

Staffordshire Health and Wellbeing Board – 01 December 2022

Learning Disability and Autism: Everybody's Business'

Recommendations

The Board is asked to:

- a. Champion the cause of people with a learning disability and autism and encourage all organisations to make a contribution to improving their lives.
- b. Endorse consultation to inform a Staffordshire Joint Whole Life Disability and Neurodiversity Strategy.
- c. Consider the Staffordshire Joint Whole Life Disability and Neurodiversity Strategy when available.

Background

1. The Department of Health and Social Care in England defines a Learning Disability as 'a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood'.
2. People with milder learning disabilities may be able to live independently and care for themselves, manage everyday tasks, work in paid employment, communicate their needs and wishes, have some language skills, and may have additional needs that are not clear to people who do not know them well.
3. People with more severe learning disabilities are more likely to need support with daily activities such as dressing, washing, food preparation, and keeping themselves safe, have limited or no verbal communication skills or understanding of others, need support with mobility, have complex health needs and sensory impairments.
4. NICE refers to autism spectrum disorders as defined by a continuum of lifelong conditions which affect brain development. Autism diagnostic criteria include three core symptoms: differences in social communication and interaction; highly focused interests or behaviours that appear to others as repetitive or restricted; and challenges with sensory hyper-or-hyposensitivity. Most people with autism can manage with minimal help with reasonable adjustments to enable access to services, however some people can be severely impacted needing help and support with everyday tasks.

5. People with a learning disability and autism report that there are barriers to accessing everyday activities and services in their local communities and that they may be isolated and excluded, which can affect their mental and physical well-being.
6. They also have poorer physical and mental health than the general population, and many face barriers to accessing NHS services to keep them healthy and provide timely diagnosis and treatment. People with a learning disability in particular are dying earlier than they should, many from conditions which could have been prevented or treated: the average age at death for people with a learning disability is 24 years younger than the general population at around 60 years; even younger for people with severe learning disabilities.
7. Families of children and young people describe battling and surviving to ensure their loved one's needs are met and their talents and ambitions are fulfilled. There are many families who report that support is not available in a timely way and that their loved ones end up in crisis situations that could have been prevented or better managed.
8. The local 'Transforming Care Partnership' has supported 120 people with a learning disability and autism to be discharged from hospital back into the community. This has offered them the opportunity to live closer to families and friends and has improved their quality of life – although it has come at a high cost to local organisations.

It is time to do something different

9. The Learning Disability and Autism Partnership (LDAP) has over the last 18 months engaged with people with a learning disability and autism. There is an overwhelming sense that they want to live a full and independent life in their local communities with access to the same opportunities as everyone else.
10. LDAP has devised a programme of work which is based on supporting as many people as possible through mainstream services with reasonable adjustments. This will enable specialist services to prevent and respond to crisis situations and avoid inappropriate admissions to hospital and expensive long-term care LDAP has agreed the following workstreams in the first instance:

Early identification and diagnostics

11. Early identification of people with a learning disability and autism and their needs is key to their physical, mental, and emotional well-being. In Staffordshire:

- a. 30,000 people have a learning disability and/or autism: 3.5% of the population.
- b. The number of people with a learning disability and/or autism is expected to rise to 31,500 by 2030 in line with overall population growth.
- c. Six thousand are recorded on GP registers; of whom just over one third had an Annual Health Check in the last year.
- d. 1800 are in receipt of care and support from the County Council.
- e. This workstream will review how their needs are identified and addressed including through GP registers, Annual Health Checks, screening programmes, and weight management programmes.

Communities

12. People with a learning disability and autism experience limited access to everyday opportunities due to a gap in public knowledge and understanding about their needs. This can lead to isolation, exclusion, and poor mental, physical, and emotional well-being.
13. Feedback suggests they want to feel safe within their own homes and local communities. They want security over their homes, education, employment, access to leisure, transport, social circles, relationships, and social settings within their community.
14. This workstream will work with community partnerships, statutory bodies as well as voluntary bodies, to encourage a change of thinking and local areas to improve access for people with a learning disability and autism by means of reasonable adjustments. The following opportunities have been identified:
 - a. Housing strategy documents can recognise the specific needs of people with a learning disability and autism and ensure that these are reflected in developments.
 - b. The employment rate for people with a learning disability and autism is 59.6% compared to 81.7% for the general population.
 - c. Employers can make reasonable adjustments to increase employment rates among people with a learning disability and autism.
 - d. Access to leisure activities can be improved and there are some really good examples to learn from such as Burton Albion Football Club that offers inclusive access to sport and social activities.
 - e. Families want to see better use of Experts by Experience who are able to share their own experiences to shape and mould community access.

NHS services

15. Access to NHS services can be problematic due to a lack of gap in staff knowledge and understanding about their needs. Reasonable

adjustments are inconsistent: there are some excellent examples and others where the needs of people with a learning disability and autism are not considered at all.

16. Communication can be a barrier along with information that is not available in a format that people with a learning disability can understand. Digital methods are often underdeveloped as is the use of other social media platforms.
17. Sensory processing issues are not consistently considered to ensure autistic people are able to access the support they need.
18. This work stream will be looking to improve people's experience and access to planned and emergency NHS services. Embedding of the health passport which is a system approach to ensuring people with communication needs are well understood when they access any health setting, defining reasonable adjustments, working alongside the outcomes from the LeDer programme which is the programme that is learning from the lives and deaths of people with a learning disability.

NHS learning disability and mental health services

19. People with a learning disability and autism have historically been referred to learning disability and mental health services rather than being supported by primary care. These services were never intended to support this level of demand, and this has resulted in long waiting lists. Services are predominantly provided during the day, with limited access beyond 5pm or at weekends.
20. The ICB currently commissions:
 - a. In South Staffordshire Midlands Partnership Foundation NHS Trust to provide an Intensive Support team, Community Learning Disability teams, Children's Learning Disability services and Child and Adolescent Mental Health services (CAMHs). The ICB also commission assessment and support services for children and young people with autism and an adult diagnostic service.
 - b. In North Staffordshire North Staffordshire Combined Healthcare NHS Trust to provide an Intensive Support Team (IST), Community Learning Disability teams, Assessment and Treatment inpatient beds, CAMHs learning disability, a specialist autism diagnostic service and six beds for respite care.
21. This workstream will review and consider future arrangements learning disability and mental health services with the aspiration that in future some people's needs will be met in primary care, therefore reducing

demand. This should mean that the people who need specialist services should get more timely access, which should minimise crisis situations.

Dedicated Care & Support

22. There are people who need more support than communities and NHS services can provide. This can mean that additional care and support needs to be commissioned, usually from the independent sector:
 - a. The County Council commissions care and support for around 1800 people. Three hundred of these are joint funded where they have both social care and health needs.
 - b. Midlands and Lancashire Commissioning Support Unit commissions care and support for people eligible for Continuing Health Care.
 - c. North Staffordshire Combined Healthcare NHS Trust commissions and provides care and support for people who are in a mental health hospital or have been discharged.
23. The local market may not be providing optimum quality or value for money in all cases. Some providers may not have the skills to work with more complex individuals.
24. This workstream will review the market to explore opportunities for integration of commissioning arrangements to improve quality and value for money.

Inpatients

25. There are currently eighteen people with a learning disability and autism detained in mental health hospitals. Most of these are placed outside Staffordshire due to limited availability of beds in county.
26. In addition, people with a learning disability and autism may be admitted to acute hospitals unnecessarily due to no other options being able to support them in their local community. People with lived experience report that inappropriate admission is extremely distressing which they struggle to recover from.
27. This workstream will review need and options to offer inpatient mental health beds locally for those who really need them, and work with acute hospitals to explore how to support people with a learning disability and autism if they are admitted.
28. The County Council and Integrated Care Board are developing a Staffordshire Joint Whole Life Disability and Neurodiversity Strategy. This will continue and where necessary adapt these workstreams and incorporate other priorities identified by people with a learning disability

and autism, their families, and other stakeholders. The intention is to begin consultation on the Strategy in December 2022.

List of Background Documents/Appendices:

None.

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