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

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**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

## For further information please contact:

Author:

Dr Lisa Thompson – Principal Clinical Psychologist – Wirral CAMHS as Learning Disabilities - Child & Adolescent Mental Health Services (LD-CAMHS) – [Lisa.thompson24@nhs.net](mailto:Lisa.thompson24@nhs.net)

Wirral Intelligence Service

Email: [wirralintelligenceservice@wirral.gov.uk](mailto:wirralintelligenceservice@wirral.gov.uk)

## Contents

<b>Introduction</b> .....	<b>3</b>
<b>Why is this important?</b> .....	<b>3</b>
Evidence base for Children & Young People with learning disabilities: FIM & Transforming Care Programme .....	4
<b>Facts, figures and information (Wirral and beyond)</b> .....	<b>6</b>
National Facts and Figures .....	6
Wirral JSNA July 2016 .....	7
Department for education statistical collections: special educational needs, local authority tables show that in Wirral in 2017: .....	7
<b>Current activity and services</b> .....	<b>7</b>
<b>What does this suggest as further actions?</b> .....	<b>7</b>

## 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 [Local Transformation Plan published on our Children and Young People: Mental Health webpage](#). This evidence base underpins that plan and our work and 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 out of area 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 inpatient admissions and out of area 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).
- Children with Special Educational Needs and Disabilities (SEND) (Ofsted, 2017).
- Beyond Transforming Care What Needs to Change (National Autistic Society, 2018).
- Learning Disabilities and Behaviours that Challenges: Service Design and Delivery (NICE, 2018).

- Overshadowed. The Mental Health Needs of Children and Young People with Learning Disabilities (Children and Young People’s Mental Health Coalition, 2019).
- Far Less Than They Deserve. Children with Learning Disabilities or Autism Living in Mental Health Hospitals. (Children’s Commissioner. Promoting and Protecting Children’s Rights, 2019).
- NHS Long Term Plan (2019).
- Support for Pupils with Special Educational Needs and Disabilities in England. (National Audit Office, 2019).

There is a consensus, based on the content of the documents highlighted above, on the kind of support that needs to be provided in the community in order to prevent unnecessary inpatient admissions and out of area placements including:

- Early diagnosis.
- Support that addresses the causes of behaviours that challenge, based on positive behavioural support.
- Strong early links with education services, with mainstream schools making children feel welcome, avoiding exclusions, addressing bullying and ensuring reasonable adjustments
- Better support within mental health services.
- Continued and joined up support for the child/young person from a multi-disciplinary team (psychologists, Occupational Therapists, speech and language therapy, social workers) rather than passing them between services or providing a time-limited programme of support with a need for re-referral backed up by good Education and Health Care plans
- Support for the whole family, including siblings. This should include short breaks and parenting classes and mental health support for the family.
- Keyworkers for each CYP. NHS England should set a clear timetable for when CYP will be provided with a keyworker and which group of CYP this will apply to, so that CYP are tracked through the system and they and their families have a lead contact to keep them informed and help them navigate the system.
- Regular screening to pick up any additional health needs and support to access wider health services.
- Jointly commissioned residential services which also provide outreach support.
- Intensive support services to manage crises and help avoid inpatient admissions and out of area placements.

[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 with a LD, of which 286,000 are CYP under the age of 18 (Emerson et al., 2012; Cooper et al., 2014).
- There are 125,000 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 behaviours that challenge (Emerson et al., 2014).
- CYP with a LD are more than four times more likely to develop a mental health problem than those without a LD (Children and Young People's Mental Health Coalition, 2019).
- Children and young people with a LD in the UK are 4-5 times more likely to have a diagnosable psychiatric problem than children without a LD.
- One in seven young people with a mental health problem in the UK also has a LD, but only just over a quarter (27.9%) of CYP with a LD and a mental health problem have had any contact with mental health services (NHS Digital, 2018).
- CYP with LD are much more likely to be exposed to social and environmental risk factors, 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).
- 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.
- There are approximately 250 children with a learning disability, autism or both in England living in children's mental health wards. (Children's Commissioner, Anne Longfield, 2019).
- 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).
- The loss of local authority early intervention and short breaks services affects CYP with LD and/or autism disproportionately.
- "This group (...LD) of CYP are the poor relations of CYP Mental Health Services (CYPMHS)" (Lenehan, 2017).
- There are 1.3 million pupils in England (14.9% of all pupils) with special educational needs and disabilities (SEND). (National Audit Office, 2019).

**The differences in the mental health of children with learning disabilities compared to other children constitutes a mental health inequality.**

## 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 with severe/profound and multiple learning disabilities with complex needs, in line with their lifelong 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 formulation driven interventions 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 in the Millennium Centre Leasowe. The team provide advice and support services to families and CYP (0-16 years) that have severe and substantial-disabilities. The Children with Disabilities Teamwork 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- 4888090. 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).
- NHS Long Term Plan (2019).

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 [Local 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, and Transforming Care Programme.
- Ensure that the workforce of the LD-CAMHS is compatible with learning disabilities service model delivery, supported by appropriate Key Performance Indicators
- 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 CYP-Dynamic Support Database, Tracker Meetings and the CETR process
- 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
- Implement an Intensive Support Function to enhance current CAMHS provision to those CYP with a LD and/or autism who are at risk of an inpatient admission or out of area placement.

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.

**For further details please contact:**

- Dr Lisa Thompson, Principal Clinical Psychologist, Wirral CAMHS as Learning Disabilities-Child & Adolescent Mental Health Services (LD-CAMHS) at [Lisa.thompson24@nhs.net](mailto:Lisa.thompson24@nhs.net)
- John Meddings, Future in Mind Project Manager for Wirral at [john.meddings@nhs.net](mailto:john.meddings@nhs.net)
- John Highton, JSNA Programme Lead at [johnhighton@wirral.gov.uk](mailto:johnhighton@wirral.gov.uk)

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