

Working Together with Parents Network



Facts and figures about parents with learning disabilities in England

Over the last 25-30 years, adults with learning difficulties have become more likely to develop relationships and form their own families. This is because they are more likely to live in the community (rather than long stay institutions) and because of the increased recognition of their rights to 'an ordinary life', just like other people - including the right to be parents.

The precise number of parents with learning difficulties is unknown, for a variety of reasons, including inconsistencies in assessment procedures and the fact that some adults with mild learning disabilities may only come to the attention of statutory services when they have a child and need to seek help (parents who are coping will not show up in official figures).

The most robust estimate is that from the National Survey of adults with learning disabilities in England which found that one in fifteen of the nearly 3000 people interviewed had a child.¹ There are an estimated 796,000 adults with learning disabilities over 20 in England². This means that there are likely to be more than 53,000 parents with learning disabilities in England alone.

Not surprisingly, there is evidence that the number of parents with learning disability on the caseloads of community teams is rising significantly³ ⁴. But many such parents are not known to services at all. This is likely to be because they have a mild learning disability, and may not have needed, or been eligible for, community care/support services (which operate to increasingly tight eligibility criteria) before the advent of their child.

We know from research (and experience) that once they are expecting or have a child, parents with learning disabilities tend to be reluctant to seek the support they need, for fear of having their child removed. This fear is well grounded. Around 40% of parents in the English National Survey of Adults with Learning Disabilities were not living with their children.⁵ (In some cases this may have been because their children had grown up and left home). 60% of the mothers with learning disabilities in the English National Survey, who were living on their own, or with a partner or

¹ Emerson, E et al, 2005, Adults with learning difficulties in England, 2003/4

²Institute for Health Research, 2004, Estimating Future Need/Demand for Supports for Adults with Learning Disabilities in England

³ DH/DfES, 2007, *Good Practice Guidance on working with parents with a learning disability* ⁴ Elvish,J et al,2006,Parents with learning disabilities: an audit of referrals made to a learning

Elvish,J et al,2006,Parents with learning disabilities: an audit of referrals made to a learning disability team, *Tizard Learning Disability Review*,11,2,April

⁵ Secondary analysis of data from Emerson, E et al, 2005, Adults with learning difficulties in England

husband, did not have their children under 18 living at home with them. Mothers were more likely to be living with their children if they were themselves living in the same household as another relative (who was presumably helping to provide the support they needed).

There appears to be great variation between different areas of the country in relation to social care practice and court decisions regarding parents with learning disabilities and their children. In one local authority about one in six family court proceedings involved at least one parent with a learning disability; in around 75% of these cases the children were permanently removed. Another study, however, found that children were permanently removed from their families in less than one fifth of cases involving parents with learning disabilities. Most of these children were fostered rather than adopted.

Worldwide research generally suggests that 30-40% parents with learning disabilities lose their children. ⁸ Certainly the email and phone requests to the Working Together with Parents Network from parents, professionals, solicitors and other family members, indicates that the issue of parents not having access to the support, information and advice they need, and the resulting substantial risk of their losing their children continues to be widespread and significant.

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⁶ Booth et al, 2005, Care proceedings and parents with learning difficulties, *Child and Family Social Work*, 10, 4, 353-360.

⁷ Cleaver,H and Nicholson,D,2007,Parental Learning Disability and Children's Needs
⁸ Tarleton, B et al, 2006, Finding the right support? A review of issues and positive practice in supporting parents with learning difficulties and their children, Baring Foundation/NFRC