together key stakeholders including professional groups in health and social care, third sector, charity, and advocacy organisations, in a series of activities to raise awareness of potential over-use of psychotropic medication and share good practice. The Challenging Behaviour Foundation is a UK national charity that supports people with intellectual disabilities and their families through the provision of information, support, and national influencing (www.challengingbehaviour.org.uk/). As part of the work of STOMP the Challenging Behaviour Foundation was commissioned to gather the experiences and views of family carers of people with intellectual disability with regard to the management of challenging behaviour and use of psychotropic medication. The work was intended to provide a platform for family carers to share their lived experience of medication being used or suggested for their relative with intellectual disability.

Methods

An internet-mediated survey was developed by two employees of the Challenging Behaviour Foundation who are also family carers, one parent and one sibling (SurveyMonkey survey platform: https://www.surveymonkey.co.uk/). The parent had personal experience of the use of psychotropic medication to manage behaviour described as challenging for their relative. The sibling, in partnership with parents, was in the process of supporting their relative through the decision about whether or not to use medication as part of the management of behaviour described as challenging. A reference panel of family carers reviewed and finalised the survey questions.

People were eligible to take part if they were a family carer for an individual with intellectual disability or autism who had behaviour described as challenging. Current or past use of psychotropic medication was not a requirement. An invitation and link to participate in the survey was sent to 314 family carers who were members of the Challenging Behaviour Foundation's Family Carers' e-mail network. The survey was also advertised through publicly-available social media including Facebook and Twitter, and by other organisations working in the field including the National Autistic Society and the Choice Forum, an online discussion site for issues affecting the lives of people with intellectual disability. The survey was open for six weeks between mid-August and the beginning of October 2016. Respondents were given the opportunity to participate via hardcopy or telephone for those who were not able, or did not wish to use a computer. Completion of the survey was entirely voluntary and no financial incentive was offered to those who took part.

The survey landing page explained the background and purpose of the work and how the collected data would be handled. After giving consent for analysis and use of anonymised responses, family carer participants were directed through a structured questionnaire that covered three major topics; demographic and clinical details of their relative with intellectual disability; experience of professional services and the management of challenging behaviour, with a focus on the use of psychotropic medication; and views about resources and materials that might be helpful to those in similar circumstances. Those who did not have personal experience of the use of psychotropic medication for their relative were automatically directed past questions specifically concerning medication. The survey contained a mix of closed (multiple choice) and open-ended (free text) questions and was estimated to take approximately 15 minutes to complete. No personally-identifiable data were collected.

Responses were automatically downloaded into Microsoft Excel. SPSS v23 for Windows was used for numerical analysis. The Student's t-test, Pearson's chi-square, and logistic regression were used to compare differences in variables between groups that had and had not been prescribed psychotropic medication and in assessment and management of challenging behaviour between children/adolescents (<18 years) and adults. All tests were two-tailed and the significance level was 0.05.

Responses to the free-text questions were analysed by question in a descriptive analysis. Responses to each open-ended question were read and reviewed independently by two members of the author team (RS and KK) who then discussed major topics in the response set for each question. Following further discussion within the author team the topics were agreed and illustrated with representative quotes.

Findings

Characteristics of respondents and their relative with intellectual disability

Ninety-nine individuals completed the survey. Just over two-thirds of respondents indicated that they were aware of the work of the Challenging Behaviour Foundation prior to participating. 85% were the parent of an individual with intellectual disability who displayed challenging behaviour.

Characteristics of the respondent's relative with intellectual disability are reported in table 1; the majority were male, had severe-profound intellectual disability (intelligence quotient <35), co-morbid autism spectrum disorder, and displayed several forms of challenging behaviour. All respondents reported that their relative displayed at least one form of challenging behaviour.

[Table 1 near here]

Management of challenging behaviour

Table 2 shows the frequency with which family carers reported different elements in the care of people with intellectual disability and challenging behaviour. Differences in the frequencies of management interventions between children/adolescents (likely to be managed by Child and Adolescent Mental Health Services and/or community paediatrics teams) and adults (likely to be managed by specialist psychiatry of intellectual disability services) in the sample are shown. Adults with intellectual disability were reported to be more likely to have a person-centred plan and an annual health check than children/adolescents with intellectual disability. Conversely family carers reported more often being involved in prescribing decisions for children/adolescents than for adults.

[Table 2 near here]

Use of psychotropic medication for challenging behaviour

Psychotropic medication had been prescribed to 82 (83%) relatives of those who responded. Of these 82 cases, psychotropic medication was used to manage challenging behaviour (either with or without a co-morbid mental health problem) in 90%. In 54% of these cases there was no past or current diagnosis of mental illness. A range of psychotropic medication had been prescribed, with the most common drug class being antipsychotics (57% those prescribed medication), followed by anti-depressants (38%), mood stabilisers (26%), and anxiolytics (23%).

There was no difference between the groups prescribed and not prescribed medication in terms of age (t=0.137, p=0.892), gender (χ^2=0.249, p=0.735), degree of intellectual disability (χ^2=0.377, p=0.828) or presence of autism spectrum disorder (χ^2=0.395, p=0.505). There were statistically-significant positive associations between the presence of mental illness and the prescription of psychotropic medication (χ^2=4.904, p=0.027) and the number of forms of challenging behaviour and prescription of psychotropic medication; those with more types of challenging behaviour being more likely to have been prescribed psychotropic medication (unadjusted odds ratio 1.820, p<0.001).

Over one-third (38%) of family carers reported that they had not been given any information about medication that was prescribed. 77 (95%) family carers indicated they had done their own research including internet searches, asking others, and contacting relevant charities for more information.

Family carers reported being aware of medication being reviewed at least 6 monthly in just less than half (44%) of all cases. Fifty-five percent of family carers reported that their relative had experienced adverse side-effects whilst taking psychotropic medication. 56 (69%) of family carers had not been asked to record information about side-effects in a systematic or structured way.

Free text results

The free text options within the survey were analysed using descriptive text analysis and major topics illustrated with quotes.

Free text question 1: Were you involved in the final decision to prescribe medication for your relative and were your views considered?

A minority (39%) of family carers felt fully and meaningfully involved in decisions about psychotropic medication use in their relative. In those cases where family members were involved, they sometimes described having very little influence over decisions. The survey also showed that other family carers reported feeling excluded from decisions around psychotropic medication prescribing. In some cases, decisions were made without any dialogue with family carers. Another topic that was regularly seen in the data was the feeling that there was a power imbalance, perpetuated in some cases by a lack of information that carers received.

[Table 3 near here]

Free text question 2: How did you feel about the decision to prescribe medication?

The decision to use psychotropic medication often evoked strong emotions in family carers, and a mixture of anger, sadness, disappointment, guilt and frustration. Family carers reported that medication was often used in the absence of other interventions which were viewed as more appropriate and several respondents conveyed a sense of desperation about their relative’s situation. Amongst the responses, there were also some positive experiences, however some concerns about side effects were a particular factor in anxiety felt by family carers.

[Table 4 near here]

Free text question 3: Has medication made a difference to your relative?

In most cases (77%) family carers indicated that psychotropic medication had made a difference to their relative. Responses naturally divided in almost equal proportions into those who reported a positive impact of medication, those reporting only negative effects, and those who reported positive effects mitigated by adverse side-effects. Some reported that medication had had a transformative beneficial effect on their relative, illustrating the varying outcomes of psychotropic medication use on people with ID. Those reporting a largely negative impact of medication tended to focus on adverse side-effects, which were often numerous and mixed.

[Table 5 near here]

Free text question 4: Overall what worked well? What could be improved?

Family carers were asked about their overall experience of the management of challenging behaviour and use of psychotropic medication with results collected into main themes. Fourteen family carers were unable to find any positives in their experience of management of challenging behaviour or use of psychotropic medication, reflected in the opinion of one respondent that *“the whole system”* needs to be improved (Respondent 97). There were numerous suggestions of improving the experience as well as endorsements of current methods that are in place. These included, more access to information as well as prevention strategies and care plans, the use of informed assessments, and access to alternative modes of management.

[Table 6 near here]

Discussion

Main findings

We used a structured online survey to investigate family carer experience and views of the management of challenging behaviour in a relative with intellectual disability, focusing on psychotropic medication use. Respondents cared for family members with a high level of support need including severe to profound intellectual disability, multiple types of challenging behaviour, and physical and mental health co-morbidities.

Relatives reported that several elements considered good practice in the holistic and pro-active care of people with intellectual disability and complex needs, such as the development of person-centred support plans and health action plans, were often not undertaken. A high proportion of both adults and children who had been prescribed psychotropic medication for challenging behaviour were reported not to have had a physical health check, despite the fact that people with intellectual disability are prone to a range of physical health problems that can manifest as changes in behaviour (Alborz, McNally, & Glendinning, 2005).

Family carers indicated that they were regularly involved in decisions to prescribe medication. While some described good experiences of partnership working with the clinical team, for others the involvement was perceived as superficial and many relatives reported feeling marginalised and powerless in treatment decisions. In addition, family carers often reported they were not provided with sufficient or relevant information to enable them to effectively participate in shared decision making.

Many family carers were uneasy about the decision to prescribe psychotropic medication. Rappaport and Chubinsky suggest that parents are often apprehensive about using psychotropic medication in their children and discuss the complex emotional response to decisions to use medication (Rappaport & Chubinsky, 2000). We saw that the issue of prescribing was often highly emotionally-charged and family carers expressed a mix of anger, sadness, and guilt about the use of medication. Many felt there was no choice but to use medication, either because alternatives were not available or had not been effective. There was considerable anxiety about medication adverse side-effects which could add to the pre-existing health conditions that many of the sample described in their relative. When medication was prescribed family carers tended to report that it had made a difference and family carers reported mixed beneficial and deleterious effects. This observation, along with the off-license nature of psychotropic medication use in in challenging behaviour, underlies the importance of regular medication monitoring (General Medical Council, 2013; Royal College of Psychiatrists, 2016) yet family members reported that medication reviews occurred less than 6 monthly in over half of cases. This result is similar to findings from a national audit of antipsychotic prescribing to people with intellectual disability which found screening for adverse side-effects in this group is poor (Paton, Bhatti, Purandare, Roy, & Barnes, 2016).

We compared responses of family carers of children/adolescents and those of adults in order that any observed differences in reported management between the groups may act as a focus for further investigation. Broadly similar results were found between the two groups, indicating there is scope to improve the service response to challenging behaviour across the lifespan. Family carers of adults with intellectual disability and challenging behaviour were significantly more likely to report that they had received an annual health check; this is understandable given the NHS programme of primary care annual health checks for people with intellectual disability currently only applies to those aged 14 and over. Family carers of those under 18 years were significantly more likely to indicate they had been involved in medication decisions. There might be differences in culture between children's and adults' services with the former having an expectation of family carer input to care decisions, or this association might imply inconsistent application of capacity legislation in adults with intellectual disability who lack capacity to consent to treatment.

The major topics identified in the free text analysis accord with previous research that has investigated the experiences of family carers of people with intellectual disability using support services. Previous research has shown that family carers value access to expert staff, continuity in professional relationships, and good two-way communication that permits effective health information exchange yet regularly report dissatisfaction with services (Kenny & McGilloway, 2007; McGill, Papachristoforou, & Cooper, 2006). In particular, family carers of people with intellectual disability report: a lack of partnership working and neglect of family carer knowledge and opinion; a ‘battle’ to be recognised and access support; reactive rather than proactive services in which a crisis situation must be reached before support is received; and lack of clear and understandable information about their relatives condition and care (Douma, Dekker, & Koot, 2006; Elford, Beail, & Clarke, 2010; Faust & Scior, 2008; Griffith & Hastings, 2014; James, 2013; McGill, Cooper, & Honeyman, 2010; Wodehouse & McGill, 2009). Many of these topics were mentioned in the survey data. Despite this, we should not neglect that some respondents reported positive experiences, including with the use of psychotropic medication. Whilst clearly in a minority in this sample, their responses show that good practice and family-centred care can be achieved in this context.

Strengths and limitations

This study adds to the limited literature that reports family carer experience of the use of psychotropic medication and the management of challenging behaviour in a relative with intellectual disability.

The work is novel in design and content. The project was largely user-controlled given that the survey was designed and conducted by people with personal experience of caring for a relative with intellectual disability and a charity committed to improving the lives of people with intellectual disability. The work reflects the priorities and concerns of family carers of those using services and on a practical level the involvement ensured that relevant questions were asked in an accessible way. We noticed no appreciable attrition as the survey questions progressed and only minimal amounts of missing data, suggesting that it was an acceptable design and confirming the importance of the topic to family carers who were keen to be heard. The online survey design enabled a relatively large number of people to describe their experience and opinions which, given resource limitations, would not otherwise have been possible. We were not restricted by geography and the survey was available for participants to take at their own convenience, an important consideration for respondents whose caring responsibilities may preclude them from participating in other research studies that require more commitment. The method gave little opportunity for the investigators to influence the results and the anonymity offered may have reduced social desirability bias. Data were collected from carers of both adults and children with intellectual disability which enabled post-hoc comparisons to be made between the two groups and could act as a stimulus for future work. The administration of the survey by a third-sector charitable organisation may have encouraged participation of those who would not ordinarily respond to approaches by statutory services or academic centres.

There are several limitations to this work. As this was an open survey we are not able to define the sampling frame or report response rate. Respondents were self-selecting and the majority were aware of the work of the Challenging Behaviour Foundation prior to completing the survey; this group may feel their needs are not being met and might not be representative of all family carers of people with intellectual disability. Although telephone support to complete the survey was offered, few people utilised this and the survey will have excluded people who do not have access to the internet and those with low functional literacy.

We had no way of validating responses and some participants may have inadvertently answered questions incorrectly. This might lead to under-estimation of the interventions for challenging behaviour. Participants may have related past experiences which are not indicative of current care and responses may have been subject to recall bias and influenced by subsequent events. By focusing on family carers in this survey we did not hear from other stakeholders and more work is needed to explore the experiences and attitudes of paid carers and those with intellectual disability themselves.

Collecting qualitative data using an online survey has limitations. The length of the text responses to open questions was limited and it was not possible to interpret subtleties of tone or body language, or explore responses in a way that would have been possible with more flexible face-to-face methods. Analysing responses by question only precluded a richer interpretation of individual experience. Further in-depth qualitative work with a smaller sample is warranted to explore some of the topics raised in this work more fully.

Summary

Family carer experience of psychotropic medication

Challenging behaviour is a common presentation in people with intellectual disability and can have serious consequences for an individual and their carers. Although the evidence base for effective interventions for challenging behaviour is lacking, standards of best practice in assessment and management are widely accepted (National Institute for Health and Care Excellence, 2016). This survey of family carer experience suggests a relatively high proportion people with intellectual disability and challenging behaviour might not receive appropriate forms of assessment and intervention. The perceived over-reliance on psychotropic medication for challenging behaviour has been highlighted and is a cause of concern for many family carers. With some exceptions, family carers often report feeling disempowered and alienated from support and treatment decisions around psychotropic medication use.

Services for people with intellectual disability who display challenging behaviour should work effectively in partnership with family carers to promote shared decision making and collaborative care planning. There is an ongoing need to ensure the provision of clear and understandable information for family carers and to improve access to non-medication strategies for the management of challenging behaviour.

References

Alborz, A., McNally, R., & Glendinning, C. (2005). Access to health care for people with learning disabilities in the UK: mapping the issues and reviewing the evidence. Journal of Health Services Research & Policy, 10(3), 173-182. doi: 10.1258/1355819054338997

Arnold, L. E. (1993). Clinical pharmacological issues in treating psychiatric disorders of patients with mental retardation. Annals of clinical psychiatry, 5(3), 189-197.

Baker, B. L., McIntyre, L., Blacher, J., Crnic, K., Edelbrock, C., & Low, C. (2003). Pre-school children with and without developmental delay: behaviour problems and parenting stress over time. Journal of Intellectual Disability Research, 47(4-5), 217-230.

Davies, K., & Honeyman, G. (2013). Living with a child whose behaviour is described as challenging. Advances in Mental Health and Intellectual Disabilities, 7(2), 117-123. doi: 10.1108/20441281311310216

Deb, S., Sohanpal, S., Soni, R., Lentre, L., & Unwin, G. (2007). The effectiveness of antipsychotic medication in the management of behaviour problems in adults with intellectual disabilities. Journal of Intellectual Disability Research, 51(10), 766-777. doi: 10.1111/j.1365-2788.2007.00950.x

Department of Health. (2012). Transforming care: A national response toWinterbourne View Hospital. London.

Douma, J., Dekker, M., & Koot, H. (2006). Supporting parents of youths with intellectual disabilities and psychopathology. Journal of Intellectual Disability Research, 50(8), 570-581. doi: 10.1111/j.1365-2788.2006.00825

Elford, H., Beail, N., & Clarke, Z. (2010). ‘A very fine line’: parents’ experiences of using restraint with their adult son/daughter with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities, 23(1), 75-84. doi: 10.1111/j.1468-3148.2009.00548.x

Emerson, E., & Einfeld, S. (2011). Challenging Behaviour (3rd ed.). Cambridge, UK: Cambridge University Press.

Emerson, E., Kiernan, C., Alborz, A., Reeves, D., Mason, H., Swarbrick, R., . . . Hatton, C. (2001). The prevalence of challenging behaviors: A total population study. Research in developmental disabilities, 22(1), 77-93. doi:

Faust, H., & Scior, K. (2008). Mental health problems in young people with intellectual disabilities: The impact on parents. Journal of Applied Research in Intellectual Disabilities, 21(5), 414-424. doi: 10.1111/j.1468-3148.2007.00411.x

General Medical Council. (2013). Good Medical Practice. Manchester.

Griffith, G. M., & Hastings, R. P. (2014). 'He's hard work, but he's worth it'. The Experience of Caregivers of Individuals with Intellectual Disabilities and Challenging Behaviour: A Meta-Synthesis of Qualitative Research. Journal of Applied Research in Intellectual Disabilities, 27(5), 401-419. doi: 10.1111/jar.12073

Her Majesty's Government. (2011). No Health Without Mental Health: A Cross-Government Mental Health Outcomes Strategy for People of All Ages Health. London

James, N. (2013). The formal support experiences of family carers of people with an intellectual disability who also display challenging behaviour and/or mental health issues: What do carers say? Journal of Intellectual Disabilities, 17(1), 6-23. doi: 10.1177/1744629512472610

Kenny, K., & McGilloway, S. (2007). Caring for children with learning disabilities: an exploratory study of parental strain and coping. British Journal of Learning Disabilities, 35(4), 221-228. doi: 10.1111/j.1468-3156.2007.00445.x

Knox, M. (2000). Family control: The views of families who have a child with an intellectual disability. Journal of Applied Research in Intellectual Disabilities, 13(1), 17-28. doi: 10.1046/j.1468-3148.2000.00001.x

Lunsky, Y., Khuu, W., Tadrous, M., Vigod, S., Cobigo, V., Gomes, T. (2017). Antipsychotic use with and without comorbid psychiatric diagnosis among adults with intellectual and developmental disabilities. The Canadian Journal of Psychiatry, e-Pub ahead of print doi: https://doi.org/10.1177%2F0706743717727240

Maes, B., Broekman, T., Došen, A., & Nauts, J. (2003). Caregiving burden of families looking after persons with intellectual disability and behavioural or psychiatric problems. Journal of Intellectual Disability Research, 47(6), 447-455. doi: 10.1046/j.1365-2788.2003.00513.x

Matson, J. L., & Neal, D. (2009). Psychotropic medication use for challenging behaviors in persons with intellectual disabilities: An overview. Research in developmental disabilities, 30(3), 572-586. doi: 10.1016/j.ridd.2008.08.007

McClintock, K., Hall, S., & Oliver, C. (2003). Risk markers associated with challenging behaviours in people with intellectual disabilities: A meta-analytic study. Journal of Intellectual Disability Research, 47(6), 405-416. doi: 10.1046/j.1365-2788.2003.00517.x

McGill, P., Cooper, V., & Honeyman, G. (2010). Developing better commissioning for individuals with behaviour that challenges services–a scoping exercise. Tizard Centre/Challenging Behaviour Foundation, Canterbury and Chatham.

McGill, P., Papachristoforou, E., & Cooper, V. (2006). Support for family carers of children and young people with developmental disabilities and challenging behaviour. Child: Care, Health and Development, 32(2), 159-165. doi: 10.1111/j.1365-2214.2006.00600.x

National Institute for Health and Care Excellence (NICE). (2016). Learning disabilities: challenging behaviour. Quality Standard [QS101]. London, UK.

National Institute for Health and Care Excellence (NICE). (2015). Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges [NG11], . London, UK.

Paton, C., Bhatti, S., Purandare, K., Roy, A., & Barnes, T. (2016). Quality of prescribing of antipsychotic medication for people with intellectual disability under the care of UK mental health services: a cross-sectional audit of clinical practice. BMJ Open, 6(12), e013116. doi: 10.1136/bmjopen-2016-013116

Rappaport, N., & Chubinsky, P. (2000). The meaning of psychotropic medications for children, adolescents, and their families. Journal of the American Academy of Child and Adolescent Psychiatry, 39(9), 1198-1200. doi: http://dx.doi.org/10.1097/00004583-200009000-00021

Redmond, B., & Richardson, V. (2003). Just Getting on with it: exploring the service needs of mothers who care for young children with severe/profound and life-threatening intellectual disability. Journal of Applied Research in Intellectual Disabilities, 16(3), 205-218. doi: 10.1046/j.1468-3148.2003.00165.x

Royal College of Psychiatrists. (2016). Psychotropic drug prescribing for people with intellectual disability, mental health problems and/or behaviours that challenge: practice guidelines.

Sheehan, R., Hassiotis, A., Walters, K., Osborn, D., Strydom, A., & Horsfall, L. (2015). Mental illness, challenging behaviour, and psychotropic drug prescribing in people with intellectual disability: UK population based cohort study. BMJ, 351, h4326. doi: 10.1136/bmj.h4326

Sheehan, R., Horsfall, L., Strydom, A., Osborn, D., Walters, K., & Hassiotis, A. (2017). Movement side effects of antipsychotic drugs in adults with and without intellectual disability: UK population-based cohort study. BMJ Open, 7, e017406. doi: 10.1136/bmjopen-2017-017406

Wodehouse, G., & McGill, P. (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), 644-653. doi: 10.1111/j.1365-2788.2009.01163.x

Table 1 Characteristics of the sample (*n*=99)

Age	
Mean (SD), years	23.8 (12.0)
<18 years, n(%)	29 (29%)
>18 years	69 (70%)
Missing	1
Sex	
Male, n(%)	80 (81%)
Missing	0 (0%)
Degree of intellectual disability	
Mild-moderate, n(%)	27 (28%)
Severe-profound, n(%)	66 (67%)
None,* n(%)	4 (4%)
Missing, n	2
Co-morbidity	
Mental illness, n(%)	40 (40%)
Autism spectrum disorder, n(%)	81 (82%)
Epilepsy, n(%)	26 (26%)
Challenging behaviour by type	
Physical aggression directed towards others, n(%)	68 (69%)
Self-stimulatory behaviours, n(%)	65 (66%)
Self-injury, n(%)	61 (62%)
Property damage, n(%)	61 (62%)
Verbal aggression, n(%)	53 (54%)
Obsessional or ritualistic behaviours, n(%)	46 (46%)
Inappropriate social behaviours, n(%)	38 (38%)
Pica, n(%)	17 (17%)
>4 of the above forms of challenging behaviour	49 (49%)

*all of these individuals had autism spectrum disorder and associated challenging behaviour

Table 2 Elements in assessment and management of challenging behaviour

		Total sample	**Children with intellectual disabilities (<18 years) (*n*=30*)**	**Adults with intellectual disabilities (≥18 years) (*n*=68*)**	**χ^2**	**p-value**
Whole sample						
Number, *n*		99	30*	68*		
Person-centred plan, n (%)	Yes	24 (24)	8 (27)	48 (71)	18.728	**0.000**
	No	69 (70)	21 (70)	16 (24)		
	Missing	6 (6)	1 (3)	4 (6)		
Behaviour support plan, n (%)	Yes	42 (42)	12 (40)	30 (44)	0.682	0.409
	No	50 (51)	18 (60)	31 (46)		
	Missing	7 (7)	0 (0)	7 (10)		
Annual health check, n (%)	Yes	55 (56)	11 (37)	44 (65)	9.019	**0.003**
	No	37 (37)	18 (60)	18 (26)		
	Missing	7 (7)	1 (3)	6 (9)		
Health action plan, n (%)	Yes	33 (33)	7 (23)	26 (38)	3.665	0.056
	No	57 (58)	23 (77)	33 (87)		
	Missing	9 (9)	0 (0)	9 (13)		
Psychotropic medication prescribed, n (%)	Yes	82 (83)	25 (83)	56 (82)	0.014	0.906
	No	17 (17)	5 (17)	12 (18)		
	Missing	0 (0)	0 (0)	0 (0)		
Those prescribed psychotropic medication						
Number, *n*		82	25*	56*		
Functional analysis of behaviour, n (%)	Yes	12 (15)	6 (24)	6 (11)	2.098	0.148
	No	67 (82)	19 (76)	47 (84)		
	Missing	3 (4)	0 (0)	3 (5)		
Baseline recording of behaviour, n (%)	Yes	14 (17)	4 (16)	10 (18)	0.118	0.731
	No	64 (78)	21 (84)	42 (75)		
	Missing	4 (5)	0 (0)	4 (7)		
Health check, n (%)	Yes	16 (20)	5 (20)	11 (20)	0.006	0.939
	No	63 (77)	20 (80)	42 (75)		
	Missing	3 (4)	0 (0)	3 (5)		
Alternative intervention to medication, n (%)	Yes	30 (37)	7 (28)	23 (41)	2.053	0.152
	No	47 (57)	18 (72)	28 (50)		
	Missing	5 (6)	0 (0)	5 (9)		
Relative involved in	Yes	57 (70)	22 (88)	34 (61)	7.723	**0.005**
	No	19 (23)	1 (4)	18 (32)		

decision to prescribe, n (%)	Missing	6 (7)	2 (8)	4 (7)		

*Age missing for one person

Table 3 Were you involved in the final decision to prescribe medication for your relative and were your views considered?

Major topics	**Supporting quotes**
Those who felt informed and involved	*"[We were] involved...possibly because we have now made two formal complaints" (Respondent 21)"* *"I was consulted and my opinions taken on board (Respondent 23)"* *"Yes, as parents we were fully involved (Respondent 45)"* *"Yes, we were given information to consider pros and cons, encouraged to research for ourselves (Respondent 51)."*
Feeling excluded	*"I'm not invited to attend appointments even though I have made numerous requests" (Respondent 27)* *"We had no voice" (Respondent 36)* *"The [service] provider got diazepam prescribed without my knowledge" (Respondent 75)*
Little influence in decision making	*"We were consulted but all our doubts [and] objections politely put aside" (Respondent 61)* *"I didn't want my son on medication but…I felt pressured, [medication] was the only way" (Respondent 40)*
Power imbalance	*"We had to accept we don't know what is good or bad…we were helpless" (Respondent 60)* *"I was involved…but I wasn't provided with the information I needed to make an informed decision" (Respondent 48)*

Table 4 How did you feel about the decision to prescribe medication?

Major topics	**Supporting quotes**
Mixed reactions to care	*"I feel very angry and that there is no explanation about the side effects" (Respondent 4)* *"I felt it was all wrong…the medication compounded a situation which…we feel could have been handled very differently" (Respondent 48)* *"Positive, especially now my son is under the care of an excellent, patient-centred psychiatrist in the CLDT, the meds are a support" (Respondent 51)*
Lack of alternatives to medication	*"Felt it was necessary but that environmental factors were not addressed…Challenging behaviour was only happening at supported living, not weekends at home with us" (Respondent 13)* *"Not enough support was given, so fell heavily on meds" (Respondent 90)* *"Felt there was no other option or support" (Respondent 62)* *"I was told this was the only option for my son who has severe challenging behaviour…you'll do anything" (Respondent 33)* *"We wished there had been other alternatives but felt desperate as behaviour was extremely challenging" (Respondent 45)*

Table 5 Has medication made a difference to your relative?

Major topics	**Supporting quotes**
Positive effects	*"Our son is much more himself…we're happy" (Respondent 96)* *"His mood is more stable and aggression and outbursts very reduced…this enables our relative to go out in the community to activities he enjoys" (Respondent 9)* *"Best thing that happened to my son. It was worrying to start with but it has been extremely effective" (Respondent 73)*
Negative impact and adverse effects of medication	*"She started to have seizures and dribble and tremble" (Respondent 55)* *"Many and varied [side-effects] …restlessness, urinary problems, digestive problems, sexual dysfunction, sluggishness…" (Respondent 48)*

Table 6 Overall what worked well? What could be improved?

“What worked well?”	
Psychosocial interventions	*“Having a person-centred plan” (Respondent 75)* *“Communication passport, social stories, clinical psychologist” (Respondent 90)*
Psychotropic medication	*“When [medication] started it was a life-saver … his behaviour really improved” (Respondent 89)*
Accessible professionals	*“Being able to see or speak to a psychiatrist” (Respondent 51)* *“Direct phone contact with [the psychiatrist] and he visits my son at home” (Respondent 30)*
Working in partnership	*“Being involved and knowing what was going on” (Respondent 77)*
“What needs to be improved?”	
A ‘medication first’ approach	*“Not to reach straight for medication in the first place, but hold off using it” (Respondent 48)* *“Medication should not be automatic…proper assessment is very important” (Respondent 39)*
Early intervention and preventive strategies	*“[We need] help before it gets to crisis” (Respondent 90)*
Monitoring	*“Side-effects to be taken more seriously” (Respondent 85)* *“Regular visits to a psychiatrist…taking an interest and monitoring” (Respondent 36)* *“It made her so numb that she didn’t recognise family, no personality, sleepy all the time [and] worse seizures” (Respondent 94)*
Providing information	*“Better information…a printed list of possible side-effects and what to do” (Respondent 15)*

	"Information which would allow me to consider benefits against side-effects and alternatives" (Respondent 7)
Listening to families	*"Parents were flagging up concerns months before [the crisis situation]" (Respondent 93)* *"Listening to and respecting and valuing the knowledge and experience that the family has" (Respondent 6)*
Expertise and consistency	*"The doctor who we saw was lovely but had no experience of special educational needs and admitted it would be hard for him to manage" (Respondent 73)* *"There is so little specialist mental health support" (Respondent 51)* *"One doctor who gets to know the patient" (Respondent 47)* *"High staff turnover is not helpful" (Respondent 21)*