

Getting the right support – the challenges faced by parents with a learning disability



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What is a learning disability?

- “A learning disability is a reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life.”
(Mencap)



So what does that mean?

- People with a learning disability often find it harder to learn certain life skills eg communication, personal care, reading, managing money, making friends etc.



A few facts

- People with a learning disability die on average **16 years younger** than the general population.
- **8 out of 10** have difficulty reading.
- **40-60%** of parents with a learning disability have their children taken into care.
- Only **17%** of adults with a learning disability are in paid work.
- Almost **1 in 3** young people with a learning disability spends less than 1 hour outside their home on a typical Saturday (Mencap, 2016).



Mental health

- People with a learning disability can be more likely to experience poor mental health.
- Some studies suggest the rate of mental health problems in people with a learning disability is double that of the general population (Cooper, 2007; Emerson & Hatton, 2007; NICE, 2016).
- But people with a learning disability often find it harder to get a mental health diagnosis and the support they need.



Barriers to equality

- Focus is often on physical accessibility but for people with a learning disability the barriers can be very different and not as obvious.
- People with 'challenging behaviour' face even more discrimination and social exclusion.



Overcoming the barriers

- Awareness and understanding of specific needs
- Reasonable adjustments
- Accessible communication
- Specialist support
- Advocacy



Parents with a learning disability

- 40-60% have their children taken into care (Wilson and colleagues, 2013).
- Lack of good quality sex and relationships education.
- Lack of staff training, awareness and understanding.
- Lack of specialist support or reasonable adjustments to access generic services.
- Lack of specialist advocacy.



The challenges some parents face

“I just feel helpless. No one is listening to me and whatever I do isn’t good enough.”

“We need to know what our rights are. We do as we are asked but the goalposts keep moving.”

“I felt pressured into sterilisation as I was told ‘Any child you have will be immediately taken from you’.”

The challenges some parents face

“My child was taken from me at the hospital and I am only allowed supervised contact. I was never given a chance or any training to help me keep my child. I was simply judged not capable. My ex is a heavy drinker, is violent and has been to prison, yet he is allowed contact with our child 4 days a week from Monday to Thursday.”

The challenges some parents face

“When professionals talk to you the language they use is often hard to understand with too many big words, especially when doing assessments.”

“Parents with a learning disability need support not judgement.”

“My son and I are both terrified of social worker visits as we are always afraid of saying the wrong thing.”

What do parents with a learning disability need?

- Good quality sex and relationships education and ongoing training
- Early intervention and support
- Accessible communication
- Joint working
- Specially adapted support
- Specialist advocacy, especially to attend court
- On-going support



But most of all...

- Parents with a learning disability need to be given the opportunity to demonstrate that they can be 'good enough' parents.
- They need to be listened to, shown respect and not be 'written off' due to misconceptions and social stigma.
- With the right support, parents with a learning disability can raise happy, healthy children in a safe and loving family environment.



What might help? The views of parents

“Someone to talk to who will really listen.”

“Someone to explain things in language we can understand.”

“Someone to be on my side for once.”

What might help? The views of advocates

“Training for professionals should involve parents with real life experience. Listening to parents’ stories and experiences will hopefully help professionals to have a better understanding.”

“Offer ongoing support when there are difficulties. Don’t criticise; show parents what they are doing wrong so they can try and get it right.”

Parental mental health

- Parents with a learning disability are likely to be very anxious and stressed.
- They are less likely to have circles of support, especially friends or other parents.
- They might find it hard to access support groups including parent and child classes.
- They might not trust professionals.
- They might find it difficult to ask for help.



Training for professionals

- Stereotyping and negative societal attitudes
- Barriers to inclusion and understanding
- Relevant legislation and guidance
- Accessible information
- Neurological differences (eg interpretation and retention of information)
- Communication difficulties
- Behavioural and social challenges

Mental health

Abuse, hate crime, 'mate crime' etc

- Issues with friendships, relationships and sexuality.



New guidance on supporting parents with a learning disability

- England and Scotland have had guidance in place for several years.
- Following many years of campaigning, Welsh Government published guidance for social workers on supporting parents with a learning disability earlier this year.

<https://www.gov.wales/guidance-social-workers-families-where-parent-has-learning-disability-html>



Thank you!



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