SUPPORTING PARENTS WITH LEARNING DISABILITIES

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OVERVIEW

- Parents’ experiences and factors which may affect parenting
- Parent training and interventions
- Rewards of parenthood
- Effects on children
- The removal of children
- Services in the UK
- Useful links and resources
- YouTube clip, exercise and discussion
How many parents with learning disabilities (LD) are there?

- Difficulties in making accurate estimates
  - Identification and definition
  - Parents may not want to be identified
  - Very little research with BME communities
- Figures range from 25,000 to 250,000 in UK
- Adults with LDs make up 2% of population (6.5% if ‘possible LDs’ included)
- Recent survey of adults with LDs found 1 in 15 had children (Emerson et al, 2005)
- Majority (2/3) of social workers (child and family), health visitors and midwives have parents with LDs on caseload
Parents’ experiences and factors which may affect parenting

Research shows more likely to:

- Live in poverty
- Be isolated and victimised
- Poor models of parenting
- Difficult relationship histories
- Insufficient social support
- Increased psychological distress
- Services often do not look beyond the label of ‘LD’
IQ – PREDICTIVE OF PARENTAL COMPETENCE?

- Only if IQ is below 55-60.
- Competency influenced by complexity of skills to be acquired, social support and characteristics of the child.
- Children can be described as vulnerable. They are at risk of developmental delay, particularly in relation to language and cognitive skills, of doing less well at school and having greater behavioural difficulties.
PARENT TRAINING AND INTERVENTIONS

- Behavioural methods most effective.
- The Parent Assessment Manual (McGaw et al. 1999, 2007) most well-known and well-used tool to identify where interventions should be targeted recommended by Dept. of Health (2000).
PARENTAL SKILLS MODEL (MCGAW & STURMEY, 1994)

Parent’s life skills

Family History

Support and resources

Child care and development
ACCESSIBLE RESOURCES


- *You and Your Little Child 1-5 years* (CHANGE, 2007).

They support behavioural teaching methods.

They use simple line drawings and are individualised, intensive and concrete.
FACTORS WHICH EFFECT SUCCESSFUL LEARNING

- Home based teaching for specific skills.
- Long-term teaching not group interventions that are time-limited.
- Parental interest in, and involvement with, the child.
- Motivation to learn.
- Social supports.
- Positive relationship with the trainer.
- Parental knowledge may increase but not necessarily translate into observable skills.
REWARDS OF PARENTHOOD

- 60-90% of women with LD want to get married and have children (Aunos & Feldman, 2002).
- Researchers concur that parents with LD can successfully raise their children if support matches their needs (Booth & Booth, 1994; Edmonds, 2000; Tarleton, Ward & Howarth (2006).
- Positive identity, satisfaction and pride (Edmonds, 2000).
- Outcome study of English and Bangladeshi parents with LD (O’Hara & Martin, 2003).
Supporting parents with learning disabilities and difficulties

Stories of positive practice

Parenting Toolkit: helping partnership boards meet the needs of people with learning difficulties

supporting us to make the choices we want
EFFECTS ON CHILDREN OF HAVING A PARENT WITH LD

- Genetics

If parents have LD it does not necessarily follow that children will have LD.

Caution is needed in interpreting the effects due to ‘nature versus nurture’ debates.
RISKS OF CHILD MALTREATMENT AND ABUSE

- Rare to intentionally harm
- ‘Unintentional’ neglect
- Abuse perpetrated by another person
- High risk versus low risk mothers (McGaw, Skully & Pritchard (2010):
  1. Childhood trauma of parent
  2. Their own special needs (physical disability)
  3. Raising a child with special needs
  4. Male partner – higher IQ and/or antisocial behaviour and criminal activity
THE REMOVAL OF CHILDREN

- 40-60% of children will be removed.
- 10% of children removed at birth.
- Court studies (Booth, Booth & McConnell, 2005) 15-50 times more likely than other parents.
- Assumption that people with LD will neglect their children- no evidence.
- Focus on IQ rather an impact of social and economic deprivation.
**Experiences of Child Removal**

- Decisions “highlight the adequacies of parents at the expense of their ordinary human feelings” (Booth & Booth, 1994).
- Baum and Burns (2007): in-depth study of 8 mothers:
  - Concerns raised by others
  - Felt bullied and victimised by the process
  - Did not understand the process
  - Blamed a violent partner, social worker or their ‘LD’
  - Little support before and after process
PROVISION ACROSS THE UK

- Varied and patchy across the UK.
- Unclear whether child or adult services should fund support. Pooled budgets? Funding long term?

Three key reports in 21st Century:
1. *A Jigsaw of Services* (Goodinge, 2000)
GOOD PRACTICE GUIDANCE ON WORKING WITH PARENTS WITH LEARNING DISABILITY (DEPT OF HEALTH, 2007) (1)

Five key features of good practice:

1. Accessible information and communication
2. Clear and co-ordinated referral and assessment procedures and processes, eligibility criteria and care pathways
3. Support designed to meet the needs of parents and children based on assessments of their needs and strengths
4. Long-term support where necessary
5. Access to independent advocacy
GOOD PRACTICE GUIDANCE ON WORKING WITH PARENTS WITH LEARNING DISABILITY (DEPT OF HEALTH, 2007) (2)

- In terms of the kinds of services offered, it recommends consideration of both the role of mainstream services and the development of a range of specialist services. This includes:

  - Expertise in working with parents with learning disabilities amongst midwifery and health visiting services
  - Liaison roles between different services (e.g. between adult and children's social care)
  - Expertise in assessments of parents with learning disabilities where there are concerns about children’s welfare
  - Parent support services – both specialist and mainstream services
  - Parenting courses, parents’ groups: both specialist and mainstream
  - Independent advocacy services
  - Direct payments support services
  - Housing and housing-related support
  - Accessible information and availability of communication resources
  - Counselling and therapeutic services, and self-advocacy/ self-help groups
PROFESSION FOCUSED GUIDANCE

- For clinical psychologists:
  *Good Practice Guidance for Clinical Psychologists when Assessing Parents with Learning Disabilities.*
  Leicester: The British Psychological Society. (Baum, Gray and Stevens, 2011)

- For midwives and nurses:
CURRENT INITIATIVES

- Innovative examples of good practice:
  Special Parenting Service in Cornwall
  (www.cornwallfoundationtrust.nhs.uk)

- Shared Lives South West
  (www.sharedlivessw.org.uk)

  *Enabling Parenting with Support: Effective working with parents with learning disabilities.*
USEFUL LINKS AND RESOURCES

- CHANGE. www.changepeople.co.uk
  You and Your Baby 0 – 1.
  You and Your Little Child 1 – 5.
  Planning a Baby.
  My Pregnancy, My Choice.
- Norah Fry: The Working together with Parents Network. www.bris.ac.uk/sps/wtpn website, blog, email, up-dates - membership is free
SUMMARY

- Many people with LD are becoming parents
- No reliable estimates of numbers
- If known to services – expectation to receive practical support and effective service provision
- Risk of losing their children
- Children described as vulnerable
- Lack of specialist services but mainstreaming
- Training programmes are effective
- Positive stories
SOME REFERENCES (1)


**Some references (2)**

ANY QUESTIONS?
PARENTS WITH LEARNING DISABILITIES

- http://www.youtube.com/watch?v=ExGnbs4Xw2Q
EXERCISE

Discussion of *YouTube* clip:

- What are you doing well already in relation to parents with learning disabilities?
- What opportunities do you have to identify and support parents with learning disabilities?
- What ideas do you think you could take into your clinical practice?