

Understanding the growing numbers of autistic adults being diagnosed and the possible impact on Leicester City Council's Adult Social Care (ASC) team.

Adult Social Care Scrutiny Commission

Date of meeting: 07/03/2024

Lead director/officer: Kate Galoppi

Useful information

- Ward(s) affected: All
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- Report version number: V2

1. Summary

- 1.1. This report has been prepared following a request by our ASC Scrutiny Commission who wanted to understand the impact on ASC in Leicester of the growing numbers of autistic adults (18+) being diagnosed.
- 1.2. This report both summarises and analyses the available evidence around both prevalence and actual diagnostic rates of autism in adults 18+ in Leicester City alongside our own ASC data in relation to those we are supporting.
- 1.3. The report addresses how the impact is being felt, and what the implications are for social care and autistic people. It also highlights opportunities to further strengthen our work with partners around the current and prospective work taking place in relation to autistic adults.
- 1.4. The report also shares and seeks support for a series of recommendations listed below which could help address some of the impact to adult social care.

2. Recommendation(s) to scrutiny:

Adult Social Care Scrutiny Commission are invited to:

- 2.1 Note the continued work of the system wide Leicester, Leicestershire and Rutland (LLR) Autism Strategy Group which are developing a response to the National Autism Strategy, agreeing to receive a report in due course which will specifically identify a range of actions that Leicester City Council might be prepared to sign up to.
- 2.2 Note the opportunity to work together with Public Health to refresh the Learning Disability and/or Autism Joint Strategic Needs Assessment (JSNA) for Leicester City, defining these new chapters through the lens of health inequity. This will under-pin the subsequent Autism Delivery Plan developed for Leicester City which the commission are invited to receive once developed.

3 Detailed report

- 3.1. In responding to the question posed by the commission, this report attempts to understand the data in relation to autism prevalence rates and how this might

help us understand the impact on Adult Social Care in Leicester, of growing numbers of people (adults18+) being diagnosed.

- 3.2. The report also highlights where work is being undertaken to support autistic people earlier, as part of a system wide response to avoid unnecessary escalations into our mental health inpatient units. There has been a worrying trend of admissions from autistic individuals that has implications for health and social care; this needs to be both better understood and addressed.
- 3.3. Despite this worrying trend of increasing inpatient admissions for autistic people, there has been a focus on developing our autism services and support in LLR over the last few years.
- 3.4. This report will show that by working together, particularly with our care providers and social workers and our colleagues in health, we are strengthening our ability as a system to intervene early, providing support that can keep people safe, preventing any escalation into statutory support.

Prevalence rates of Autism in Leicester City

- 3.5. In determining prevalence rates of autism, the [National Strategy for Autistic Children, Young People and Adults: 2021 to 2026](#), says that nationally there are 700,000 autistic adults and children in the UK – approximately 1.1% of the population. In addition, there are an estimated 3 million family members and carers of autistic people in the UK (source: [National Autistic Society](#))
- 3.6. The proportion of the population diagnosed as autistic in England is however growing significantly, and over recent years that rate of growth has accelerated, with rising diagnostic rates for both children and adults. However, whilst diagnostic rates are growing it is also strongly suspected that there are large numbers of autistic people who do not have an autism diagnosis, theories which are grounded in research (source: [The Lancet](#)).
- 3.7. In line with the trend being seen in England, using a nationally available prevalence tool, the figures for Leicester City suggest that the numbers of adults and children are growing too. The table below shows this in more detail:

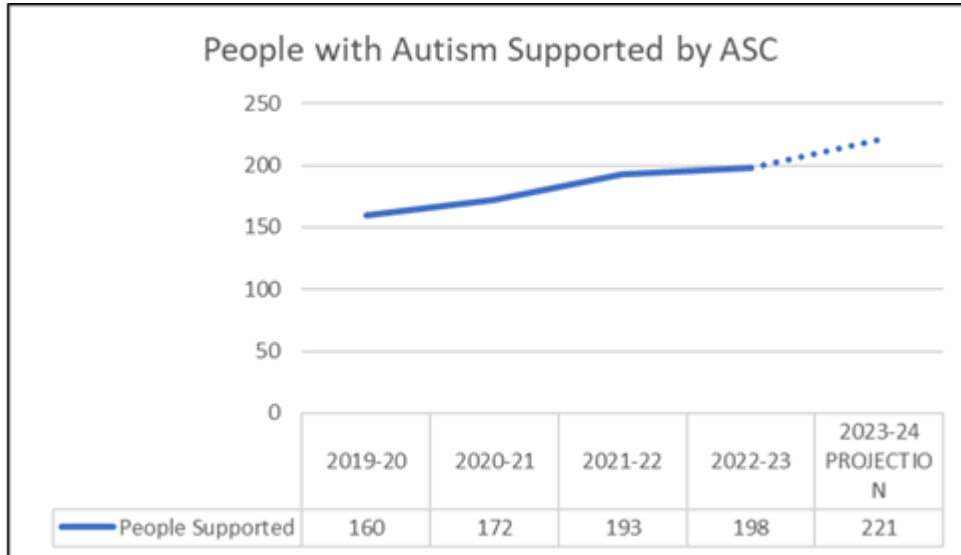
1 Table showing prevalence rates 2020 -2035 for autistic people in Leicester City

	Estimated population of autistic people calculated at 1.1% of resident population			
	2020	2025	2030	2035
Total Population	3,980	4,110	4,230	4,340
Total Population - Children and Young People	960	1,000	1,000	1,000
Total Population – Adults	3,020	3,110	3,230	3,350

- 3.8. In terms of how many autistic adults we are supporting in adult social care, Liquid Logic data below shows the numbers of people recorded on the system as autistic, regardless of whether they are recorded under the Learning Disability or Mental Health category. From this data it is evident that there is an increasing number of autistic adults being supported since 2019, with a

projection (via simple extrapolation and cross-referencing back to the last quarter in previous years) that this will continue through 2023-24.

- 3.9. It should be noted that this will not represent autistic people who are supported by ASC but who remain undiagnosed and for those whose diagnosis is not recorded.



- 3.10. To ensure we are really exploring what this data means to Leicester City, a request has been made to our public health colleagues to update the [2016 JSNA chapter for Learning Disabilities and Autism](#). This includes a request to separate the chapters, creating a new autism only chapter, which will properly assess the needs of this population as distinct from those with just a Learning Disability or autistic people who also have a Learning Disability.
- 3.11. At the time of writing, a revised JSNA was not available for this report, however, the request was made on the basis that it will enable important insights into the needs of these respective populations as our data and understanding grows. Though we are still unclear on timescales, Public Health colleagues are supportive of the request to develop and revise these new and improved chapters.
- 3.12. What is clear from the data available to us in adult social care is that whilst we are supporting more people, we are seeing some increases in the cost of services too. Whilst we are seeing fairly stable service provisions across residential and supported living services with limited growth - there is a marked increase in the provision of home care services and access to services through a direct payment.
- 3.13. Work has been done to try and understand this and the advice of the Heads of Service for learning disabilities and adult mental health, is that support is needed for families as a way to address gaps in other areas for example through short breaks or access to more preventative options that could work for autistic people.

- 3.14. This advice is backed up by the coproduction work that has happened through various strands of work connected to developing our (LLR) response to the National Autism Strategy.
- 3.15. Colleagues in the Adult Mental Health team also advised that a lack of specialist local providers with an expertise in autism is an issue for us locally. Anecdotally we know this can lead to placement breakdowns and in some cases, people being moved to mental health inpatient settings such as the Bradgate Unit.
- 3.16. Whilst there are commissioned specialist providers ready to provide care and support, they are experiencing difficulties acquiring suitable accommodation. This is driving some important work to bring forward accommodation in line with [building the right support](#) that can meet needs.

Addressing known health inequalities for autistic people

- 3.17. As well as mental illness autistic people and people with a learning disability experience distinct health inequity compared to the general population. Research cited by The National Autism Strategy found that autistic people have a shorter life expectancy by 16 years compared to the general population and autistic adults with a learning disability were found to die more than 30 years before non-autistic people.
- 3.18. As part of the work of the LLR Learning Disability and Autism (LDA) Collaborative, there has been recent local investment in a system wide Health Inequalities Champion Network, to understand and address these inequalities. Whilst the work of this network is still developing Leicester City Council has a nominated health inequality champion.
- 3.19. [LeDeR](#), a national service improvement program which reviews people's deaths with an aim to reduce inequity, originally focused on people with a learning disability, however, in February 2022 the criteria changed to include autistic people, with no learning disability. Whilst this change was welcomed, referrals for autistic only individuals remains low and work is required to raise awareness locally.
- 3.20. Nationally there has been a need for standardised, co-designed and co-delivered autism and LD training. [The Oliver McGowan Mandatory Training on Learning Disability and Autism](#) is now the preferred and recommended training for health and social care staff, meeting the statutory requirements under the Health and Care Act 2022. This is the advice that is also being given to any registered care and support providers too.

Concluding thoughts

- 3.21. Whilst pressure is being seen and felt in adult social care, particularly by the adult mental health team, supporting autistic people with no learning disability, building our capacity and ability to intervene and support people and families earlier is important. Likewise is our ability to have care and support providers

with the specialist skills and knowledge to work effectively and safely with autistic people.

- 3.22. This is recognised as a key priority and in that context is an area identified for continued development. This work is being built into our place-based action plan which is in development, and which will ensure a coherent response to the National Autism Strategy.
- 3.23. In line with findings shared in this report, work to address known gaps is being planned and actioned, a summary of this activity is given below. The intention is that a lot of this activity will be built into the city's place-based plan where it is relevant to our local need. This will ensure that any agreed actions are monitored appropriately, and officers are held to account for their delivery.
- 3.23.1. The commissioning team continue to work closely with the Adult Mental Health Team (AMH) for example training is being arranged around the newly refreshed Dynamic Support Pathway (DSP) ¹
- 3.23.2. Short breaks for unpaid carers is a priority area, which will be explored through a local engagement exercise commissioners are about to undertake.
- 3.23.3. Recognising the importance of meaningful employment, we continue to make the links with the Supported Employment project which offers opportunities and support for people with a learning disability and/or autism.
- 3.23.4. Following a well-attended drop in organised by commissioners in 2023 for Leicester City Council employees, the commissioner leading the autism work has started to develop an Autism Staff Network. This is a council wide specialist staff network providing peer-to-peer support, raising awareness of autism, and sharing good practice initiatives.
- 3.23.5. We continue to develop and strengthen the LLR Autism Partnership Board. This is now co-chaired by a person with Lived Experience, who brings a wider group of autistic perspectives to the board. There is also a wider membership including parent carers and the VCSE sector.
- 3.23.6. NHS Leicestershire Partnership Trust Directorate of Mental Health (DMH) have identified the growing need of people with a learning disability and/or autism requiring their services and the Head of Nursing is beginning to focus on this group of people to gain a greater understanding of the local picture.
- 3.23.7. Work is needed to understand and address why the number of autism only LeDeR notifications remains so low across LLR. This is a key

¹ The Dynamic Support Pathway (DSP) has been developed to provide support for individuals of all ages with a learning disability, autism or both who are deteriorating in their health and well-being whilst living in the community. This was first introduced in LLR in December 2021.

feature of the LeDeR action plan which the Collaborative and our associated partnership boards continue to monitor.

- 3.23.8. Continued promotion and development of the Autism Space [webpages](#), as part of the 'Information Advice and Guidance' requirement under the Care Act will continue. Originally developed by Leicester City Council and coproduced with autistic people, the website is now managed by NHS Leicestershire Partnership Trust. This continues to be a resource both praised and welcomed by professionals locally and our autistic population.
- 3.23.9. There is an opportunity to work with our mental health partners to promote services that are being funded through the [Getting Help in Neighbourhoods](#) initiative.
- 3.23.10. An example of low-level social support which is valued by autistic people and their families is The Monday Club. This local charity provides a weekly peer-to-peer support group for autistic adults. Funding for this group continues to be short-term. Commissioners continue to appeal for sustainable funding through the system wide LDA Collaborative.
- 3.24. This list of activity and positive action is making important inroads into our local provision and collective understanding of both the gaps but also the opportunities. The LLR LDA Collaborative provides an important space for commissioners to develop and drive this work forward, coproducing solutions with autistic people.
- 3.25. Whilst we know that most autistic people will not require or meet the threshold for a statutory adult social care service, nonetheless they have told us they may still struggle with issues around employment, education, self-help strategies and independent living skills.
- 3.26. Alongside our strong Collaborative arrangements and the work to revise and update our JSNA, of key significance is the development of our place-based plans. These plans will ensure we consider what further actions are needed to help shift our focus more to prevention, responding to the support, information and advice autistic people are telling us they need.

4. Financial, legal, equalities, climate emergency and other implications

4.1 Financial Implications

This report sets out different work strands that seek to develop the joint thinking and modelling of working practices to better support people with autism.

There are no known cost implications arising from this work at this time. However, should any of the proposed initiatives specifically identify a range of actions or outcomes that require an element of additional resource allocation then those initiatives should be costed

to allow for any decision to commit resources in terms of any wider cost implications to ASC.

Matt Cooper, Business Manager – Finance, Ext 2145

4.2 Legal Implications

There are no commercial implications that I can see.

Alex Powers, Principal Solicitor – Commercial, Ext 37 2489

The Council's statutory duties under the Care Act 2014 and Mental Capacity Act 2005 are observed within this report; there are no additional legal implications for the lead member to consider.

Mark Kamlow, Principal Solicitor, Social Care & Safeguarding, Legal Services.

Tel: 0116 454 0123

4.3 Equalities Implications

Under the Equality Act 2010, public authorities have a Public-Sector Equality Duty (PSED) which means that, in carrying out their functions, they have a statutory duty to pay due regard to the need to eliminate unlawful discrimination, harassment and victimisation, to advance equality of opportunity between people who share a protected characteristic and those who don't and to foster good relations between people who share a protected characteristic and those who don't.

Protected Characteristics under the Equality Act 2010 are age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, sexual orientation.

The report provides insights and key messages into the impact on ASC in Leicester of the growing numbers of autistic adults (18+) being diagnosed and the work that is being done to understand and respond to local need. Autism is a lifelong developmental condition which affects how people communicate and interact with the world. There are several names used to describe the autism spectrum, including Autistic Spectrum Disorder, Autism Spectrum Condition, and others which have been used to describe a part of the spectrum, such as Asperger Syndrome or Classic Autism. Autism affects people of all ages, ethnicities, and genders. It is important to recognise that not all autistic people see themselves as disabled. Inequalities experienced because of autism may interact with discrimination and barriers based on other protected characteristics. Reduction in health inequalities and improved health access can lead to improved quality of life for people and communities.

Surinder Singh, Equalities Officer, Ext 37 4148

4.4 Climate Emergency Implications

There are no significant climate emergency implications directly associated with this report. As service delivery generally contributes to the council's carbon emissions, any impacts of changes to service delivery could be managed through measures such as encouraging sustainable staff travel behaviours, using buildings efficiently and following sustainable procurement guidance, as applicable to the service.

Aidan Davis, Sustainability Officer, Ext 37 2284

5. Background information and other papers: n/a

6. Summary of appendices: None