

Down's syndrome and Complex Needs

Mental health - an introduction

January 2023

What is mental health?

Mental health is our capacity to deal with everyday life and how we cope with stressors that arise. Mind, the national mental health charity describe mental health being like physical health in that we all have it and we need to take care of it in order to stay healthy.

The mental health needs of people who have a learning disability have been overlooked in the past. It wasn't until 2016 that the NICE guidelines 'Mental health problems in people with learning disabilities: prevention, assessment and management' were published to highlight mental health issues in this population.

What can impact our mental health?

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Mental health and Down's syndrome

People who have Down's syndrome are susceptible to the same physical and mental ill health as anyone in the population. However, whilst certain biological differences coupled with environmental stresses may make mental health issues more likely, they are not inevitable. As with all of us, there are things that can promote positive mental health and reduce the likelihood of issues arising. For example, facilitating positive relationships and empowering people through providing choice and opportunity and keeping physically active.

Common behaviours in people who have Down's syndrome may be mistaken for poor mental health. For example, self-talk has historically been misdiagnosed as evidence of psychosis. We now know that self-talk is developmentally appropriate and that it can serve a number of useful purposes. If it moves along a continuum into becoming disruptive to everyday life, then the person may need to be supported with strategies to help reduce the impact.

Any sudden behaviour change is always a cause for concern and may be a sign that the person needs additional support. Some behaviours that may indicate that things are not right for the person include:

- Loss of skills or needing more prompting to use skills
- Social withdrawal
- Irritability
- Avoidance
- Agitation
- Loss of interest in activities they usually enjoy

There may be things that can help such as reducing demands on the person, putting in extra support and structure, using visual prompts and supports, breaking information and tasks down into manageable segments. You will find further suggestions in DSA's supporting emotional well-being resource.

Complex needs

In common with other people who have Down's syndrome, people who have more complex needs may at times experience poor mental health. In this population it is less likely that mental health needs will be recognized and therefore diagnosed. This group of people may have less opportunity for self-expression, autonomy, and connection which may increase the chance of a person experiencing mental ill health. It may be small behaviour changes that indicate a person is having difficulties. Putting in place preventative measures that support positive well-being are imperative for people who have complex needs.

Seeking help

If you are still concerned after having put strategies in place then talk to a professional such as a paediatrician, GP or learning disability nurse.

We would always suggest a thorough health check-up to see if there are any underlying health issues that may have caused, or be contributing to, the changes you are seeing.

Community Learning Disability Team (CLDT)

CLDTs have been set up to serve the health needs of adults who have learning disabilities. CLDTs vary in size and make-up but typically they will contain community learning disability nurses, a psychologist, and a psychiatrist. Your GP can make a referral to the CLDT on your behalf. Some CLDTs also take direct referrals from people who have learning disabilities, their families, or paid supporters. You can find your local CLDT by searching online; the details are usually to be found on your local NHS Trust website.

Child and Adolescent Mental Health Services (CAMHS)

CAMHS are the NHS services that assess and treat young people with emotional, behavioural and/or mental health difficulties. You can find your local service by searching online; the details are usually to be found on your local NHS Trust website. In some area there may be a specialist learning disability CAMHS service.

Mental health conditions

We have further factsheets about some of the more common mental health issues that can be experienced by people who have Down's syndrome. There is comprehensive information about mental health issues in young people and adults in 'Mental Wellness in Adults with Down syndrome' by Dennis McGuire & Brian Chicoine (Woodbine House, 2021, 2nd Ed).

References and further reading

Chicoine, B &, McGuire, D (2021, 2nd Ed) Mental Wellness in Adults with Down's syndrome – A Guide to Emotional and Behavioral Strengths and Challenges (Woodbine House)

Overview | Mental health problems in people with learning disabilities: prevention, assessment and management | Guidance | NICE

DSA Emotional Well- Being Resource for Supporters

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