



**WIRRAL
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Future in Mind Evidence Base: Children and Young People with a learning disability

**Wirral Future in Mind
Steering Group and Wirral
Intelligence Service**

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Future in Mind Evidence Base: Children and Young People with a learning disability

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Introduction

[Future in Mind](#) is the government's approach to improve the emotional health and wellbeing of children and young people. It was published in 2015 and calls for action on five themes:

- Promoting resilience, prevention and early intervention.
- Improving access to effective support – a system without tiers.
- Care for the most vulnerable.
- Accountability and transparency.
- Developing the workforce.

Wirral's local approach in response to this national direction and local need is set out in our annually refreshed [Transformation Plan](#). The evidence base that underpins this work is outlined below.

Why is this important?

Promoting equality and addressing health inequalities are at the heart of NHS England's values and the [Transforming Care Programme](#) (TCP).

Children, young people (CYP) and adults with a learning disability (LD) and/or autism who display behaviour that challenges, including those with a mental health condition, have the right to the same opportunities as anyone else to live satisfying and valued lives and to be treated with the same dignity and respect. They should have a home within their community, be able to develop and maintain relationships and get the support they need to live a healthy, safe and fulfilling life (NHS England, LGA, ADASS, 2015).

As part of the national TCP, the aim is to transform services for people of all ages with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition. TCP is in line with the 2015 [Building the Right Support – A national plan to develop community services and close inpatient facilities](#). The plans cover 2016 - 2019.

The function of TCP is to work with individuals with a learning disability (LD) and/or autism and their families/carers to agree and deliver local plans for the programme. There has been a greater focus on CYP more recently with regards to services and pathways to avoid CYP being required to go into inpatient facilities or residential placements.

The aims of TCP are:

- To improve quality of care and the quality of life for CYP with a LD and/or autism.
- To enhance community capacity to support the needs of this population, thereby reducing inappropriate hospital admissions and residential placements.

The TCP is focused on the following CYP:

- CYP with a LD, and/or autism who have or are at risk of developing a mental health condition such as anxiety, depression, or a psychotic illness, and those with personality disorders, which may result in them displaying behaviour that challenges.
- CYP with an LD, (often severe), and/or autism who display or are at risk of developing self-injurious or aggressive behaviour, not related to severe mental ill health. Some of whom will have a specific neuro-developmental syndrome and where there may be an increased likelihood of developing behaviour that challenges.
- CYP with a LD, and/or autism who display or are at risk of developing, risky behaviours which may put themselves or others at risk and which could lead to contact with the

criminal justice system (this could include things like fire-setting, abusive, aggressive or sexually inappropriate behaviour).

- CYP with a LD, and/or autism, often with lower level support needs and who may not traditionally be known to health and social care services, from disadvantaged backgrounds (e.g. social disadvantage, substance misuse, troubled family backgrounds) who display or are at risk of developing, behaviour that challenges, including behaviours which may lead to contact with the criminal justice system.

Evidence base for Children & Young People with learning disabilities: FIM & Transforming Care Programme

The key national drivers to improve outcomes for this group of CYP are listed below and it is these that will support vulnerable CYP to have their needs met in safe environments: promoting quality of life, independence and choice, while allowing them access to effective needs led specialist services and ensuring access to crisis care when needed.

- The Children and Families Act (2014).
- Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition: Service model for commissioners of health and social care services. (NHS England, 2015).
- Building the Right Support. A national plan to develop community services and close inpatient facilities for people with a learning disability and/or autism who display behaviours that challenges, including those with a mental health condition (NHS England, 2015).
- Future in Mind. Promoting, protecting and improving our children and young people's mental health and well-being. (DOH, 2015).
- Paving the Way: How to develop effective local services for children with learning disabilities whose behaviours challenge (Council for Disabled Children, 2015).
- THRIVE. Elaborated (Anna Freud Centre, 2016).
- Care Education and Treatment Reviews: Policy and Guidance (NHS England, 2017).
- Developing support and services for children and young people with a learning disability, autism or both (NHS England, 2017).
- These Are Our Children (Council for Disabled Children, 2017).
- Good Intentions, Good Enough? (Council for Disabled Children, 2017).
- 'Good intentions, good enough?' The Lenehan review into residential special schools.
- Children with Special Educational Needs and Disabilities (SEND) (Ofsted, 2017).

[This document provides a more detailed overview of these key aspects of legislation, research and policy.](#)

National Facts and Figures

- There are an estimated 1.2 million people in England, of which 286,000 are Children & Young People (CYP) with a learning disability (LD) under the age of 18 (Emerson et al., 2012; Cooper et al., 2014).
- There are 125,000 children & young people (CYP) under the age of 18 with autism (Baird et al. 2006).
- 40,000 of CYP under the age of 18 with a LD are believed to display challenging behaviour (Emerson et al., 2014).
- For every 1 million general population, there will be 750 CYP with a LD and/or autism whose behaviour challenges.
- Amongst CYP with learning disability (LD), 36% have psychiatric disorders, compared to 8% amongst CYP with no learning disability (Emerson et al., 2012).
- CYP with autism are three times more likely to be excluded permanently than CYP with no Special Educational Needs and Disabilities (SEND) needs (Lenehan, 2017).
- CYP with LD are much more likely than others to live in poverty, to have few friends and to have additional long term health problems and disabilities such as epilepsy and sensory impairments (Foundation for People with Learning Disabilities).
- Nearly 40% of this group will experience a significant psychiatric disorder, compared with less than 10% of those without a LD.
- 25% of CYP in custody have a LD.
- There are currently 82,000 CYP in contact with CYP mental health services who have a LD and/or autism.
- This group of CYP are often admitted to residential care unsuited to supporting their needs, and which does not support preparation for transition to adulthood and independent living (Lenehan, 2017).
- CYP with LD and/or autism tend to be in poorer families and live in challenging circumstances.
- The loss of local authority early intervention and short breaks services affects CYP with LD and/or autism disproportionately.
- “This group (...LD) of children & young people (CYP) are the poor relations of CYP Mental Health Services (CYPMHS)” (Lenehan, 2017).

Wirral JSNA July 2016

- 9.1% of Wirral school children are receiving some form of support in schools for a special education need and almost 50% of that percentage is those with a learning disability.
- 3,942 CYP (reception year to year 11) have a diagnosis of a LD.
- Almost 50% of that Special Educational Needs (SEN) school population receives support for a learning disability.

Department for education statistical collections: special educational needs, local authority tables show that in Wirral in 2017:

- There were 1068 CYP with a moderate learning disability (MLD) known to schools (**lower** than the national figure).
- There are 364 CYP with a severe learning disability (SLD) known to schools (**higher** than the national average).
- There are 55 children & young people with a profound and multiple learning disability (PMLD) known to school (**similar** to the national average).

Current activity and services

Learning Disabilities-Child & Adolescent Mental Health Services (LD-CAMHS) is a specialist multi-disciplinary team who work with children and young people (CYP, 0-18 years) with severe/profound and multiple learning disabilities with complex needs, in line with their life long disability, including behaviours that challenge and co-morbid mental health issues.

LD-CAMHS accept parent/carer referrals, alongside referrals from allied professionals. The team provides holistic child and family centred assessment and intervention working within Positive Behaviour Support (PBS) and Person Centred Planning (PCP) models of care.

The LD-CAMHS works closely with:

- The Children with Disabilities Team which is a Wirral wide service based at Wallasey locality office. The team provide advice and support services to families and CYP (0-16 years) that have severe and substantial disabilities. The Children with Disabilities Team work with CYP where their disability is impacting on their ability to be equal, safe and achieve. The services provided are to support CYP in need and their families who have severe or substantial disabilities. The Children with Disabilities Team can be contacted on 0151-606-2008. Also see [Local Offer website](#).
- Local Authority Specialist Schools
- Primary Mental Health Services
- Wirral Child Development Centre
- Voluntary Services

What does this suggest as further actions?

Further actions are informed by a number of national publications:

- the Winterbourne View – Time for Change (DOH, 2014),
- FIM (DOH, 2015),
- Building the Right Support (DOH, 2015)
- These Are Our Children (DOH, 2017)

The overall aim of the TCP is to take a strategic overview and consider what practical steps need to be taken to make the system more effective in co-ordinating care, support and intervention for CYP with LD and/or autism and behaviour that challenges, and co-morbid mental health issues. This will involve working with commissioners using current funding to best value, in line with Sustainability and Transformation Plans (STPs) and Future in Mind [Transformation Plan](#).

Further actions are:-

- Work collaboratively with commissioners to inform, design and develop an effective service model to meet the needs of CYP with LD and/or autism as part of FIM, Transforming Care Programme, and Wirral All Age Disability strategy
- Ensure that the workforce of the LD-CAMHS is compatible with learning disabilities service model delivery, supported by appropriate Key Performance Indicators
- Introduce Children and Young People's Dynamic Support Register

- Work with commissioners, Local Authority and Special Educational Needs lead to identify CYP who are currently in expensive residential placements to consider support via local services closer to where CYP live
- Ensure the right support is in place, at the right time, by the right professionals to reduce crisis and inappropriate residential placements/ hospital admission. This support will be informed by the CETR process
- Work in partnership with commissioners and all age multi-agency services to ensure appropriate co-location
- Support colleagues outside the Learning Disabilities team regarding autism, learning disabilities and behaviours that challenge. Primary prevention may also include the provision of support by members of specialist CAMHS
- Enhance community capacity in the form of intensive support services, with a step up and step down capacity

Working in partnership with commissioners and multi-agencies to implement the Transforming Care Agenda for CYP will:

- Prevent CYP being isolated from their community, in residential placements, thereby reducing stigma, and helping CYP to access a full community life
- Provide safe, effective needs led services for CYP with LD and/or autism
- Prevent under 18s becoming the next Transforming Care cohort
- Promote an understanding of inequalities in access to healthcare faced by individuals with a LD and/or autism as emphasised in the Confidential Inquiry into Premature Deaths of people with LD and the introduction of Learning Disability Mortality Reviews

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