

2023-07

Survey of parents of children with intellectual disabilities and/or autism who experience chronic constipation

Rooney, J

<https://pearl.plymouth.ac.uk/handle/10026.1/21089>

10.1111/jar.13101

Journal of Applied Research in Intellectual Disabilities

Wiley

All content in PEARL is protected by copyright law. Author manuscripts are made available in accordance with publisher policies. Please cite only the published version using the details provided on the item record or document. In the absence of an open licence (e.g. Creative Commons), permissions for further reuse of content should be sought from the publisher or author.

Survey of parents of children with intellectual disabilities and/or autism who experience chronic constipation

James Rooney¹ | Rebecca Hodge¹ | Jade Smith¹ | Kelly Vanstone¹ |
Richard Laugharne^{2,3} | Rohit Shankar^{2,3}

¹NHS South Central and West, Eastleigh SO50 5PB, UK

²Cornwall Partnership NHS Foundation Trust, Truro TR1 3QB, UK

³Cornwall Intellectual Disability Equitable Research (CIDER), University of Plymouth Peninsula School of Medicine, Truro TR1 3QB, UK

Correspondence

Rohit Shankar, Threemilestone Industrial Estate, Truro, TR 4 9LD UK.
Email: rohit.shankar@plymouth.ac.uk

Abstract

Background: Constipation is common in children with intellectual disabilities and/or autism, but poorly researched. This study looks to understand parental knowledge, attitudes and management practices towards constipation in children with intellectual disabilities and/or autism.

Methods: A cross-sectional online survey developed with patient facing organisations was circulated to parents of children with intellectual disabilities and/or autism using an exponential and non-discriminatory snowballing method for recruitment. A smaller sample were purposively sampled for their in-depth experiences.

Results: Of 68 responses, people were open to discussing constipation and knowledgeable about risk factors. In the qualitative interviews, of 15 parents, they wanted to be treated as an expert in their child's care. They desired a service that was more responsive when in difficulty. While wanting more information about medication options, parents want a more holistic approach.

Conclusions: Services need more emphasis on holistic management. Listening to parents and treating them as experts is important.

KEYWORDS

bowel problems, constipation, developmental disabilities, neurodevelopmental disorders, service access

1 | INTRODUCTION

Intellectual disabilities are characterised by significant impairments of intellectual and adaptive functioning with onset before adulthood (WHO, 1992). Autism is a group of non-progressive developmental disabilities of variable severity appearing in early childhood that affect thinking leading to difficulties in social interaction and communication (American Psychiatric Association, 2013). There exists a bi-directional relationship of intellectual disabilities and autism (Srivastava & Schwartz, 2014). Around 70% of autistic people will also have some level of intellectual disabilities (Mefford et al., 2012; Newschaffer et al., 2007;

Wilkins & Matson, 2009). It is estimated approximately 2% of the population will have an intellectual disability, autism or both (Office of National Statistics, 2020). These impairments can be complicated by a significant presence of physical comorbidities including constipation (Kinnear et al., 2018).

Constipation is a symptom based heterogeneous condition which is overrepresented in people with intellectual disabilities and/or autism (National Institute of Clinical Excellence (NICE), 2017b; Maslen et al., 2022). Population estimates report a third to half of people with intellectual disabilities experience constipation (Kinnear et al., 2018; Robertson et al., 2018). Similarly, higher levels of constipation are

This is an open access article under the terms of the [Creative Commons Attribution](https://creativecommons.org/licenses/by/4.0/) License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

© 2023 The Authors. *Journal of Applied Research in Intellectual Disabilities* published by John Wiley & Sons Ltd.

reported with people with autism (Maslen et al., 2022). Constipation in people with intellectual disabilities and/or autism may be caused by a range of pathological processes such as neurological and genetic conditions (Maslen et al., 2022). There has been recognition of constipation often not recognised as a reason for distress behaviours associated with people with intellectual disabilities and/or autism (diagnostic overshadowing) (Marsh & Sweeney, 2008). In spite of this recognition it continues to remain a major cause of concern recognised as a significant influencer to premature mortality (LeDeR, 2022).

It is important to recognise that outcomes for children with intellectual disabilities and/or autism are governed by factors over and above a purely medical perspective. A recent systematic review has showcased how clustering of socio-environmental issues such as minority ethnicity, maternal mental illness, early life motherhood, recreational drug abuse and low socio-economic status play in precipitating and perpetuating potential determinants of developmental disabilities (Leonard et al., 2022). Looking deeper complex issues at an individual level such as immutable characteristics such as race and sex play a significant role in diagnosis and outcomes (Becerra et al., 2014). Family impact often linked by socio-economic status and available supports of extended family and friends can influence whether the child has the safety net of a family with higher resilience and capacity to meet their additional needs including additional un-costed expenses of support. In addition, of significant influence is professional community support and services availability. This availability is in turn impacted by issues such as geography, rural/urban presence, race, immigration status, income, taxation, housing and other local and national policies (Brisendine, 2017). All these can play a role in weak social capital role facilitating ignorance, poor understanding of complex needs and delayed engagement leading to late diagnosis, poor service delivery, poor access of services and worse outcomes to the child (Anderson et al., 2022; Hosozawa et al., 2020). These can significantly contribute to health inequalities, to constipation impact on children's wellbeing. Further, chronic constipation in this population can raise vulnerability to exclusion of children with intellectual disabilities and/or autism from many mainstream places and activities, resulting in children having less opportunities to be active either due to the direct reasons of constipation per se (Swanwick, 1991) or secondary issues of psychological well-being (Guldberg et al., 2022).

In the United Kingdom, the expectation of health care delivery is that it be free and as needed for all citizens. To ensure equitability for vulnerable populations such as people with intellectual disabilities and/or autism legislation such as the Equality Act (2010) and the Autism Act (2009). Unfortunately, while policy should make a level playing field postcode lottery continues in health and social care delivery. A host of factors, such as those enumerated above, contribute to this skew in service delivery. There are added challenges even within this vulnerable population, for example, those with non-verbal presentations are more likely to have increased health and social complexities and more likely to encounter diagnostic overshadowing (May & Kennedy, 2010).

Constipation in children is estimated to be present in 5%–30% of children and remains an underexplored and under-reported matter possibly due to the attached embarrassment and stigma attached

(NICE, 2017a). Quality of life and health outcomes in children with constipation is recognised to be poorer than their peers (Belsey et al., 2010; Vriesman et al., 2019). Constipation in children also has a significant impact on health-related quality of life outcomes of affected children caregivers, particularly on their family functions (Wang et al., 2013).

While constipation is an over-represented and recognised problem in people with intellectual disabilities and/or autism there is very little evidence on the perceptions of the specific needs and challenges of the impact of constipation on the lives of children with intellectual disabilities and/or autism and on their families. A good place to start in understanding the needs of children in this situation is to ask parents how they perceive they are served by current services.

The aim of this study was to explore the experiences of parents of children with an intellectual disability and/or autism who suffer from regular constipation across England.

2 | METHODS

The Strengthening the reporting of observational studies in epidemiology (STROBE) guidance for cross-sectional studies was used to report the study findings (Data S1).

2.1 | Study design

A mixed methods approach using quantitative and qualitative elements was designed to provide an understanding of the impact of constipation on individual lives, the challenges of living with and managing constipation, experiences of services and seeking support and treatment. The study was divided into two stages.

The first was to gather information through a cross-sectional survey which consisted of questions with predetermined answers and questions that allowed for free text comments (Data S2). The survey had 28 questions. The survey sought to gather basic demographic data including the age, sex, ethnicity, current clinical diagnoses and additional needs of children. It further inquired into parental comfort levels to discuss bowel health issues, their confidence in managing constipation and the impact it has on their daily lives. It also looked to ascertain information on parental experiences in relation to seeking support, help and treatment. Survey questions were co-designed with a range of stakeholders including clinical representatives of the NHS England and Improvement Southwest, NHS England Clinical Reference Group, parent-carer forums and ERIC the Children's Bowel and Bladder Health Charity. The survey was carried out electronically using the "Join the Conversation" <https://jointheconversation.scwcu.nhs.uk/> engagement platform and was made available for a period of 4 weeks from 27 May 2022 to 24 June 2022. It was estimated to take ~10 min to complete. Parents were targeted through several parent-carer forums and social media.

The second stage of the work consisted of a semi-structured interviews with parents to gather more in-depth data on their

experiences. The interviews followed a broad appreciative inquiry approach and sought to allow participants to provide more detailed information on their experiences. Particular focus was on relation to the support and advice they had sought from professionals, and what worked and did not for them and their child. As with the survey questions, the interview topic guide (Data S3) was co-designed with the stakeholder group.

Interviewees were purposively sampled from those who had participated in the survey (and had consented to being contacted to discuss their experiences further), to ensure that information-rich accounts were obtained. A range of different viewpoints and experiences such as geographies and ethnicities was considered. A pre-design estimate was to conduct interviews of 15 respondents of the total survey respondents who noted that they were happy to be contacted further, on a “first come first served basis.” A number of those who had consented initially did not respond to invitations to participate in an interview, or were not contactable, and so others were then identified until all requisite interviews were completed.

2.2 | Inclusion and exclusion criteria

Parents and caregivers of children with intellectual disabilities and or autism over 2 years of age but younger than 18 and having chronic constipation were invited to participate.

2.3 | Ethics

As per the NHS Health Research Authority tool (<http://www.hra-decisiontools.org.uk/research/index.html>) no formal ethical approval was necessary for this study (Data S4). Governance was established via NHS England framework as outlined in Data S5.

The research was commissioned by NHS England and Improvement South West (NHSEI SW; now NHS England South West). The survey questions and interview topic guide were co-designed with healthcare professionals and parent/carers and approved by the Clinical Reference Group (CRG) chaired by NHSEI SW. The CRG included a range of health care professionals from NHS services across the South West of England specialising in bowel and bladder health. Additionally, the CRG included the CEO of the charity ERIC and representative from the South West Parent Carer Forum.

All participants were advised at the start of the study that participation was voluntary and their replies, if they chose to participate, would be anonymised and analysed. No participant identifier data was collected unless they were interested and consented to be contacted for Stage 2. Data were pooled prior to analysis. Further, it was to a participant group where consent was implicit by participation as they were not a direct patient group.

For Stage 2 potential interviewees who had explicitly agreed to be contacted were communicated by either phone or email to invite them to participate in an interview and were given further information on the purpose and nature of the interviews, as well as the

opportunity to ask any questions before making a decision on whether or not to participate. Interviews were conducted either by phone or using Microsoft Teams (depending on the preference of the participant) and participants were taken through a consent process at the start of each interview, to ensure informed consent was obtained. This is included as Data S2. In keeping with Good Clinical Practice guidelines (Otte et al., 2005) both the survey stage and during interviews participants were asked to contact and/or inform the study team if they found any situation challenging or distressing.

2.4 | Study analysis

The Stage 1 survey used an exponential and non-discriminatory snowballing technique. This involves commencing with key contacts in professional and charity organisations of the authors in different participating organisations and requesting them to forward the request and link within their own professional networks. This should be considered non-probability sampling, as it does not include complete coverage of services in the field and/or any sector. Descriptive statistical analyses were carried out using Microsoft[®] Excel[®] for Microsoft 365 MSO (Version 2203 Build 16.0.15028.20242) to analyse the qualitative data.

For stage 2 in each interview, detailed notes were captured and written up by the interviewer, both during and immediately following the interview. Where possible (and where consent was given by the interviewee), the interviews were audio recorded. Due to time and budget constraints interviews were not transcribed, but instead a reflexive and iterative process was used to develop comprehensive notes of each interview for analysis and to ensure that all key messages were captured, broadly following the approach advocated by Halcomb and Davidson (2006). Data from the interview notes were then combined with the qualitative/free text data captured by the surveys of Stage 1 to create a full and rich data set for analysis.

The qualitative data set from the interview notes and free text survey responses were descriptively thematically analysed by three reviewers in order to identify key findings from within the data (Doyle et al., 2020; Hunter et al., 2018). Descriptive thematic analysis is often used in healthcare research that has a strong link to practice. The identified thematic results consist of a descriptive summary of the data to present it in an accessible way for readers under descriptive main headings. Each reviewer undertook an initial review of the data set and after which they met to collaboratively discuss the data and develop an initial coding framework for further analysis. This framework was then tested with a sample of three sets of interview notes, coded by all three reviewers and the coding framework was then refined further. Each reviewer then undertook coding of one third of the overall data set, with ~10% being coded by all three reviewers to ensure standardisation and achieve a greater degree of objectivity. Reviewers met regularly during the coding process to discuss queries, review progress and refine the coding framework as needed. This allowed both for a degree of challenge and reflection with a view to reducing biases and improving objectivity. Once all the data had been

coded, data was organised by code using an excel based tool and the data reviewed and analysed the data to identify potential themes. All three reviewers met regularly to engage in a process of identifying, testing and refining potential themes, until a final set of themes were agreed.

3 | RESULTS

3.1 | Quantitative analysis

In total 68 responses were received of whom 51 (76.1%) were parents for a male and 15 for females (22.4%) with one (1.5%) not stating either and one (1.5%) declining to state. All respondents reported that their child either had experienced or was currently experiencing constipation. Survey respondents identified that they were completing the survey for children of a full range of ages up to the age of 18. The mean age was 8.4 years, median age 9 years, interquartile range being 8 and mode being 2 years ($n = 7$).

Of the respondents 29 (43.4%) identified their child as having intellectual disabilities, 27 (40.3%) as having a diagnosis of autism, 28 (41.8%) as having other additional health needs and 13 (19.4%) as having both an intellectual disability and autism diagnosis with possibly other additional health needs. One respondent did not complete this question. It should be noted that this was not a mutually exclusive question and respondents could identify multiple needs if these related to their child. It is important to note that of the 27 who identified their child as having a diagnosis of autism, 11 (16%) respondents reported that their child solely had a diagnosis of autism with no co-morbid intellectual disabilities or any other additional needs.

Of the 28 (41.8%) respondents who identified their children as having other additional health needs, a range of co-morbid conditions were identified including physical and neurodevelopmental disabilities, sensory issues and mental health concerns. The detail provided ranged from general to very specific details of conditions and needs. Table 1 outlines in full the additional needs identified by respondents.

Comfort levels in discussing constipation with professional, educational, and social groups.

All 68 respondents reported feeling either “very comfortable” ($n = 61$; 89.7%) or “somewhat comfortable” ($n = 7$; 10.3%) talking about constipation issues with their families. Similarly, respondents reported high levels of comfort in discussing such issues with health-care professionals, such as GPs, health visitors, paediatricians and consultants, with 55 (80.9%) reporting feeling “very comfortable” and 12 (17.6%) reporting feeling “somewhat comfortable.”

Forty participants (58.8%) reported feeling “very comfortable” and 19 (27.9%) “somewhat comfortable” in discussing matters with their child’s school, a minority of four (5.9%) noted that they were “not at all comfortable” with discussing it with educationalists.

Of all respondents, 26 (38.2%) reported feeling “very comfortable,” 33 (48.5%) “somewhat comfortable,” and eight (11.8%) that they were “not at all comfortable” in discussing constipation and

TABLE 1 different disorders and co-morbidities of participant children.

Attention deficit hyperactive disorder	ALG13-CDG	Anxiety
Attachment disorder	Bowel inflammation	Complex cardiac heart disease
Developmental Coordination Disorder	Down's syndrome	Dyslexia
Dyspraxia	Dystonic cerebral palsy	Eating disorders
Epilepsy	Generalised anxiety disorder	Global developmental delay
Hearing impairment and difficulties	Hirschsprung disease	Hypertonia
Hypermobility	IBS	Metatarsus adductus
Microdeletion of gene	Motor function and coordination difficulties	Noonan syndrome
Quad cerebral palsy	Receptive language impairment	Scoliosis
Sensory difficulties	Selective learning disability	Sleep issues
Sensory processing disorder	Speech delay and impairment	
Stomach ulcers	Visual impairment	18p deletion (rare chromosome disorder)

related matters with their friends. Twenty-four (35.3%) reported feeling “very comfortable” and 29 (42.6%) “somewhat comfortable” discussing constipation and related issues with other wider groups while seven (10.3%) noted that they were “not at all comfortable.”

3.1.1 | Recognition of important factors in the management of constipation

Survey respondents were asked of their knowledge of how important diet, hydration, exercise, toilet routine and addressing problems early were in managing constipation.

As Figure 1 shows, most respondents felt that in general all the activities listed in the survey were “important” in managing and dealing with constipation. Although all 68 survey respondents did answer this question, at least two respondents chose not to express a view on all the listed factors. Seven participants (10.3%) felt that getting plenty of exercise were either “not important at all or were neutral” on their importance. Similarly, for having a regular toilet routine 10 participants (14.7%) expressed “neutral or not important.”



FIGURE 1 Important factors in managing constipation.

3.1.2 | Confidence in managing aspects of constipation

Forty-seven (69.1%) respondents reported that they felt “very confident” that they know the signs of constipation, while 19 (27.9%) reported that they felt “somewhat confident” and two (2.9%) were “not at all confident.” Forty-one (60.3%) identified that they felt “very confident” that they know how to manage diet, exercise and fluid intake, while 24 (35.3%) reported that they felt “somewhat confident” and three (4.4%) that they were “not at all confident.” Finally, 40 (58.8%) respondents noted that they felt “very confident” that they know what they would do if their child showed signs of constipation, while 24 (35.3%) respondents reported that they felt “somewhat confident” and three (4.4%) acknowledged that they did “not feel at all confident” that they would know what to do.

A large majority of respondents reported feeling “very confident” ($n = 41$; 60.3%) or “somewhat confident” ($n = 26$; 38.2%) that they know when to seek advice and help from others. One respondent (1.5%) reported that they did “not feel at all confident.”

A greater level of uncertainty and lack of confidence was expressed by respondents when considering if they felt they knew where to seek help and advice from. While 36 (52.9%) reported that they felt “very confident” and 24 (35.3%) noted that they felt “somewhat confident” in this regard, eight respondents (11.8%) reported that they did “not feel at all confident” that knew where to go for help and advice to deal with constipation.

3.1.3 | Health-seeking behaviour and perceptions of advice received

A large majority of respondents, that is, 65 people (95.6%) reported that they had at some time or another sought help and advice about constipation. Of the three respondents (4.4%) who reported that they had not sought help and advice, none of them reported that they had experienced any barriers or issues which prevented them from seeking advice.

A large majority of respondents reported that they had at least sought advice from their child's GP (56; 86.2%), Other sources of advice included ERIC—the Children's Bowel and Bladder Charity (18; 27.7%), from Parent-Carer Forums (16; 24.6%); Specialist Nurses (16; 24.6%) and the Internet (15; 23.1%). Smaller numbers of respondents also reported seeking support from health visitors (11; 16.9%), school nurses (10; 15.4%), NHS Choices (5; 7.7%), and the National Autistic Society (2; 3.1%).

Of those respondents who reported having sought help and advice, most (49; 75.4%) reported that they had “felt listened to” when they wanted advice. However, nearly a quarter (16, 24.6%) responded “not felt listened” when they sought help. Of 65 responses, 47 (72.3%) believed the advice and treatment given was helpful while 18, (27.7%) did not.

3.1.4 | The impact of constipation on daily living

Two respondents skipped this question entirely and a number of others chose not to fully complete all sections of this section. Major difficulties (“massive” or a “lot”) in a range of issues were found in a significant minority (Figure 2).

3.2 | Qualitative analysis

Fifteen semi-structured interviews were conducted with those who had responded to the survey and indicated that they were happy to be contacted to discuss their experiences further. Of the 68 respondents, 23 (33.3%) declined to be contacted further. Of those who explicitly gave consent to be contacted one had provided a wrong number, 15 people did not respond before the requisite 15 interviews were reached. These semi-structured interviews sought to elicit more detailed information on the support and advice sought from professionals and what worked and did not. The average duration for an

What impact does your child's constipation have on the following activities?

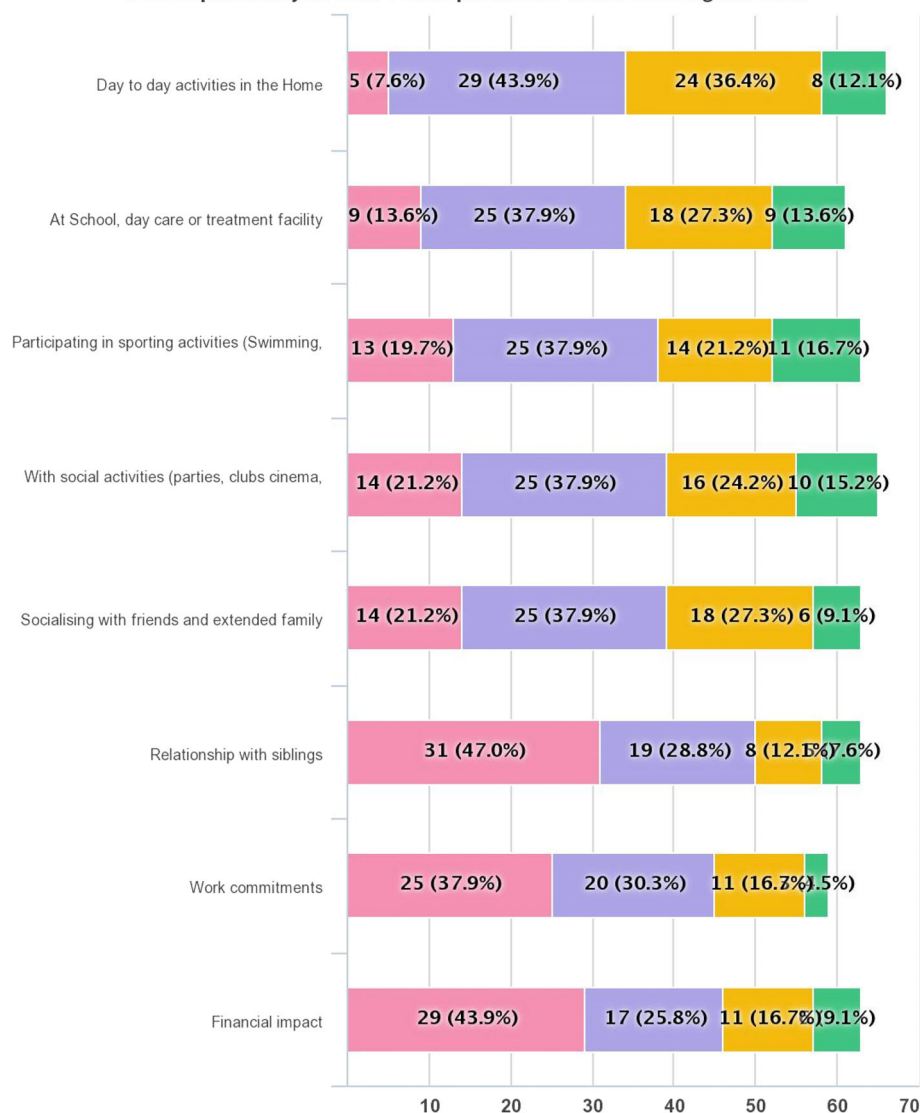


FIGURE 2 Impact of child's constipation on aspects of daily life.

Question options

(Click items to hide)

- None (I do not have to worry about it at all)
- A little impact (I just must take simple and sensible precautions)
- A lot (I must plan and prepare in case there is an issue and be available to manage if necessary)
- Massive (I must plan everything to the last detail to make sure there is not a problem)

interview was 15 min (range 10 to 20 min). Thematic analysis of these interviews identified seven key themes. These are further explored below, sub-domains presented in Table 2 and raw data presented in Table 3. Support quotes where needed have been referenced to Table 3.

3.2.1 | Theme 1: Use and impact of medication

Understanding the medications being prescribed for their child, their use and impact was a key theme which emerged from analysis. In general, respondents and interviewees understood that medication can,

and does, play a very important role in helping to manage and treat constipation and its symptoms. Parents generally understood the importance as part of a rounded approach to managing their child's constipation (see Table 3 1.1). It was reported that medications were being prescribed in different circumstances, including those medicines which primarily increase the volume of liquid within the bowel and soften the stools (such as Movicol, Laxido and Lactulose) and those medicines which stimulate the bowel to facilitate a bowel movement (such as Sodium Picosulphate). However, it was felt that medication was being used too liberally, sometimes prescribed to "make them go away," to avoid further investigation and treatment, or referral on to other services (see Table 3, 1.1).

TABLE 2 Themes and sub-domains of themes.

Theme	
Use and impact of medication (including appropriateness of medication, long-term usage and impact, information and understanding)	Primary and community care support (including clinical knowledge and understanding of constipation, experience of services, third sector and additional support)
Availability of, and access to, services and support (including availability of services (particularly psychological and non-medical support), access to services, signposting to advice and support (who to ask), impact of COVID-19)	Support from education (including support from schools, managing absence from school)
Feeling listened to and heard (including being believed, the parent as expert, compliance with clinical advice, communication and collaboration)	Managing constipation (including barriers to going to the toilet, the importance of establishing routine, impact of diet and fluid intake)
Availability and quality of information around constipation (including availability and age appropriateness of information)	

In this regard, there did appear, in some cases, to be a lack of real understanding about how the medication prescribed for their child worked. It was reported that the information supplied when any medicine was prescribed, was either inadequate or not helpful. More information to understand the different medication options available was identified as being important, to help make informed decisions. Parents felt that advice and information would be useful in order for them to persuade their child to take the medication. (see Table 3 1.3) There was also a strong feeling among many respondents and interviewees that medication should be used primarily as a short-term fix to treat symptoms, rather than a long-term solution. The lack of a holistic approach, concerns of long-term prescribing and dependence on medication to defecate were recurrent concerns. While recognising the need to treat the constipation, overall, it could make life more difficult on occasions for children not being in control of their bowel movements and the potential to cause diarrhoea. Where interviewees seemed most happy using medication was in situations where their child's constipation was being managed well through other means and the medication was a back-up or a safety net for when things went wrong. (See Table 3, 1.2).

3.2.2 | Theme 2: Availability of and access to services and support

Another key theme was respondents noting the importance of having access to a wide variety of appropriate services and support in order to effectively be able to help their child. Having specialist psychological and other non-medical support was identified as very important to dealing with their children's constipation, rather than solely relying on medication. There appeared to be (or at least was perceived to be) often a lack of availability of services and support which could potentially offer alternatives to supplement medication use. Many respondents felt that their child's situation was more psychological in nature than medical and questioned how helpful medication is particularly in the long term without other forms of support and therapy alongside. Although the term "psychological support" came up in all of the interviews it is clear that this was not solely about the availability of

narrowly defined clinical psychology services but rather a wider expectation and desire to be able to access a range of holistic services including behavioural support, toilet training, education support (including educational psychologists), nutrition and diet support, and support to deal with anxiety and fears. Furthermore, where support was accessed, including through bowel and bladder clinics the view was that services did not always seem prepared to effectively support children with intellectual disabilities and/or autism. This often meant that support and advice was not overly helpful, and often still relied on medication as the default treatment. However, in general those who had been able to access specialist services, reported that they had some useful and helpful advice.

Where services and additional support (both medical and non-medical) were available, it was noted that these services had been difficult to access. It was reported by parents that they felt the need to fight very hard to get their child referred into specialist services and support. Getting referred had seemed to be a large barrier in many cases. Long waiting times for an appointment caused continued frustration for some. However, once referrals to services had been obtained, it was felt that the support available had, in the main, been helpful. The potential for having a walk-in or drop-in clinic or sessions with a nurse as a potential solution to having to wait a long time for an appointment was suggested. It was felt that this would negate the need to have regular follow-up appointments and would help to provide quick reassurance.

As well as accessing specific services, the issue of general advice and support was identified as important. The uncertainty expressed by a sizeable number of those interviewed in knowing where to go, who to ask, advice and reassurance for general queries which many felt did not warrant a full appointment was evident. Changes to services over the life of their child due to reductions and other changes meant that staff were overworked and had too many duties. This made it hard to know where to go and who to ask for general queries, advice and reassurance when needed. Participants reported that where they had tried to seek advice via phone or email from services, queries were not answered and that they were often bounced from person to person without getting a satisfactory response. Respondents had greater success obtaining information from more informal

TABLE 3 Summary of themes.

Themes summary	Sample comments
1. Use and impact of medication	
1.1. <i>Appropriateness of medication and medicines being lone interventions</i>	<p>1.1.1. "That is the way he goes. If he doesn't have that medication ... cause obviously it makes very loose stools, and then he can't really hold it ... but if he doesn't, and I did try and have a break as it does say short term use only and I was a bit concerned about that ... I tried to use more holistic methods, things which were more natural, just increasing different things in his diet ... it did soften the stools I noticed, but he still seemed to have a problem passing them"</p> <p>1.1.2. "At some points, when he's been very compacted, we've been taking eight sachets a day ... at the moment he's just on taking a couple of sachets a week because actually his diet's really good and it doesn't seem an issue with the consistency, it's just getting it out ... sometimes it's quite tricky."</p> <p>1.1.3. "Ultimately we had Movicol and it's been excellent."</p>
1.2. <i>Long term usage and impact</i>	<p>1.2.1. "Drugs aren't the answer to everything."</p> <p>1.2.2. "It worries me ... that we're sticking a plaster on the problem, and not really getting to the root cause."</p> <p>1.2.3. "We've not had any real investigations done and my son has just been put on laxatives since he was a baby."</p> <p>1.2.4. "That prescription hardly got used. It was a waste of taxpayers money because it was unsuitable for him. I did try it and it did nothing for him."</p> <p>1.2.5. "My opinion is that there's both a short-term solution ... and a long term solution that's needed, because you're not going to remove those anxieties and you're not going to magically improve diet overnight, so we need something to help with the pain and the constipation now. And then hopefully some insight for long term goals as well ... medication, in my opinion, should always be a short-term solution ... until can work on the anxiety or other issues longer term ... we don't want them on medication for ever."</p> <p>1.2.6. "Nobody wants to give their kids medication all the time."</p> <p>1.2.7. "If he is impacted, I follow the directions on the Movicol, the continence team have not reviewed this prescription for 2–3 years."</p> <p>1.2.8. "[My son has] been seen by Gastro team since [he was a] few months old. [He has a] history of withholding stools. Now [he is] unable to open [his] bowels without medication."</p>
1.3. <i>Information and understanding</i>	<p>1.3.1. "Movicol doesn't really help. It leads to poo-magedon and poo everywhere."</p> <p>1.3.2. "My son still won't go on the toilet for bowel movements and he has to have medication for constipation so this is very messy. It's bad for his self-esteem generally and it impacts social movements."</p> <p>1.3.3. "The recommended use of movicol isn't really effective enough in my opinion. This is an ongoing issue for my son and we have lots of concerns of long term damage in the future."</p> <p>1.3.4. "For years she was on Movicol, and the sachets that go into the drinks ... but what I didn't really realise, as nobody really told me ... is that the Movicol only provides ... takes the fluid to the poo so it makes it softer. I always thought that it stimulated the bowel to help you go ... she was on that for ages and eventually I thought this really isn't working ... and that's obviously why because all it was doing is ... when she did actually go ... making it softer; rather than actually stimulating the bowel to make her go."</p> <p>1.3.5. "We were prescribed Movicol but not really given any instructions on how to use it effectively."</p> <p>1.3.6. "[The] GP advice wasn't always clear, the approach taken was to 'see how they get on with it and adjust along the way'."</p> <p>1.3.7. "There's a lot of misinformation out there ... so [I] would appreciate more guidance."</p> <p>1.3.8. "It [the Movicol] tastes disgusting ... Trying to get a two year old to take something they don't like is not easy"</p> <p>1.3.9. "We were prescribed lactulose but too hard to get him to take it so we gave up on that and still have issues with it."</p> <p>1.3.10. "My Child takes a long time to empty his bowels. He struggles to understand the medication will help him go the toilet ... It's a constant battle to get him to take the medication."</p>
2. Availability of, and access to, services and support	
2.1. <i>Availability of services particularly psychological and non-medical support</i>	<p>2.1.1. "My son gets constipated because his mental health issues mean that he withholds his faeces as long as possible. There does not appear to be any service that can offer help or advice for a child in this situation. The only advice/help we have been given is medication for constipation."</p> <p>2.1.2. "At this point I'm not really sure whether it's a physical thing or a behavioural thing. I guess I feel like if we tried it [the medication], it would maybe work for a while and then it would just go back to being an issue without resolving it, cause it might just be a behavioural thing like it's</p>

TABLE 3 (Continued)

Themes summary	Sample comments
	<p>happening because he isn't willing to go anywhere else besides home ... it might not actually be something we can fix with medication.”</p> <p>2.1.3. “She doesn't drink as much as I'd like her to. She only has a wee twice a day tops. [I] would like advice on negotiating this with an older child as I know she doesn't go to the toilet at school and can still go for long periods at home without a poo.”</p> <p>2.1.4. “The bowel clinic I speak to every 3–6 months I suppose, obviously with covid it has been not in person but on the phone ... but we don't seem to be going any further forward. We still seem to be in the same boat we were in 3 years ago.”</p> <p>2.1.5. “We eventually saw somebody up at Oxford, who really explained how much anxiety can impact constipation ... I think, having spoken to her, was just amazingly informative; and she was right, actually. When we looked back on it, at things like school holidays, when there was less stresses and less demand, constipation wasn't as bad ... and, you know, probably even a normal bowel habit at that point.”</p> <p>2.1.6. “Through her neurologist in London we were able to get a learning disability nurse who made the connection [between her daughter's behaviour and constipation]. It was only that she, as we were going through things talking about it, that she said to me ... ‘how often does she poo?’ ... and I said ... ‘sometimes she does not poo for 4 days’ ... the nurse said that's probably the issue and what's making her behaviour bad.”</p>
2.2. Access to services	<p>2.2.1. “It wasn't really until the second appointment with the third GP that ... it was almost as if she just got fed up of me and was just like well we'll send you a referral just to shut you up.”</p> <p>2.2.2. “It took a few years of reporting constipation to GP/Community Paediatrician (and treating daily with Movicol etc.) to gain a referral to hospital for proper review. The referral was due to withholding urine (24 hrs+) though not for the constipation itself. I now feel that things are progressing and we are better supported.”</p> <p>2.2.3. “We are usually just told to up the dose of movicol. We had asked for a referral to a gastroenterologist but GP did not refer us. Our daughter suffers from severe bouts of constipation and impaction.”</p> <p>2.2.4. “You get a sense that GPs don't understand how to manage [constipation] or who to refer to. [They] also [seem] resistant to referring. [They] don't understand how damaging it is day to day.”</p> <p>2.2.5. “It's quite difficult to get into hospitals these days and get to see the right people because you're often waiting months for a clinic appointment.”</p> <p>2.2.6. “It took a long period of time to get any help or support ... [the long wait] was really not necessary.”</p> <p>2.2.7. “Rather than having to wait months for an appointment, you just need someone to have a quick feel [of the child's stomach]!”</p>
2.3. Signposting to advice and support (who to ask)	<p>2.3.1. “Sometimes as a parent you just need someone to say, ‘yes, what you're thinking of doing is the right way’ ... or ‘you're right, that isn't normal for your child. Maybe we should look into this a bit further.’”</p> <p>2.3.2. “Looking after a child with physical disabilities and autism is hard work. Plus on top you ... it's all the chasing and trying to find out who you need – that's the big one as well ... There's no one who can ever give you an answer ... it just seems that nobody seems to know any more. They just keep putting stuff off to different people or in the end they get so inundated that it doesn't get looked at properly and it's not followed through.”</p> <p>2.3.3. “It's very hard to find somebody to speak. You've got to go through the children's therapy team and then you email someone and they go ‘oh, I'll email so and so’ and then you don't hear anything and you keep chasing.”</p>
2.4. Impact of the pandemic	<p>2.4.1. “It's always just been a phone conversation and I'm not an expert and I don't know what they would expect to see if they did actually see her, but I just find it difficult to understand ... over a phone conversation they say she's holding in her poo, but how are they going to know that if they aren't seeing her ... how can they know if there's anything wrong or if she has like an intolerance to anything ... they haven't tried to find out what's happening.”</p> <p>2.4.2. “We were offered phone appointments, but for me ... that's not particularly helpful because what I'm seeking when I come in to see the nurses is for someone to feel the bowel and just check its all soft and that there's nothing going on inside there.”</p>
3. Feeling listened to and heard	
3.1. Being believed	<p>3.1.1. “I think sometimes doctors assume that mums are just being over worried about things ... so they just kind of brush it off.”</p> <p>3.1.2. As a parent I felt I had to continually prove my child does eat 8+ portions of fruit and veg, loads of water and exercise.”</p>

(Continues)

TABLE 3 (Continued)

Themes summary	Sample comments
	<p>3.1.3. "It is so annoying when health professionals say 'it's common with DS [Down's Syndrome].' Yes it may be but that doesn't mean its not something that needs addressing and sorting out.</p> <p>3.1.4. "... to be honest, it just made me feel like a bit of a crap parent ... go to the GP and there's sort of an eye role and a what are you looking for, a magical cure type of answer."</p> <p>3.1.5. "Yeah, I do feel that they're empathetic, and show compassion ... I feel that yes ... I suppose it's more that they're limited, that they're beyond what they can actually do ... what they can suggest ... we need something a little more specialist."</p>
3.2. <i>The parent as expert</i>	<p>3.2.1. "His usual GP is fantastic and usually defers to me as being the expert with my son ... I'm really fond of my GP; he's fantastic., he always listens and he always says he will always see my son if he can ... but I am quite aware of the limitations of a GP as being a jack of all trades and master of few."</p> <p>3.2.2. "I felt patronised by many 'experts' who felt they knew best, despite me trying to explain about trauma and attachment and the impact on my child's toilet issues."</p> <p>3.2.3. "It's always just been a phone conversation and I'm not an expert and I don't know what they would expect to see if they did actually see her, but I just find it difficult to understand ... over a phone conversation they say she's holding in her poo, but how are they going to know that if they aren't seeing her ... how can they know if there's anything wrong or if she has like an intolerance to anything ... they have not tried to find out what's happening."</p>
3.3. <i>Compliance with clinical advice</i>	<p>3.3.1. "[I] spoke to [the] health visitor and doctor. Prescribed laxatives. Wasn't using them effectively so internet search came up with encopresis which was very relevant to our lives. Went back to doctor and got much better advice on laxative usage i.e. duration if use and reasons behind it."</p> <p>3.3.2. "I sought advice from the GP and was given Lactulose. This did not help. I ended up seeking advice through the PADS charity and June recommended Movicol. I had to push for this through my GP. They eventually prescribed it but were very reluctant."</p> <p>3.3.3. "I will be continuing to follow their advice on toilet training as I feel they are able to offer significant evidence based advice around toilet training, specifically for children with Down syndrome."</p> <p>3.3.4. "I've got IBS myself, so I gave him some of my [medication] ... I read that it was suitable and I gave him a couple of them so he had them instead."</p>
3.4. <i>Communication and collaboration</i>	<p>3.4.1. "So I think Medway is where you get let down a bit, the health services in Medway ... it just seems that there's so many different things and that nobody communicates very well."</p> <p>3.4.2. "We did an online consultation and put in all the information, a description of issues and support needed, and then got a call back from a GP and had to repeat everything. It didn't feel that they had read the e-consult at all."</p> <p>3.4.3. "It does seem to be a conversation 'try this' and then that's it ... then nothing's changed so you have another conversation and its 'try this' ... it's just so bitty." "I suppose if nobody's seeing him, if nobody's actually meeting him, asking him the right questions ... how is anyone going to know ... there's no-one assessing him visually to see how he reacts to things."</p> <p>3.4.4. "When I go to appointments with my son, you know I'm really keen that people speak to him. I think there's sometimes a tendency with learning disability that people are spoken about in their presence ... but generally, people are addressing him and talking to him and are quite respectful, and that's something I notice and that I really appreciate."</p> <p>3.4.5. "It's a concern that you sometimes see in schools or in other places where people kind of talk about him in his presence rather than actually talking to him."</p> <p>3.4.6 "[I would like to see] something really local where children can build relationships with staff ... almost a bit like play therapy or social skills therapy."</p>
4. Availability and quality of information around constipation	
4.1. <i>Availability of information</i>	<p>4.1.1. "We found the info on ERIC website helpful – Oxfordshire PDF info leaflet that provided guidance on how much a child at that age should be drinking. It would be helpful to receive from GPs so they as parents [we can] understand how much a child of a certain age should be drinking."</p> <p>4.1.2. "That's the thing I find, there isn't much out there to tell you about constipation, and there's not much literature about it ... I think that's something, there needs to be some more education around constipation."</p> <p>4.1.3. "There's no central place that parents can say 'right, look at this and there's a section on constipation.'"</p>

TABLE 3 (Continued)

Themes summary	Sample comments
4.2. <i>Age appropriateness of information</i>	<p>4.1.4. "I don't think that constipation is just a thing that happens, there's got to be something that's causing it. So I would like more information on what can cause constipation and how they would investigate it."</p> <p>4.2.1. "I will add, around constipation and toileting issues ... there's a lot for younger children, so there's a lot for like your under 10s, your under 5s; there needs to be some sort of teenage level leaflets for young people to read. Because my son he get's given a leaflet and its aimed at maybe a 5 or 6 year old and they deem its relevant for him. But, he's now a teenager so he looks at it and if it looks babyish, if it looks overly simplified he just thinks its patronising and it gets thrown. So there needs to be ... publications that are in between the children's and the adults publications ... we find it all the time, everything's babied or its too adult for him."</p>
4.3. <i>General knowledge, education and understanding (including training)</i>	<p>4.3.1. "I think there's probably a high degree of expertise required in being able to feel whether these children are constipated or not; and parents, and quite often GPs, don't have that knowledge or that training."</p> <p>4.3.2. "[Constipation] is a much more common problem than I think lots of parents of children with Down's syndrome realise, and I think maybe there should be a bit more early intervention and education. Not just coming from the community paediatrician who sees him once a year or every six months when they're very small ... but yeah, just maybe a little more awareness and a little bit more ease of access to the service, or to a professional person ... because as parents we're often just completely guessing."</p> <p>4.3.3. "I think people take it for granted ... and think 'oh, it's just constipation.' I don't think they realise how serious it was, because I didn't realise as well that if she doesn't go properly then ... it could end up stretching the bowel and then you're going to run into ... having serious bowel problems ... so it's not just about being constipated, there are a lot of other things it can cause as well."</p> <p>4.3.4. "There needs to be a drive for people to talk about their bowel movements more ... it's healthy as bowel cancer and things can be silent killers. So, children ... need to be taught from a youngish age that it's ok to talk about it, because there's a lot of stigma around it."</p> <p>4.3.5. "I never realised that there was a link between autism & constipation until very recently. Getting awareness out there would be good."</p> <p>4.3.6. "The best advice and support is through DSUK group on Facebook. They have a wonderful children's bowel UK specialist who answer any questions and advises through experience and also other parents on there that are experiencing the same. They have been a huge help to get my son going regularly."</p>
5. Primary and community care support	
5.1. <i>Clinical knowledge and understanding of constipation</i>	<p>5.1.1. "My GP surgery aren't really trained in feeling my son's bowel for constipation. We were once told by a GP that my son's bowel was clear, only to be told by a specialist nurse the next day that he was very constipated."</p> <p>5.1.2. "[My] child holds poo for up to 9 days. GP wasn't very experienced in ASC. Need to seek more specialist advice tailored to my child rather than a one size fits all approach."</p> <p>5.1.3. "[The GP was] was lovely but like a lot of GPs they don't have the experience of dealing with special needs kids"</p> <p>5.1.4. "Yes, maybe when you've got a small child, a toddler or under 8 maybe massage would help. But when you've got a big lad whose got sensory issues ... that's just ridiculous ... it was about as useful as a chocolate frying pan! ... It was almost ... not patronising, patronising's not the right word ... but it was almost like why did I even bother. Why bother when I'm going to get stupid answers like that."</p>
5.2. <i>Experience of services</i>	<p>5.2.1. "In general, everybody that we come into contact with through the children's hospital and children's NHS services is fantastic ... having accessed adult services, it's a slightly different kettle of fish! ... in general we're always more than happy with the service we get and how people deal with my son and the treatment and care that he gets."</p> <p>5.2.2. "GP is great and does listen, community support not as helpful."</p> <p>5.2.3. "We moved areas a couple of years later and again I sought some advice from my GP regarding his constipation. It was only through a local parent support group that I found out there was a Bladder and Bowel Clinic with specialist nurses."</p> <p>5.2.4 "it felt like it was passing the buck a little bit ... like nobody really wants to take responsibility."</p> <p>5.2.5. "[I] spoke to the Health Visitor when she was young – not very helpful, didn't even say to go to GP just said e.g. more liquids/try prunes. Didn't seem to think it [the constipation] was a problem."</p>

(Continues)

TABLE 3 (Continued)

Themes summary	Sample comments
5.3. <i>Third sector and additional support</i>	<p>5.3.1. "ERIC were the most help for us ... ERIC were also the most understanding of behavioural issues and had realistic advice."</p> <p>5.3.2. "Peer support is really helpful. Then you feel as though you're not failing, that you're not the only one."</p> <p>5.3.3. "I've also been putting her on the potty following the advice of Positive About Down Syndrome (PADS) and June Rogers from Bladder and Bowel UK who works with them, and that has been totally revolutionary - she is pooing very easily while on the potty, while she is straining in other positions. I will be continuing to follow their advice on toilet training as I feel they are able to offer significant evidence based advice around toilet training, specifically for children with Down syndrome that is missing from interactions with many health professionals."</p> <p>5.3.4. "The best advice and support is through DSUK group on Facebook. They have a wonderful children's bowel UK specialist who answer any questions and advises through experience and also other parents on there that are experiencing the same. They have been a huge help to get my son going regularly."</p>
6. Support from education	
6.1. <i>Support from schools</i>	<p>6.1.1. "She's got really wonderful teaching staff, but one amazing teacher and one amazing teaching assistant won't make 20 other children disappear ... and their noises and all those other things ... Being autistic, those social situations ... are difficult to manage."</p> <p>6.1.2. "It's a concern that you sometimes see in schools or in other places where people kind of talk about him in his presence rather than actually talking to him."</p> <p>6.1.3. "I think it was primary school or GO who referred to CBABS. Our CBABS nurse is excellent and would have felt lost without her to turn to when child's soiling and wetting felt like it was taking over family life."</p>
6.2. <i>Managing absence from school</i>	<p>6.2.1. "[Our] daughter is academically behind and so has quite low self-esteem which also doesn't help and impacts the anxiety."</p> <p>6.2.2. "You can't send a constipated kid to school. I'm sorry, you just can't."</p> <p>6.2.3. "In Jan 2020 (pre-COVID) he had a great deal of time off school (at mainstream at the time) - had no work sent home, they should've done this and kept up his education but didn't really understand his needs."</p> <p>6.2.4. "We have stopped laxatives in the past and kept him off school for no reason."</p>
7. Managing constipation	
7.1. <i>Barriers to going to the toilet</i>	<p>7.1.1. "So then it seems the issue is the passing ... the sensation of ... I don't think he sort of pushes out ... it's almost like he doesn't push it out so ... we have to have the medication to make it sort of fly out."</p> <p>7.1.2. "He has a fear of going on the toilet to pass a bowel movement."</p> <p>7.1.3. "... the thing is, I can't control him. I can't physically make him do something that he absolutely refuses to do ... it's like fighting a tiger ... he won't sit on the toilet or crouch to do it."</p> <p>7.1.4. "I think the main challenge ... is that he can't tell me how he feels, so it's very difficult to diagnose whether he is constipated or not. So it is a real balancing act."</p> <p>7.1.5. "You see you have pull-ups made up to the age of 15 ... and he's aware of that as I keep saying 'well we can't keep doing this as they're not going to fit you,' but he says 'that's ok they're up to the age of 15!'"</p>
7.2. <i>The importance of establishing routine</i>	<p>7.2.1. "He is made that way ... anything that like becomes the norm ... he even voices himself now that he's older 'well I'm not programmed that way.' ... so it's really hard to get him to attempt to try something different."</p> <p>7.2.2. "[My son] his mind doesn't pick up on his body cues, and also he's not really motivated to go (likely due to his ADHD). But if I tell him I'll give him 50 p and then he goes to the toilet."</p> <p>7.2.3. "It might not work today, but maybe 3 months down the line it might work ... I think always encouraging an open mind definitely helps ... and I think helps you're child as well. Because they sort of feed off of you, and if you're restricted in that we've tried it once and it won't work, then your child's going to have that mentality too."</p>
7.3. <i>Impact of diet and fluid intake</i>	<p>7.3.1. "When she was 4 I started working in an autism specialist school, and ... actually at that point I realised how bad some peoples' diets can get ... at that point I really took the decision to education myself on a good way to approach diet. From then on we went on a very slow journey and she now eats like a huge, wide variety of food. We grow lots of it ourself. It's all organic and some days you actually have to stop her from eating it and tell her 'you need some carbohydrates and some proteins and some things like that.'"</p>

TABLE 3 (Continued)

Themes summary	Sample comments
	7.3.2. "The issue is he just doesn't recognise he's thirsty, so if he's not told to drink or reminded to drink I've known him go a couple of days without drinking anything ... or I've not seen him drink ... so he ends up constipated when he does it ... it's only happened a handful of times because I quite quickly realised why it was happening and I was able to tell him that he needed to drink and got him a bottle ... with the times on, so you've got to drink down to a certain level before a certain time ... so he can see very clearly what he's got to do."
	7.3.3. "When she was younger she had a very restricted diet – always had fruit and veg, but often raw. Because of sensory issues related to her autism, the journey to get her to eat a wider variety was quite difficult."
	7.3.4. "He eats well and eats quite a bit of fruit and vegetables but this doesn't really help."

routes, such as Parent-Carer Forums and Facebook groups (such as the Bowel and Bladder Facebook group).

Finally, here interviewees and survey respondents noted that accessing services and support had become more difficult due to the pandemic. In particular, the lack of face-to-face appointments proved challenging for some, who expressed concern that their child was not being examined and felt the quality of the consultation and advice provided was negatively impacted. Furthermore, a number noted that they were offered only phone consultations where they felt video consultations or similar might have been more appropriate for their child's circumstances in the absence of face-to-face appointment availability.

3.2.3 | Theme 3: Feeling heard and listened to

A strong theme which was articulated by many was a sense that they felt they had often struggled to be heard and believed by health professionals. This appeared to go beyond a simple sense of clinicians not hearing what they said, though this was undoubtedly articulated as an issue. There was a routine feeling of not being taken seriously and their concerns being ignored; and a need to constantly push to be believed by healthcare professionals when they talked about their child, their experiences and their concerns. There was a sense of having to constantly prove to GPs and other clinicians that their child had a good diet and was eating enough fruit and vegetables, as well as drinking enough water. In many cases it was felt that clinicians were potentially dismissive of concerns and behaved in a patronising manner, making parents feel that their concerns did not count or feel like they did not understand the situation. This does appear to have had an impact in making parents become wary of seeking advice because of concerns about being dismissed or not taken seriously. This was particularly so when dealing with clinicians that they were not familiar with, for example, a locum GP.

Some parents reported positive experiences of being listened to and having their troubles taken seriously by clinicians. In these cases, even where the respondent felt that the outcome of the consultation and any advice had not been what they had wanted, they noted that they had felt their concerns were listened to and addressed.

In the cases of several parents, the issue went beyond just feeling that they were not listened to. Several parents pointed out that they

felt they were the expert when it came to their child. They explained that they are with their child every day and felt that they know what is and is not normal for them. They, therefore, felt that their views were important and should be considered by healthcare professionals when making decisions. Where they felt they were taken seriously and treated as an "expert" they were much more positive about the consultation and interaction and much more likely to feel happy with it even if the outcome was not entirely as they expected. By contrast, unsurprisingly, where individuals reported being dismissed and treated as a "worried parent," they were much more negative about the interaction.

Parents feeling listened to, believed and treated like an "expert" on their child, appears to have been important in determining whether, and how far, the parent followed the advice given by the clinician. Where an individual reported that they felt ignored or dismissed, or where the outcome was very different from what they were expecting, they were much more likely to end up doing their own thing in order to manage things themselves. This included ignoring the advice given or medication prescribed and instead looking for and turning to alternatives such as support from other parents on internet forums. A small number of interviewees also reported that they outwardly appeared to take the clinical advice given seriously in order to avoid discharge and maintain access to services, but in reality, they tended to follow their own intuition. Conversely, where individuals felt listened to and taken seriously, they were much more likely to follow the advice given and make use of medication prescribed, even if they were not entirely satisfied with the projected outcome.

In terms of improving things in this area, and helping parents and carers to feel listened to and engaged; participants particularly raised the importance of communication and having information shared between the different teams and services they were accessing, when interacting with health services about their child's constipation. Those interviewed noted that they wanted to be able to tell their story once, rather than having to do it repeatedly and expected information to be shared as appropriate among the services they were accessing. This, they suggested, would help to make their experiences of services more positive. The tendency of some clinicians to only talk to them as the parent, rather than talking to, engaging with, and examining their child was highlighted. It was felt very strongly that the child should be treated with courtesy and respect.

3.2.4 | Theme 4: Availability and quality of information

The availability and quality of information produced about constipation in children with a learning disability and/or autism, and how to manage it was also identified as currently challenging and an area where things could be improved. Individuals identified that there was a lack of (useful) information and guidance about constipation and how to manage it. Where material does exist, those interviewed reported that it was often hard to find and not easy to access. In particular, more information about the causes of constipation, how to prevent it and when to seek further advice would be useful. Furthermore, where information for children on constipation did exist and was given out, it did not always appear to be appropriate to the age of the child. This was identified as a particular issue for pre-teen and teenage children.

Parents believe there is a stigma involved that made it more difficult to talk about constipation and its related issues and to therefore ask for help and support when needed. It was felt a greater emphasis needs to be placed on increasing knowledge, education and understanding about the issues constipation can cause, both for clinicians, specifically and the wider society. This could make it easier to talk about constipation and to seek help and support (both for themselves and for their children). Training in constipation-related matters was important and helpful to parents. Since having training they felt better able to identify the signs of constipation and to manage it more successfully and mitigate potential concerns to support their children more effectively.

3.2.5 | Theme 5: Primary and community care support

Although linked to Theme 2 (see above), a particular theme around support from services which was noted was the skill, experience and ability of primary care services to be able to support this cohort of individuals. A potential gap in the knowledge and experience of GPs as well as other primary care staff and community services in respect of diagnosing, managing, and treating constipation in children (particularly children with intellectual disabilities and /or autism) was reported. A common sentiment that was expressed was that although they believed that GPs and others were doing their best, they often did not feel confident that those assessing and diagnosing their child had the requisite experience and specialist knowledge to do so successfully.

The most positive experiences of services reported was in respect of specialist secondary and tertiary services where these were used/ accessed. By contrast, support from primary and community services appeared to be much more variable, with some examples given of very good support and care and some other examples where the support received appeared to have been much less helpful. Many reported that it felt like services were under pressure with limited staff.

The vast majority stated how important services and support from the third sector had been to them. They noted that third-sector support had often played a really important role for them in plugging perceived gaps in support from statutory services and in providing

practical advice and support to help them manage their child's constipation more effectively. Those who reported making use of third-sector services and advice noted they had sourced support from a wide range of places, including organisations who specialise in bowel and bladder issues in children, Parent-Carer Forums; play centres and less formal avenues such as Facebook sites (e.g., the Bladder and Bowel Facebook group).

3.2.6 | Theme 6: Support from education

The other area specifically identified around support issues was that of schools and the wider education sector. Schools had often not been helpful until health services or other statutory organisations got involved. This was less of an issue in primary schools as they had more experience to support young children around toileting issues. However, on progressing into secondary education, it became more difficult to find appropriate understanding and support. This particularly appeared to be an issue for children with autism but who had no other disabilities or additional needs. Mainstream education presented a significant challenge.

Parents reported that their child was frequently absent from school due to issues with their constipation. This often meant their child fell behind with schoolwork and their education attainment suffered. This then impacted upon their child's self-esteem. This seemed to worsen the child's constipation and related issues (such as their behaviour). There was expressed uncertainty between trying to maintain their child's academic attainment while ensuring not to exacerbate problems for their child by sending them to school when constipated.

3.2.7 | Theme 7: Managing constipation

Finally, there was a definite theme around how to most effectively manage constipation, and the experience of these parents in trying to identify what works best for their child. A range of issues and barriers were reported on the challenges children faced in going to the toilet and which may have contributed to their constipation. These ranged from psychological issues and anxiety, with some children only feeling comfortable to go to the toilet in certain places, to others who appeared not to recognise or fully understand their bodily cues. The difficulties in being able to identify when their children needed the toilet or were constipated, particularly those who are primarily non-verbal and so unable to say how they feel was enumerated. There were reported challenges of trying to make children who were reluctant to toilet, go to the toilet and the need to focus on educating them to help them understand the importance of going to the toilet regularly and to create a happy and secure environment in which the child felt comfortable to go. Many expressed worry and concern about how their children might cope as they got older and became adults.

The importance of establishing a routine and rhythm around going to the toilet in order to successfully support their child to go regularly and to manage their constipation was identified. Strategies

included developing reward methods to encourage children to go. The importance of perseverance to keep on trying even if they do not work at first was noted.

The other element that participants noted as being important to successfully and effectively manage their child's constipation was diet and fluid intake. The challenges in many cases of getting children to eat a balanced diet of fruit and vegetables, and drink appropriately particularly in those had more restrictive diets were expressed strongly. The impact of autism on restricting choice of food and drink was highlighted.

4 | DISCUSSION

Our study outlines the challenges, concerns and worries of parents and caregivers of children with intellectual disabilities and/or autism. It highlights that constipation and its implications has a significant impact on both the child and their carer day-to-day life. Interestingly, in the majority of respondents feeding back there is no evidence of stigma or embarrassment in discussing constipation matters with professional and social groups. This is yet variance from other similar research (Flanckegård et al., 2022). This could be because the group surveyed here are already part of a well-established network and more aware and confident of the issues and concerns. In addition, majority of respondents believed they were confident in recognising and managing constipation concerns in their children and being able to seek help as and when necessary. While majority appreciated the help accessed around a quarter of respondents felt they were not listened to or did not receive any productive support.

The thematic analysis reveals interesting observations. These were broadly consistent with a recent study from Canada (Thompson et al., 2021). The Canadian study conducted 16 interviews of parental experiences while caring for a child with chronic constipation (not specifically intellectual disability and/or autism) and identified four broad themes. These included being un-noticed and not valued by society or professionals, being not taken seriously particularly by professionals, poor support and information and strained relationships. Our study while touching on these similar findings also had other areas of interest.

Conventional approach in the management of constipation has medication central to it. Parental attitude while recognising the benefits of it highlight the need for medication to be reviewed, be considered along with psycho-social interventions and most importantly take parents into confidence in formulating long-term management plans on it. This is consistent with recommended best practice (NICE, 2017a; Rubin & Dale, 2006).

The importance of holistic assessment and management was stressed. This is also recognised as an important issue to prevent constipation (Mitchell, 2019). It might require to be modified and reasonably adjusted to suit children with intellectual disabilities and/or autism. The practicalities of managing constipation particularly identifying social and emotional cues of distress is important.

Linked to this was the lack of suitable and consistent services and the postcode lottery of its availability. This was not just about direct health

services but the larger community including awareness in the education system such as schools and other social support systems. Again, this puts a specific spotlight on the larger issues of how socio-economic determinants pre-determine this (Hosozawa et al., 2020; Anderson et al., 2022).

Of note is the consistent and repeated issue of parents wanting to be taken as "partners" in the care and management of their children. This is consistent with similar recent research (Flanckegård et al., 2022). Again, this is not new or unique to constipation or children with intellectual disabilities and/or autism and is a well-researched area. A meta-aggregation review evidenced that parents valued co-operation defined as parental participation, negotiation, mutual trust and respect, shared roles and decision-making, and communication (Barratt et al., 2021). This has led to evidence-based models to involve parents in decision-making for children with long-term conditions (Smith et al., 2015). It is worth considering testing these models in this population group.

4.1 | Limitations

The study has some important limitations. The survey had no formal validation. It had face validity in that key clinical and expert by experience opinion from all associated sectors contributed to its development.

In relation to the demographics of those who completed the survey, and were subsequently interviewed, the vast majority of those who completed the survey (79.4%) identified as "White British" or "any other White background." Furthermore, almost all those who agreed to be contacted further identified as being from a white background. This meant that of those interviewed, 14 of the 15 participants identified exclusively as being from a white background. The other interviewee identified as being of mixed White and Asian background. Further work may need to be undertaken in future to capture and understand the experiences of those from other, none-white backgrounds and how these experiences and needs may differ.

A significant limitation is not knowing how good the response rate to the survey is. While the project team endeavoured to circulate and advertise the survey as widely as possible to the target population using the methodology of "exponential snowballing" they were only able to target a limited number of routes. The survey was only available for a limited period (~1 month). Second, this was an internet-based survey. It could be access to internet is limited for some in the target population. Third, the internet design might be that they were treated suspiciously as spam by some. Therefore, this is likely to have necessarily impacted on and restricted the numbers of people who saw and were able to engage with the survey (and subsequent interviews). Again, this should be taken into consideration for any future work in this area to ensure that data can be captured from a broader cross-section of the population, and particularly harder-to-reach groups. Similarly, it is acknowledged that the sample group from which the interviewees were selected, was partly self-selecting; given that survey participants were able to decide whether or not they were happy to be contacted further. This likely limited the size and scope of the sample pool available for interview. It is also probable, that those who put themselves forward for

interview may disproportionately have had either very good or very poor experiences of services and may therefore have excluded a range of other experiences from being captured through the interviews. Furthermore, it is noted that the number of interviews undertaken ($n = 15$) was small and limited given the resources and time available. This, again, may limit the generalisability of any findings from this project. Finally, the authors acknowledge that while every effort was made to follow a robust data collection and analysis framework, there were a few occasions at the interview stage in which interviews could not be recorded, either for technical reasons or because of a lack of participant consent. While reviewers in these cases made every effort to capture detailed written notes that were faithful to the sentiments expressed by the participant, it is nonetheless understood that the lack of audio recording may have allowed for elements of what was said to have been misunderstood, misrepresented or not adequately captured. This therefore may have impacted upon the quality of some of the data that was captured. The authors do not believe the limitations outlined negate or invalidate the work undertaken or the findings from this study as findings have been tested and triangulated where possible and appear to correlate with other, albeit limited, work that has been undertaken in this area.

4.2 | Implications for clinical practice

The survey suggests that parents are comfortable discussing constipation with family and professionals and confident in managing their child's bowel health. The recognition of possible risk factors is good except for toilet routine. Constipation has an impact on many parents' daily life and schooling. There is some dissatisfaction with the professional advice given. About a quarter of respondents did not feel listened to and that advice was not helpful. From the qualitative findings, parents feel that they are not well informed about medication which they feel is over-used in preference to further investigations or holistic management. At times this causes diarrhoea. Parents want a greater emphasis on holistic care and would like easier access to this. They want to understand medication options and how these differ. They were more likely to take professional advice if they felt listened to and treated as an expert on their child's condition. They were concerned that constipation can disrupt education. Services need to prioritise listening to parents, provide education on medication for constipation, improve access to flexible holistic management services and consider educating secondary schools on constipation issues. It is important to give attention to parents' most important expectations on the holistic care. This includes behavioural support, toilet training, education support (including educational psychologists), nutrition and diet support, and support to deal with anxiety and fears.

4.3 | Implications for research

Research should focus on how education on medication and holistic management for constipation might be better delivered to parents

and carers and impact on patients. Evaluation of communication skills with carers so that parents and carers feel listened to and regarded as experts in their child's care would be beneficial. Parents find it difficult to access specialist services. They want a simple access to quick advice but services are often bureaucratic and unwieldy, demanding waits for full appointments. Implementation science may be important in delivering a more agile, responsive expert service.

4.4 | Implications for policy

Parents want better education of how to manage their children's constipation. The implementation of this education is challenging in a health environment that is stretched, but parents value the third sector which may be utilised. Digital delivery of education may meet this need for informing parents. Services need to offer a quick response without the need for formal appointments.

ACKNOWLEDGEMENTS

None.

FUNDING INFORMATION

None.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

DISCLOSURES

Rohit Shankar has received institutional and research support from LivaNova, GW pharma, UCB, Eisai, Veriton pharma, Averelle and Desitin outside the submitted work.

REFERENCES

- American Psychiatric Association (Ed.). (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). American Psychiatric Association.
- Anderson, K. A., Roux, A. M., Steinberg, H., Garfield, T., Rast, J. E., Shattuck, P. T., & Shea, L. L. (2022). *National Autism Indicators Report: The intersection of autism, health, poverty and racial inequity*. Policy and Analytics Center and Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University.
- Barratt, M., Bail, K., & Paterson, C. (2021). Children living with long-term conditions: A meta-aggregation of parental experiences of partnership nursing. *Journal of Clinical Nursing*, 30, 2611–2633. <https://doi.org/10.1111/jocn.15770>
- Becerra, T. A., von Ehrenstein, O. S., Heck, J. E., Olsen, J., Arah, O. A., Jeste, S. S., Rodriguez, M., & Ritz, B. (2014). Autism spectrum disorders and race, ethnicity, and nativity: A population-based study. *Pediatrics*, 134(1), e63–e71. <https://doi.org/10.1542/peds.2013-3928>
- Belsey, J., Greenfield, S., Candy, D., & Geraint, M. (2010). Systematic review: Impact of constipation on quality of life in adults and children. *Alimentary Pharmacology & Therapeutics*, 31, 938–949. <https://doi.org/10.1111/j.1365-2036.2010.04273.x>
- Brisendine, A. E. (2017). Autism Spectrum Disorders and Social Ecological Models: Understanding How Context Drives Prevalence" (Working Paper). <https://scholars.org/contribution/how-social-and-environmental-factors-affect-diagnosis-and-treatment-autism-spectrum>

- Doyle, L., McCabe, C., Keogh, B., Brady, A., & McCann, M. (2020). An overview of the qualitative descriptive design within nursing research. *Journal of Research in Nursing*, 25(5), 443–455. <https://doi.org/10.1177/1744987119880234>
- Flanckegård, G., Mörelus, E., & Rytterström, P. (2022). Everyday life with childhood functional constipation: A qualitative phenomenological study of parents' experiences. *Journal of Pediatric Nursing*, 67, e165–e171. <https://doi.org/10.1016/j.pedn.2022.07.021>
- Guldberg, K., Wallace, S., Bradley, R., Perepa, P., & Ellis, L. (2022). MacLeod an investigation of the causes and implications of exclusion for autistic children and young people. <https://www.birmingham.ac.uk/documents/college-social-sciences/education/reports/causes-and-implications-of-exclusion-for-autistic-children-and-young-people.pdf>
- Halcomb, E. J., & Davidson, P. M. (2006). Is verbatim transcription of interview data always necessary? *Applied Nursing Research*, 19, 38–42.
- Hosozawa, M., Sacker, A., Mandy, W., Midouhas, E., Flouri, E., & Cable, N. (2020). Determinants of an autism spectrum disorder diagnosis in childhood and adolescence: Evidence from the UK millennium cohort study. *Autism*, 24(6), 1557–1565. <https://doi.org/10.1177/1362361320913671>
- Hunter, D. J., McCallum, J., & Howes, D. (2018). Defining exploratory-descriptive qualitative (EDQ) research and considering its application to healthcare. In *Proceedings of Worldwide Nursing Conference 2018* (worldwide nursing conference 2018). <http://nursing-conf.org/accepted-papers/#acc-5b9bb119a6443>
- Kinney, D., Morrison, J., Allan, L., Henderson, L., Smiley, E., & Cooper, S. A. (2018). Prevalence of physical conditions and multimorbidity in a cohort of adults with intellectual disabilities with and without down syndrome: Cross-sectional study. *BMJ Open*, 8, e018292. <https://doi.org/10.1136/bmjopen-2017-018292>
- LeDeR 2022 <https://www.kcl.ac.uk/news/2021-leader-report-into-the-avoidable-deaths-of-people-with-learning-disabilities>
- Leonard, H., Montgomery, A., Wolff, B., Strumpher, E., Masi, A., Woolfenden, S., Williams, K., Eapen, V., Finlay-Jones, A., Whitehouse, A., Symons, M., Licari, M., Varcin, K., Alvares, G., Evans, K., Downs, J., & Glasson, E. (2022). A systematic review of the biological, social, and environmental determinants of intellectual disability in children and adolescents. *Frontiers in Psychiatry*, 13, 926681. <https://doi.org/10.3389/fpsy.2022.926681>
- Marsh, L., & Sweeney, J. (2008). Nurses' knowledge of constipation in people with learning disabilities. *The British Journal of Nursing*, 17(4), S11–S16. <https://doi.org/10.12968/bjon.2008.17.Sup2.28718>
- Maslen, C., Hodge, R., Tie, K., Laugharne, R., Lamb, K., & Shankar, R. (2022). Constipation in autistic people and people with learning disabilities. *The British Journal of General Practice*, 72, 348–351.
- May, M. E., & Kennedy, C. H. (2010). Health and problem behavior among people with intellectual disabilities. *Behavior Analysis in Practice*, 3(2), 4–12. <https://doi.org/10.1007/BF03391759>
- Mefford, H. C., Batshaw, M. L., & Hoffman, E. P. (2012). Genomics, intellectual disability, and autism. *The New England Journal of Medicine*, 366, 733–743.
- Mitchell, A. (2019). Carrying out a holistic assessment of a patient with constipation. *The British Journal of Nursing*, 28(4), 230–232. <https://doi.org/10.12968/bjon.2019.28.4.230>
- National Institute for Health and Care Excellence. (2017a). *Constipation in children and young people: Diagnosis and management*. National Institute for Health and Care Excellence (NICE) (NICE Clinical Guidelines, No. 99). Available from. <https://www.ncbi.nlm.nih.gov/books/NBK554924/>
- National Institute for Health and Care Excellence. (2017b). *Constipation in children and young people: diagnosis and management* [NICE Guideline No. 99]. <https://www.nice.org.uk/guidance/cg99>
- Newschaffer, C. J., Croen, L. A., Daniels, J., Giarelli, E., Grether, J. K., Levy, S. E., Mandell, D. S., Miller, L. A., Pinto-Martin, J., Reaven, J., Reynolds, A. M., Rice, C. E., Schendel, D., & Windham, G. C. (2007). The epidemiology of autism spectrum disorders. *Annual Review of Public Health*, 28, 235–258.
- Office for National Statistics. (2020). Population estimates for UK, England and Wales, Scotland and Northern Ireland: 2020. <https://www.beta.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/adhocs/13197autismprevalenceuk2020>
- Otte, A., Maier-Lenz, H., & Dierckx, R. A. (2005). Good clinical practice: Historical background and key aspects. *Nuclear Medicine Communications*, 26(7), 563–574. <https://doi.org/10.1097/01.nmm.0000168408.03133.e3>
- Robertson, J., Baines, S., Emerson, E., & Hatton, C. (2018). Constipation management in people with intellectual disability: A systematic review. *Journal of Applied Research in Intellectual Disabilities*, 31(5), 709–724.
- Rubin, G., & Dale, A. (2006). Chronic constipation in children. *British Medical Journal (Clinical Research Ed.)*, 333(7577), 1051–1055. <https://doi.org/10.1136/bmj.39007.760174.47>
- Smith, J., Swallow, V., & Coyne, I. (2015). Involving parents in managing their child's long-term condition—a concept synthesis of family-centered care and partnership-in-care. *Journal of Pediatric Nursing*, 30(1), 143–159. <https://doi.org/10.1016/j.pedn.2014.10.014>
- Srivastava, A. K., & Schwartz, C. E. (2014). Intellectual disability and autism spectrum disorders: Causal genes and molecular mechanisms. *Neuroscience and Biobehavioral Reviews*, 46(Pt 2), 161–174. <https://doi.org/10.1016/j.neubiorev.2014.02.015>
- Swanwick, T. (1991). Encopresis in children: A cyclical model of constipation and faecal retention. *The British Journal of General Practice*, 41(353), 514–516.
- The Autism Act (2009) <https://www.legislation.gov.uk/ukpga/2009/15/contents>
- The Equality Act (2010) <https://www.legislation.gov.uk/ukpga/2010/15/contents>
- Thompson, A. P., MacDonald, S. E., Wine, E., & Scott, S. D. (2021). Understanding Parents' experiences when caring for a child with functional constipation: Interpretive description study. *JMIR Pediatrics and Parenting*, 4(1), e24851. <https://doi.org/10.2196/24851>
- Vriesman, M. H., Rajindrajith, S., Koppen, I. J. N., van Etten-Jamaludin, F. S., van Dijk, M., Devanarayana, N. M., Tabbers, M. M., & Benninga, M. A. (2019). Quality of life in children with functional constipation: A systematic review and meta-analysis. *The Journal of Pediatrics*, 214, 141–150. <https://doi.org/10.1016/j.jpeds.2019.06.059>
- Wang, C., Shang, L., Zhang, Y., Tian, J., Wang, B., Yang, X., Sun, L., Du, C., Jiang, X., & Xu, Y. (2013). Impact of functional constipation on health-related quality of life in preschool children and their families in Xi'an, China. *PLoS One*, 8(10), e77273. <https://doi.org/10.1371/journal.pone.0077273>
- Wilkins, J., & Matson, J. L. (2009). A comparison of social skills profiles in intellectually disabled adults with and without ASD. *Behavior Modification*, 33, 143–155.
- World Health Organization. (1992). *The ICD-10 classification of mental and behavioural disorders: Clinical descriptions and diagnostic guidelines*. WHO.

SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Rooney, J., Hodge, R., Smith, J., Vanstone, K., Laugharne, R., & Shankar, R. (2023). Survey of parents of children with intellectual disabilities and/or autism who experience chronic constipation. *Journal of Applied Research in Intellectual Disabilities*, 1–17. <https://doi.org/10.1111/jar.13101>