

# Helping patients with intellectual disability lead better lives

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# Declaration of Interests

SS has received honoraria from Angelini, Eisai, Jazz and UCB Pharma

# Topics

- Epidemiology
- Defining intellectual disability (ID)
- Recognising ID
- Adapting the environment
- Case-based discussion – capacity versus understanding?

Guidance

# Learning disability - applying All Our Health

Updated 22 March 2023

## Epidemiology

- 950,000 adults with intellectual disability (ID) in UK
- 0.5% those registered with primary care
- 26% of half a million children with ID attending mainstream school

More likely to be:

- Living in overcrowded environments
- Misusing alcohol/ recreational drugs
- Be socially isolated
- Be subject to social stigma



# No wrong door

A vision for mental health, autism and  
learning disability services in 2032

# Mental health services for adults with mild intellectual disability

Over 20% those with mild ID have  
mental health symptoms

Point prevalence goes up to 40% if  
considering all with ID

£119 billion



was the **economic and social cost of mental health problems** in 2019/20, and this is set to grow in the next decade.<sup>1</sup>

More than

75 per cent

of **autistic people sought support for their mental health** in the last five years.<sup>5</sup>

Higher rates



of most common **mental health difficulties are in women and girls** than men and boys.<sup>6</sup>

 NHS Confederation

Centre for Mental Health



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About

10 million



more people, 1.5 million of them under 18, **will need extra support** for their mental health because of COVID-19.<sup>2</sup>

Only

1/4 to 1/3



of people with a **mental health difficulty receive treatment** for it.<sup>3</sup>

4x



**as many black people** than white people in England are **likely to be sectioned under the Mental Health Act** and ten times more at risk of getting a community treatment order.<sup>4</sup>

1 in 6



**children had a mental health difficulty** compared with 1 in 10 in 2004 and 1 in 9 in 2017.<sup>10</sup>

3x



more likely to find a **mental health difficulty in children with a learning disability.**<sup>9</sup>

More than

2,000



**autistic people and people with a learning disability are in a mental health hospital**, the vast majority under the Mental Health Act.<sup>7</sup>

An average of

15-20 years

**shorter life expectancy in people with learning disabilities and people with long-term mental health problems** compared with the general population.<sup>8</sup>

# Median age at death 62 yrs

Why mental health, autism and learning disability services have to change

# Improving identification of people with a learning disability: guidance for general practice

**NHS England and Improvement Publishing Approval Reference: 001030**





## Learning Disability Register Inclusion Tool

**Definition of a learning disability:** A significantly reduced ability to understand new or complex information, to learn new skills (Significantly impaired intelligence)  
**AND** A reduced ability to cope independently, (Impaired social / adaptive functioning)  
**AND** Which started before adulthood (onset before aged 18) with a lasting effect on development

## Factors which MAY indicate No learning disability

- Normal development until other factors impact (before 18)
- **Diagnosis of ADHD, dyslexia, dyspraxia or Asperger's**
- Successfully attended a mainstream education facility without support
- Gained qualifications (GCSE and/or A 'Levels)
- Able to function socially without support
- Independently manage their financial commitments
- Able to drive a car

## Factors that MAY indicate a learning disability

- Record of delayed development/difficulties with social functioning & daily living before the age of 18.
- Requires significant assistance to undertake activities of daily living (eating & drinking, attending to personal hygiene, wears appropriate clothing) and/or with social/community adaptation (e.g. social problem solving/reasoning).
- **NB need for assistance may be subtle.**

- **Contact with mental health services**
- **Recorded IQ above 70**
- Communication difficulties due to English as a second language

- Presence of all three criteria for LD i.e. impairment of intellectual functioning/social adaptive functioning and age of onset.
- Range of information presenting a picture of difficulties in a number of areas of function, not explainable by another 'label'
- Contact with specialist learning disability consultant.
- Attendance at specialist education facility for people with intellectual delay



# Performance against the learning disability improvement standards

Findings from the Year 4 National Benchmarking exercise 2020/21

October 2023

## Learning Disability Year 4 Improvement Standards

### Key findings











 206 Trusts registered	 189 organisations submitted data	 3,608 staff surveys submitted	 2,675 service user surveys submitted
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 <b>Organisational survey</b>	<b>66%</b>  of NHS trusts can identify people with a learning disability and/or autistic people who are waiting to be seen	<b>86%</b>  of NHS trusts provide staff with up-to-date learning disability / autism awareness training	<b>84%</b>  of NHS trusts provide specialist services, including crisis support as part of their intensive community services
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 <b>Staff survey</b>	<b>76%</b>  of staff agreed they could identify reasonable adjustments people with a learning disability and/or autistic people need	<b>80%</b>  of staff felt people with a learning disability and/or autistic people are always treated with dignity and respect	<b>70%</b>  of staff said they received mandatory training on meeting the needs of people with a learning disability and/or autistic people
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 <b>Service user survey</b>	<b>92%</b>  of people with a learning disability felt NHS staff treated them with respect	<b>82%</b>  of people with a learning disability felt staff explained things to them in a way they could understand	<b>74%</b>  of people with a learning disability felt their appointments / meetings were arranged at times and of a duration to suit them
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## Learning Disabilities Standards

	<p><b>Coding/flagging</b> We will know which of our patients are living with Learning Disability or Autism so we can support them.</p>
	<p><b>Daily review</b> Every patient with a Learning Disability or Autism will be seen by a senior member of staff to make sure we are doing everything we can to help support them in hospital.</p>
	<p><b>Mental capacity</b> Every person with a Learning Disability or Autism will be asked if they understand everything that is happening to them while they are in hospital.</p>
	<p><b>Hospital Passport</b> Patients who do not bring a Hospital Passport with them to the hospital, will be given one to write in while they are in hospital which will help the doctors and nurses to look after them.</p>
	<p><b>Responsibility for care</b> All patients with a Learning Disability or Autism will have a Consultant in charge of their care.</p>
	<p><b>Multi-disciplinary approach</b> A meeting of all of the doctors and nurses looking after patients with a Learning Disability or Autism will be arranged within 72 hours of the patient coming into the hospital.</p>
	<p><b>Reasonable adjustments</b> To help to support a person with a Learning Disability or Autism whilst in hospital, we can make changes that will make their stay in hospital easier.</p>
	<p><b>Stopping Over Medication of People (STOMP)</b> We will look at every patient's medicine and tablets to make sure they are not taking too many.</p>
	<p><b>Think carer</b> Every carer/family of a patient with a Learning Disability or Autism will get a "Partners in Care" leaflet.</p>
	<p><b>Flexible visiting</b> Staff will change visiting times if it helps to support patients with a Learning Disability or Autism</p>

# Coding

- Two databases 2006-2019
- 2500 patients with ID, over 27000 admissions
- ID accurately recorded in 2.9% admissions. Some recorded as ‘undefined developmental disorder’
- ID most likely to be ‘unrecorded’ in those who had mild ID and were married.

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[PLoS Med.](#) 2023 Mar; 20(3): e1004117.

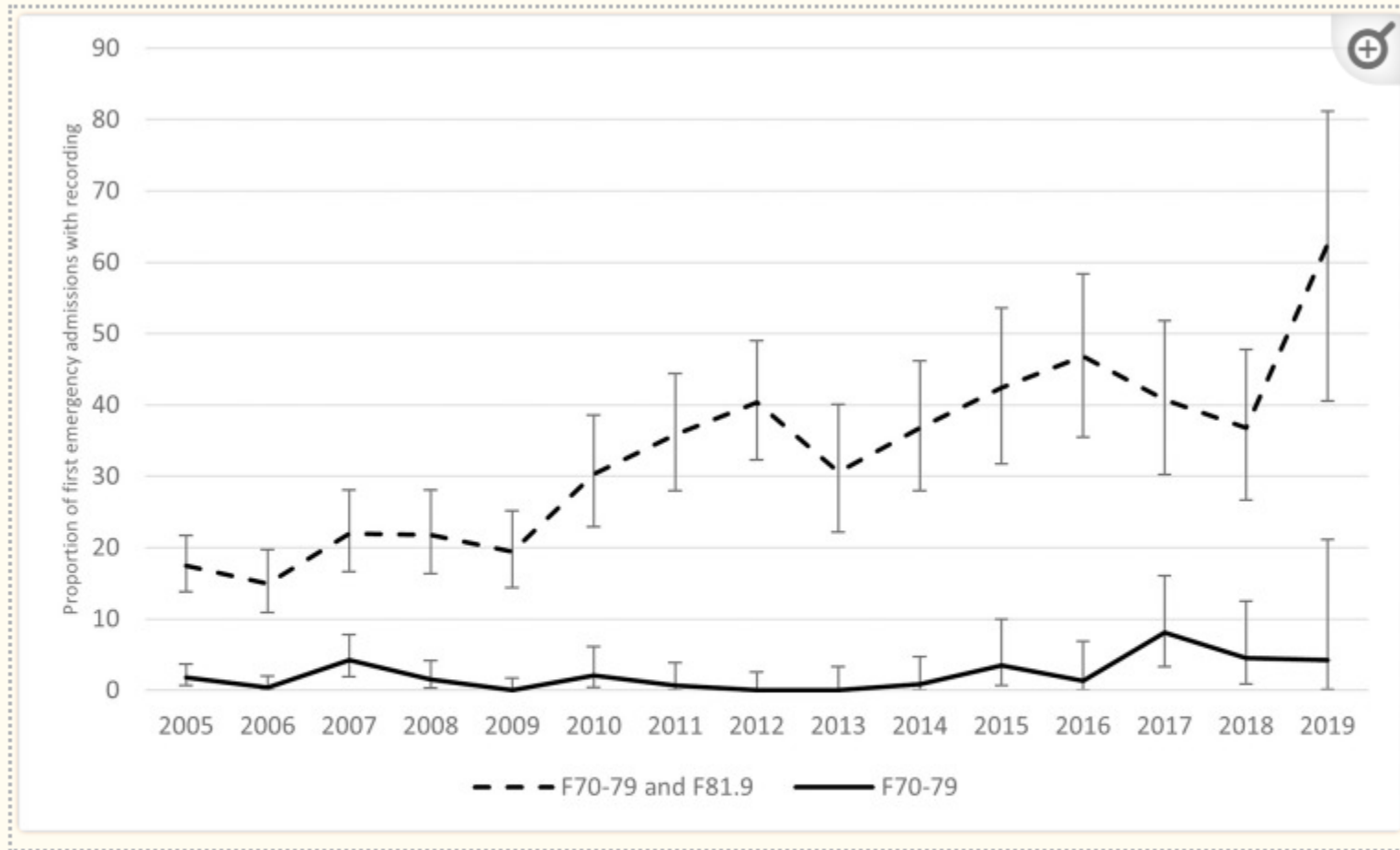
Published online 2023 Mar 20. doi: [10.1371/journal.pmed.1004117](https://doi.org/10.1371/journal.pmed.1004117)

PMCID: [PMC10069786](#)

PMID: [36940198](#)

## **Recording of intellectual disability in general hospitals in England 2006–2019: Cohort study using linked datasets**

[Rory Sheehan](#), Conceptualization, Data curation, Formal analysis, Methodology, Project administration, Writing – original draft, Writing – review & editing,<sup>✉</sup> <sup>1</sup> · [Hassan Mansour](#), Conceptualization, Data curation, Formal analysis,



[Fig 1](#)

**Time trends in recording of intellectual disability in those admitted to a general hospital in England, 2005–2019.**

F70–F79, codes for intellectual disability; F81.9, additional nonspecific code for developmental disorder of scholastic skills, unspecified. Error bars represent 95% confidence intervals.

# Reasonable adjustments

- Educational HealthCare Plan: EHCP
  - Transition starts from age 14!
- Environment
  - Flexibility of access to caregiver
  - Appropriate level of sensory stimulation
  - Time!

# “TEACH” FOR PATIENTS WITH LD

**Time** – you may need to take more time than you would with another patient. It'll be worth it.

**Environment** – does your ED have a safe, quiet space for people with LD to wait in, if they need it? Whilst assessing your patient can you cut out extra noise, people, equipment?

**Attitude** – don't assume anything about the quality of life of your patient with LD. Admit what you don't know. Can you keep an open mind about treatments and think outside the box about assessment?

**Communication** – find out how best to communicate with your patient. Make the most of their family and carers. Read their hospital passport and emergency care plan. When giving information make it as accessible as possible. Does your ED need to consider LD-friendly posters or leaflets?

**Help** – what does your patient need? What do their carers need? How can you help them achieve this? Who else can help you to care for your patient?





# Case 1

- 29 yr old male
- Referred from another centre via epilepsy surgery programme
- 'Aspergers, mild ID'
- Felt to be unsuitable for epilepsy surgery
- Transfer of care as moving from parental home to supported living

# Case 1 considerations

- Did he have capacity – YES
- Formal intellectual assessment required – did not appear to have ID
- Rigidity of thinking
  - He perceived unsuitability for resection as catastrophic
  - Convinced that only way to reduce medication burden was with surgery

## **Lessons learnt**

- Formal capacity assessment is critical
- Aspergers does not necessarily mean ID
- Understanding the patient beyond the potential for surgery....

# Case 2

- 50 yr old male
- Referred for treatment of epilepsy
- Normal birth and early development
- Meningitis aged 7 yrs, developmental regression since then
- Minimally verbally, dependent on parents



Image courtesy of Young Epilepsy  
[www.youngpilepsy.org.uk](http://www.youngpilepsy.org.uk)

# Case 2 considerations

Presented on multiple meds

Vagal Nerve Stimulation 2018

Cannabidiol 2021

Antipsychotics reduced 2021

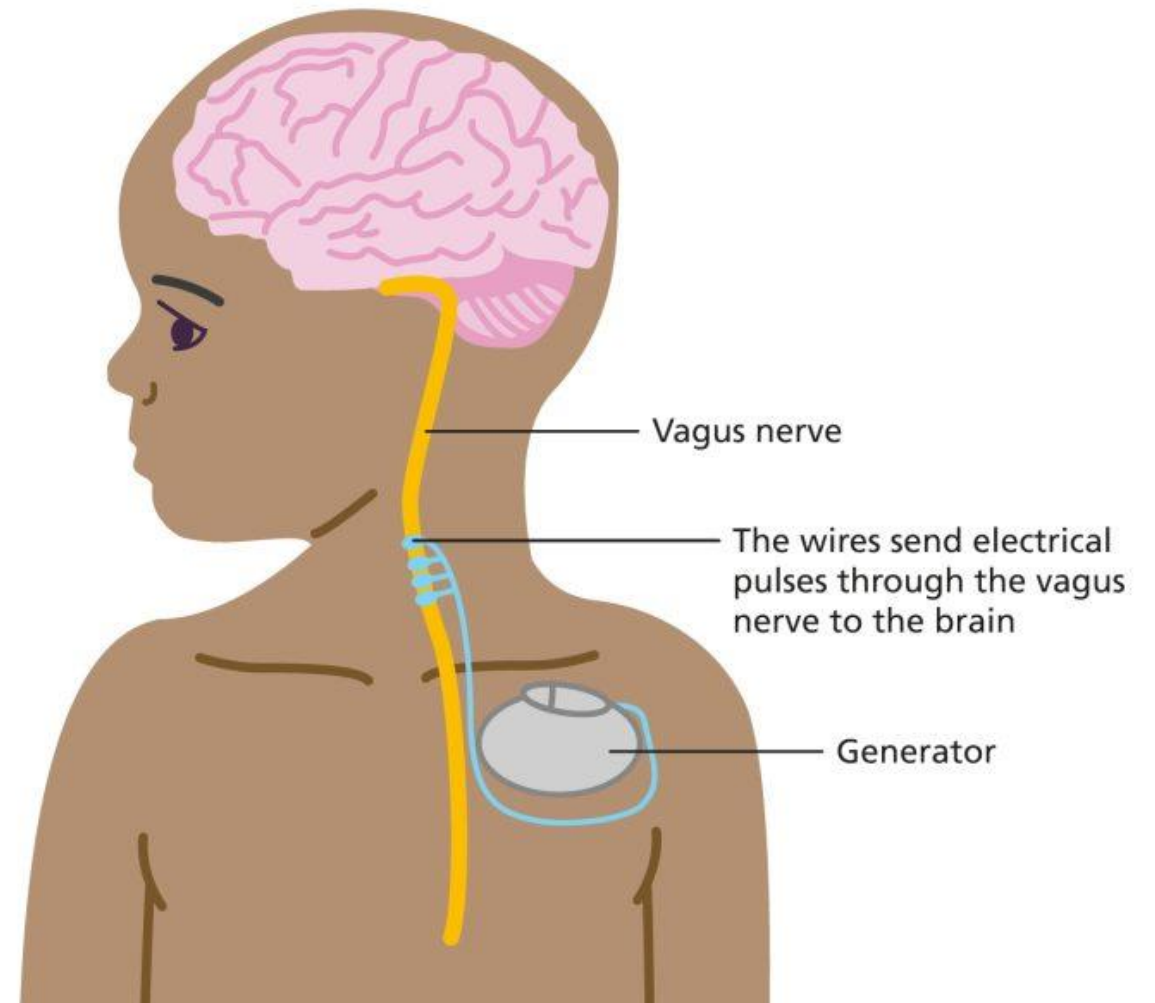


Image courtesy of  
[library.sheffieldchildrens.nhs.uk](http://library.sheffieldchildrens.nhs.uk)

# Stopping **Over-Medication** of People with a Learning Disability, Autism or Both

**(STOMP)**

# Background and Recommendations

- STOMP launched 2016
- Public Health England 2015: 35000 patients with ID prescribed antidepressant/ psychotropic without clear indication
- Reduce one medication at a time
- Assessment of environmental triggers for behaviour
  - Constipation/ fatigue/ infection/ excitement/ seizures
- Review positive behaviour support systems



**KING'S**  
*College*  
**LONDON**



**LeDeR Annual Report**

**Learning from**

**Lives and Deaths:**



Year of death	Age at death (median; interquartile range)	
	All those with LeDeR reviews*	Adults with LeDeR reviews
2018	60.1 (48.2 to 70.3)	61.8 (52.2 to 71.1)
2019	60.0 (45.5 to 70.3)	61.7 (50.8 to 71.1)
2020	61.9 (50.9 to 71.8)	63.0 (53.3 to 72.3)
2021	62.1 (51.6 to 71.8)	62.4 (52.9 to 71.9)
2022	62.7 (53.1 to 72.3)	62.9 (53.6 to 72.4)

\*Note that, for interpretation and completeness, this column includes those under 18 years old; however, for 2022 LeDeR does not have complete data for deaths in this age group.

Adults with ID are living longer

**Table 3.3a:** Summary of long-term condition variables for those whose age at death was recorded.

Variable	Level	Total (number, %)
Cancer	Yes	224 (11%)
	No	1669 (80%)
	Unknown	191 (9%)
Cardiovascular conditions	Yes	798 (38%)
	No	1095 (53%)
	Unknown	191 (9%)
Degenerative conditions	Yes	61 (3%)
	No	1832 (88%)
	Unknown	191 (9%)
Dementia	Yes	380 (18%)
	No	513 (73%)
	Unknown	191 (9%)
Epilepsy	Yes	776 (37%)
	No	1117 (54%)
	Unknown	191 (9%)

\*Recorded as part of a focused review (498 people had focused reviews); all other information recorded as part of an initial review.



Understanding Rare Chromosome and Gene Disorders

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# Welcome to Uniqüe!

Uniqüe provides support, information and networking to families affected by rare chromosome and gene disorders.

Our helpline team can help you understand your family member's diagnosis and connect you with others. Why not join us today? Alternatively, have a look around first and contact us when you're ready....



# Conclusions

- Those with ID often go under the radar
  - accurate coding enables better allocation of resources
- Gradual transition to adult services
  - Early consideration about long term care needs
  - Cross specialty? ITU input for the most complex?
  - Involve social care
- LEDER - opportunity to learn from deaths
- STOMP – are the antipsychotics necessary?
- Potential for improvement in the most refractory patients

To Anna

I am writing this letter, and tell you how good the 2nd year been more better then the 1st with the Cannabidiol Oil August 2nd 2021 when I started and finish August 2nd 2022 with 97 Minors & majors. I started the cannabidiol oil with 2.00 ml it was increased 7-2-2022 night all so Epilim 500 mg to 700mg. The 2nd year with it 2-8-2022 to 29-2-2023 27 weeks only 31 Minors, if I don't have a major in March 2023 it will be 9 months since I have had a major 24-6-2022 beside my self and the starter can't believe how long it has been. Dad gave me a copy of your letter saying about that you might change the VW's battery in the magnet, if you are will you be sending me a letter? January 2022 is still the worse months I have had with 10 minor 2 majors 9-8-2022 cannabidiol oil was increased by 0.1 day so I take 2.05 ml. 16-2-2023 it was nice to and see you with Dad, I am back at the Queen Elizabeth on the 24-8-2023. If you are sending mail to my

Thank you