Review of constipation in people with a learning disability and autistic people: Summary Report

South West Learning Disability and Autism programme
NHS England and NHS Improvement – South West

Joining the dots across health and care
Acknowledgements
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Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tr>
<td>ACSCs</td>
<td>Ambulatory Care Sensitive Conditions</td>
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<td>ASC</td>
<td>Autistic Spectrum Condition</td>
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<td>ED</td>
<td>Emergency Department</td>
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<td>GI</td>
<td>Gastrointestinal</td>
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<td>GP</td>
<td>General Practitioner</td>
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<td>LeDeR</td>
<td>Learning from lives and deaths – People with a learning disability and autistic people (formerly known as the Learning Disability Mortality Review Programme)</td>
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<td>MCCD</td>
<td>Medical Certificate of Cause of Death</td>
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<td>PHE</td>
<td>Public Health England</td>
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<td>SMRv</td>
<td>Structured Medication Reviews</td>
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Executive Summary

Purpose
This report presents a summary of findings from an evidence and qualitative review conducted to understand constipation and its management in people with a learning disability and autistic people. The literature review (Annex A) builds a picture of the prevalence, morbidity, mortality and management of constipation in all age groups. The survey, semi structured interviews and case studies (Annex B) are aimed at providing a thematic understanding of the experience of children and young people and their carers.

Key points
• There is significant and consistent evidence that the prevalence of constipation in people with a learning disability and autistic people is higher than amongst the general population and that there appears to be a correlation with condition severity and constipation, physical inactivity and constipation, but not with age and constipation, which is seen in the general population.
• Whilst the data should be interpreted with caution, National Commissioning Data Repository (NCDR) activity data suggest that people with a learning disability and autistic people are overrepresented in acute admissions for constipation, when compared with the general population.
• There are numerous recent, methodologically robust guidelines which have been developed for the identification and management of constipation of both children and young people, and adults in the general population, however fewer guidelines have been produced specifically for those with a learning disability and autistic people.
• Despite the availability of clear, robust guidelines, our research found that patient experience of accessing appropriate support is variable.
• GPs were cited most commonly as the service accessed for advice on managing constipation, and difficulty in accessing specialist services was noted as well as a view that services do not always seem prepared to effectively support children with a learning disability and autistic children.
• Families seeking support for constipation often struggle to be heard and believed by health professionals, feeling that they are routinely not taken seriously, and their concerns ignored. Some feel they have to constantly push to be believed by healthcare professionals when they talk about their child, their experiences and their concerns.

Recommendations
Further work should be carried out to understand the views and training needs of primary care practitioners including GPs. The experience of management of constipation at GP level was highlighted repeatedly throughout the review. Most survey respondents (86%) had sought advice from their GP and the GP was the most popular place to have sought help and support from, it is therefore important that the GP voice is captured and considered in any further quality improvement initiatives going forward.
Suitable materials to be developed for adolescents and children and young people with ASC. Feedback gathered suggests that the resources available are aimed at either young children or adults with a learning disability, however, there seems to be a lack of resources available that are accessible for older children and adolescents, or that take into account the particular communication needs of young people with ASC.

Data quality requires review and improvement. Further work is required to understand and manage acute admissions for constipation. Data suggests that 75% of admissions for constipation are non-elective and further work is required to establish how many of these are primarily to treat constipation as the primary condition. This work would need to focus on the variation in clinical coding sequencing utilised on discharge and necessitate expert coding knowledge to perform a drill down of coding between providers of care.

Research to understand the role of virtual appointments in bowel and bladder health. As services move in to the ‘new normal’ following the Covid-19 pandemic and system recovery pressures mount, it is important if virtual appointments are to continue that this is informed by empirical evidence and meet the needs of the individuals involved. This will be particularly key in the cohort of people with a learning disability and autistic people.

Structured Medication Reviews (SMRvs) to be conducted for patients prescribed regular, or long-term, laxatives. The evidence review highlighted that inappropriate laxative prescribing and over-prescribing of medicines which can contribute to constipation is a causal factor in the poorer outcomes for people with a learning disability and autistic people. It is therefore likely to be beneficial for GP Practice clinical pharmacists to conduct an SMRv with patients/carers. The SMRv will provide an opportunity to identify possible deprescribing, offer support around appropriate medication use and consider interventions that offer holistic medicines understanding.

Further education and support materials for schools with older children and adolescents with toileting issues. Further work is required to understand the educational requirements of the school teams supporting older children and adolescents with toileting issues, this should include remote training, education resources and access to support services.

Guidelines and support for clinicians to enable reasonable adjustment modifications to general population guidelines for the management of constipation. It is important that implementation of existing best practice is optimised to ensure National guidance is followed. Further training and resources are needed to help tailor the approach for people with a learning disability and autistic people to improve outcomes, including accompanying tools to help develop bespoke care plans. Medical approaches alone can treat a single episode of constipation, however without acquiring toileting skills, an individual is likely to become constipated again therefore repeating the cycle.
1. Introduction

The Learning from lives and deaths – People with a learning disability and autistic people (LeDeR) programme was established in May 2015 to support local areas across England to review the deaths of people with a learning disability, to learn from those deaths and to put that learning into practice. The fourth annual report of the LeDeR programme presents information about the deaths of people with a learning disability aged 4 years and over notified to the LeDeR programme between 1st July 2016 and 31st December 2019, with a focus on deaths reviewed during 2019. From 1st July 2016 to 31st December 2019, 7,145 deaths were notified to the LeDeR programme with 3,060 deaths notified in 2019.

This report found that 23% of completed reviews of deaths of people with a learning disability identified constipation as a long-term health problem and 33% reported that the person was usually prescribed laxatives. Deaths thought to be related to constipation were also reported although, because constipation is rarely included as a cause of death in Part I of the Medical Certificate of Cause of Death (MCCD), precise numbers are unknown. Some causes of death are described as being due to bowel ischaemia, intestinal blockage or volvulus, which appear to have chronic constipation as a contributory cause. It is clear from the data that constipation is a significant problem for people with a learning disability.

The purpose of this report is to provide a thematic understanding of managing constipation in people with a learning disability and autistic people. Autism will be included in the LeDeR programme from late 2021 due to the need for reliable data on the health inequalities faced by autistic people.

Firstly, this report presents a brief summary of a rapid review of the literature that addresses the following key lines of enquiry:

- Test the assumption that constipation and its complications in people with a learning disability and people with ASC results in increased morbidity requiring hospitalisation and / or increases mortality.
- Identify national and international best practice guidance and standards on constipation management and bowel continence management.
- Undertake an academic literature review of studies which explore the approaches, models of care and services which involve the effective management of constipation and bowel continence.

Literature for all ages was considered, as well as guidelines and best practice recommendations aimed at the general population where these are likely to be applicable to people with a learning disability and autistic people. The full literature review is available in Annex A.

Secondly, the report presents a brief summary of findings in relation to parent / carer’s experiences of managing constipation and service access for children and young people with a learning disability and autistic children. The report focuses on this cohort as establishing good bowel habits in childhood may to lead to better outcomes in adulthood. Annex B provides a full report of the qualitative and quantitative data from surveys and semi structured interviews with families and carers; and presents three service case studies that illustrate ways in which services are looking to address some of the known issues that are identified in the parent and carer feedback.
Finally, a supplementary report has been produced for NHSE/I that includes an analysis of admissions data from the National Commissioning Data Repository (NCDR). As per guidelines in using NCDR data, the report has been published for NHS operational and management purposes only and is not to be used as official statistics for general public use.

2. Evidence Review

A rapid evidence review methodology was used to identify and review literature that addressed the key lines of enquiry. A range of resources were accessed including evidence-based guidelines, trials and studies published in academic journals, and relevant grey literature. A full description of the methodology, including search terms and appraisal frame works, are included in Annex A.

Summary of findings

- There is significant and consistent evidence that the prevalence of constipation in people with a learning disability and/or ASC is higher than amongst the general population and that there appears to be a correlation with condition severity and constipation, physical inactivity and constipation, but not with age and constipation, which is seen in the general population.

- There is evidence that constipation, along with other Gastrointestinal (GI) problems, is one of the key causes of avoidable emergency admissions to hospital in this population and rates of admission for this Ambulatory Care Sensitive Condition (ACSC) are higher than for the general population. It is recognised that emergency admissions for ACSCs for potentially preventable causes and the corresponding use of in‐patient beds, are substantially higher for people with a learning disability than for others.

- There is still insufficient evidence to determine the effect that the introduction of health checks for individuals with a learning disability has had on subsequent overall emergency or elective admissions. However, when only potentially preventable emergency admissions are considered, there is evidence that GP practices which were fully participating in health checks experienced a greater fall in admissions than those not participating. Data analysis did not consider impact of health checks on admissions for constipation in isolation. Evidence for impact on mortality is less clear, with very few reported cases in the academic literature.

- Uncertainty about precise prevalence and/or admission rates for constipation in people with a learning disability and/or ASC is due to the heterogeneity of populations, definitions and methods used in published studies.

- It has been suggested that the way in which deaths are recorded could contribute to the under-reporting of deaths due to constipation. Listing “learning disabilities” (or an associated condition) as the main underlying cause of death is common. It may be that data solely taken from Medical Certificate of Cause of Death (MCCD) are not adequate for understanding the mortality experiences of people with learning disabilities.

- There are numerous recent, methodologically robust guidelines which have been developed for the identification and management of constipation of both children and young people, and
adults in the general population. However, fewer guidelines have been produced specifically for those with a learning disability and/or ASC. There is agreement that the principles of prevention and treatment of constipation outlined for the general population are the same for people with a learning disability and/or ASC as long as additional adjustments for assessment, management and support are made.

- Most of the guidelines relating to constipation have been based on recent research evidence and there is a lack of any additional evidence in the literature to inform appropriate interventions for the management of constipation in this specific population. However, the evidence does show that, despite the availability of these guidelines, management of constipation in people with a learning disability and/or ASC remains unsystematic and suboptimal with little evidence that existing best practice guidelines are followed.

- There is also some evidence from expert opinion suggesting that coordinated care that combines more traditional medical management with behavioural interventions should be used, with communication between the providers of care being key for improving outcomes.

3. Qualitative Review

The qualitative review consisted of three parts: an electronic survey followed by semi-structured interviews with parents / carers of children and young people with a learning disability and/or autism, and a series of service case studies (n=4). Parents / carers were targeted through a number of parent and carer forums and social media. In total 68 responses were received (n=68). Quantitative data from the surveys was then analysed utilising excel the Join the Conversation platform to identify key findings and messages.

Interviewees (N=15) were purposively sampled from those who had participated in the survey and had consented to being contacted to discuss their experiences further. The interviews followed a broad appreciative inquiry approach and sought to allow participants to provide more detailed information on their experiences; particularly in relation to the support and advice they had sought from professionals, and what worked and didn’t work for them and their child. As with the survey questions, the interview topic guide was co-designed with a range of stakeholders, including NHS England and Improvement, and members of the NHSE/I led Bowel and Bladder Health Clinical Reference Group. A full description of the methodology used and findings are included in Annex B.

Summary of findings

- Overall, experiences of accessing support were found to be variable.

- Whilst it is understood that medication can, and does, play a very important role in helping to manage and treat constipation and its symptoms; families and carers reported sometimes feeling that medication is used too liberally, and potentially sometimes prescribed to “make them go away,” rather than a more holistic approach being offered that may include behavioural interventions. Often families and carers do not feel that they have sufficient understanding of how the medication they are being prescribed works.
When seeking advice for managing constipation, the service most commonly accessed is the GP, with difficulty in accessing specialist services was noted, both in getting referred to and then experiencing prolonged waiting times following referral. When specialist services are accessed, there is a view that services do not always seem prepared to effectively support children with a learning disability and autistic children.

There seems to be an incongruence between the views of professionals and families around virtual appointments: professionals suggest that the use of phone appointments has made it easier for parents to talk about bowel and bladder problems, however incidentally a small number of families and carers reported that the lack of face-to-face appointments has proved challenging during the COVID-19 pandemic. Families and carers are concerned that children have not being examined and the quality of the consultation and advice provided was impacted. This was incidental information captured within semi structured interviews/surveys to exploration of experience of care, further exploration may be beneficial.

Families seeking support for constipation often struggle to be heard and believed by health professionals, feeling that they are routinely not taken seriously, and their concerns ignored. For example, a number of families we interviewed reported that they felt they had 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 they felt that clinicians were potentially dismissive of their concerns and behaved in a patronising manner towards them, making them feel that their concerns did not count or feel like they did not understand the situation.

It appears that whether or not parents and carers feel listened to, or whether advice tallies with what they are expecting to hear, impacts on whether they follow and comply with the advice given for their child.

Families and carers report that currently there is a lack of (useful) information and guidance about constipation and how to manage it. Where material does exist, families feel it is often hard to find and not easy to access. Additionally, materials are aimed at either young children or adults with a learning disability, however, there seems to be a lack of resources available that are accessible for older children and adolescents, or that take in to account the particular communication needs of autistic young people.

Clinicians, families and carers all report that greater emphasis should be placed more generally on increasing knowledge, education and understanding about constipation.

A common sentiment that was expressed by a number of parents and clinicians that we have spoken to was that although they believed and accepted that GPs and others were doing their best to help effectively manage constipation, they often did not feel confident that they had the requisite experience and specialist knowledge to do so successfully and provide confidence in the care being received.

A number of those interviewed reported that they felt that their child’s school had often not been helpful until health services or other statutory organisations got involved. Whilst this was less of an issue in primary schools, where it was generally felt that they were more experienced
to support young children around toileting issues, many felt that once their children grew older and progressed into secondary education, it became more difficult to find appropriate understanding and support. This has been echoed in our engagement with professionals. It is noted that the voluntary sector organisation, ERIC, provide resources, including a letter template, to support engaging education around toileting troubles.

4. Conclusion

Constipation is common in people with a learning disability and/or ASC across the life course and may be under-recognised and under-reported. It is one of the key causes of hospitalisation in this group. Evidence is lacking about the impact of constipation on mortality. There are many examples of good quality, robustly developed guidelines for the management of constipation in the general population that can be applied to these specific populations, taking into account a number of reasonable adjustments as highlighted by PHE.

Early recognition and effective management through dietary modifications, physical exercises, and regular scheduled toileting habits with optimal toileting posture and sufficient privacy and time are key in treating and preventing constipation in people with a learning disability and autistic children. Medication management including appropriate laxative use and holistic advice at the point of prescribing, education to increase awareness, and good communication are also important. Medicines reviews e.g. by GP practice clinical pharmacists, should be considered to identify possible deprescribing, consider interventions that offer holistic medicines understanding and support around appropriate use.

A clear structured bowel care plan should be developed and lead by a named clinician, with multidisciplinary input to support consistent implementation of interventions that is effective and holistic. Other treatment modalities such as abdominal massage and biofeedback may be considered as part of an individualised, integrated bowel management programme.

Better recognition and management of constipation may reduce the incidence of associated health conditions, reduce hospital admissions, and improve quality of life. Strategies for the integration of individual interventions and designation of roles and responsibilities between healthcare professionals and organisations need to be explored.

A qualitative review of the experiences of parents and carers of children with a learning disability and or autism who suffer from constipation identifies a number of areas where current support and services could be improved, from a potential over reliance on prescribing medication, to the need for greater information and education (both for parents, children and clinicians). The importance of taking a holistic approach to treatment and management which includes the availability of non-medical support was an apparent key theme, as well as they impact of both experience of service and treatment concordance when families do not feel heard by professionals.

Service case studies carried out as part of this report (contained within Annex B) highlight a drive from professionals to improve early intervention, either by upskilling clinicians who see patients at the start of their journey, initiating triage processes or by providing materials to aid self-management. It is clear from professionals that the consequences of not intervening in a timely
manner can be severe, with children receiving invasive but avoidable interventions and suffering unnecessary morbidity.

An aim of this report was to include a review of admissions data, however due to issues of data quality, this has been produced for internal circulation only.
References