Course participants will be able to:

- Recognise that disabled parents have the same rights as other parents
- Reflect on the nature of the judgements which have to be made
- Describe some of the effects of disability on families and the dilemmas they face
- Identify the challenges of joint working
- Apply their knowledge to ways of positive working with disabled parents
 Disabled parents

Their perspective

• The DVD was made by disabled parents to let people know the issues and concerns they have

• What are the main issues the parents’ describe?

• What seems to have made it possible for these parents to succeed?
What we know about disabled parents

We have no data about disabled parents as a whole – some available about parents with learning disabilities – e.g.

- 40% of them were not living with their children when surveyed
- A disabled father was more likely to be with children than a disabled mother
- Those who lived with other relatives were more likely to be with their children
- 60% of mothers living on own or with partner not with children

Emerson et al 2005
“Unless justified as a proportionate and necessary response to a risk to the child, ... compulsory removal of a child from the care of its parents poses a significant infringement of the rights of both the child and its parents, to respect for their family life.”

(Page 59 – in discussion of the experiences of parents with learning disabilities)
What does ‘parenting’ mean to you?
Expectations of parenting

Four types of expectations:

• to prevent harm
• to provide routine and consistent physical care
• to know about and meet developmental levels
• to be emotionally available and sensitive

(Woodcock, 2003)
“Parenting is a useful concept for practitioners provided it is kept in mind that parenting is something which is embedded within the whole world of the child.”

Jones, D (2001)
Balancing duties
Overcoming false assumptions

- In our pursuit of our duty to secure the best interests of children, do we sometimes overlook our duties towards disabled parents?

- Are our assessments always free of underlying false assumptions about the capacity of disabled parents?
Professional context
Child protection environment

- Assess and act in the best interests of the child
- Balance present risk with longer term consequences
- Predict the situation to come – with 20/20 forward vision!
Child protection environment

- Being able to assess potential change and rate of change – will/can the family work with you?
- Expectation of change in relatively short time
- Determining how much evidence there might be to take formal legal measures
- Child protection workers may lack knowledge and/or experience of disability
- Lack of resources for longer term work
Disability environment

• Supporting disabled people to achieve full potential
• Promoting their rights as citizens – making choices and living adult lives – that means adult relationships and having children
• But also exercising a duty of care and helping them to keep safe – trying to help avoid situations with which they will not cope
• Working to a long-term timescale
Discussion

Where is the balance between these different duties and environments?
Where does the balance lie?

- The child’s interests are paramount
- Parents have an entitlement to help
- Duty to act (equality law)
- Least detrimental alternative for child is a concept which can help with decision-making
- Having the same expectations of all families – we want them to do their best but the standard they must reach is ‘good enough’
Where does the balance lie?

Continued

- Long term support needs should not be equated with not being able to look after children
- Accepting change and development takes time – but timescales for children and adults might be different
- Support can work
Context for families with disabled parents

• This will be variable

• Some disabled parents live normal lives and are in a supportive environment

• However, for many disabled parents who come to the notice of the authorities and particularly those with learning disabilities, their environment is likely to involve:
  – A history of low expectations, poor experience of loss and lack of involvement
  – Poor communication
  – Expectations of dependency and conformity
  – Stigma and lack of community acceptance
Context for families with disabled parents

Continued

- There are likely to be environmental and financial issues, poor housing and a high level of needs
- There may be bullying of children and their homes targeted
- Mainstream family/parenting resources inaccessible (e.g. parent and toddler groups)
- Parents are out of the loop, suffer isolation and stress

(SCIE, 2005; Cooke, 2005; CHANGE 2005; Cleaver & Nicolson 2005)
John’s story

• What are the barriers to John’s family receiving help?
• What are the parents’ strengths?
• What are the parents’ weaknesses?
• What are your concerns about John’s children?
• What are the key challenges if you were to try to help John and his family:
  – in the short term
  – in the long term

(John’s story is from Fair Deal for Families – SCLD)
Experience of disabling attitudes can create fear

“The attitudes of health and social services professionals can actually deter disabled parents from asking for practical assistance because there is a fear that their children will be taken away.”

Jenny Morris (2001)
Dilemmas for these families

- Who can I trust?
- If I ask for help will I be judged as not coping?
- What if I am misunderstood?
- What if I don’t understand?

“Asking for support from the same organisation that takes your child away is always going to be difficult.”

(Fair Deal for Families? 2008)
Expectations of young carers

“Children of disabled parents have been described as 'little angels' who are forced to 'neglect their homework and friends' in order to look after us. However, if we applied the social model of disability to the situation of disabled mothers we can see that there are a number of social factors which create a situation where children might have to provide some help to their parents.”

Jenny Morris (2001)
The reality for young carers

- Many had educational problems, missed school, failed to attain qualifications. This, combined with ongoing caring responsibilities, served to exclude some young carers from the labour market.

- Leaving home was problematic particularly if they had a parent who required considerable help and support. As a result, some young people delayed moving out.

(Dearden & Becker – 2000)
Where a parent had a severe and enduring mental health problem, some left home prematurely, sometimes to be taken into care.

They matured quickly and gained practical skills that aided independence ... but this was easily outweighed by decreased educational, social and employment opportunities.

Virtually all parents were in receipt of welfare benefits - experience of poverty and social exclusion was common.

(Dearden & Becker – 2000)
“We need to replace all the debates about 'young carers' with a clear understanding about what rights disabled people have to receive practical assistance in their home.”

Jenny Morris (2001)
Outcomes for children of parents with learning disabilities

• Adults whose parents had learning disabilities experienced no problems of a type and magnitude to distinguish them from others from similar socio-economic background

• Growing up with parents with learning disabilities may have a plus side for children with learning disabilities

• Role reversal or reverse dependency did not have any resonance with the now adult children in our study

(Booth & Booth 1998)
The views of adults of their parents with learning disabilities

Of 27 adults who had parents with learning disabilities:

- 24 had love, gratitude, respect for at least one parent
- 25 were close to mother (22 had learning disabilities)
- All had kept close contact
- None wanted to make a complete break
- Substantial majority positive about grand-parents
- 2/3 critical of parents but minority critical of parent with learning disabilities

(Booth & Booth 1998)
Building skills to work with disabled parents

- Using guidance
- Early intervention
- Joint work
- Building trust
- Getting communication right
- The right kind of ongoing support
- Draw on support from wider policy
Using guidance

These Guidelines published in 2009 cover:

• ways of working with parents including good practice examples
• good practice in commissioning
• summary of research – what works?
• law and policy background
• resources
Users’ views on the Guidelines

“I have used the Guidelines copiously particularly to challenge the support previously provided to parents with learning disabilities from Social Work Children & Families departments”

“We have used more accessible formats; schedules; role play; prompting to reinforce. Involved other professionals to assist; involved parents in interviews and devising questions for interviews”
“Being more confident is advocating for parents/better understanding of the problems they face/more aware of current legislation.”

“One of the ways that the best practice guidelines have changed my practice relates to early intervention. My team now looks to build parenting skills from the pre-birth period by the provision of practical support in the home.”
“…all professionals were invited to join regular network meetings where we share any relevant information, and discuss ways in which we can improve our practice and invite speakers to share any good practice.”
Joint working

• Same issue as in work with children with disabilities

• Joint working better for families with disabled children than for other families generally (Stalker et al 2010)

• Separation between child protection workers and adult disability workers can and must be dealt with
Building trust

- Parents are likely to mistrust workers who they perceive as wishing to remove their children or who are from agencies they have previously had poor experience of
- Other workers they trust may act as a bridge
- Consider worker for parents and worker for child
- Consider an independent advocate for parents
- Be honest and open even when the message is hard
- Actions speak louder than words!
Getting communication right

One of the biggest barriers which may need specialist help.

Communication needs

- A system to produce (speech but also signing, electronic or practical aids)
- A system to receive (hearing devices, interpreters, adapted/simpler language)
- It may also need support from advocate or other trusted intermediary
Communication

The basics

- Not all communication difficulties need specialist help
- Many professionals are simply inhibited in their communication with disabled people, fearful of using the wrong terms or seeming discriminatory

Some tips for any situation...
Respect

- Treat adults as you would other adults. Call a person by their first name only when extending that familiarity to all others present
- Speak to the disabled person not their carer
Strategies that help

- Using short, simple sentences
- Adding clear well known gestures alongside spoken information
- Showing a photo or a picture
- Showing a relevant object/prop
Strategies that help

Continued

- Talking about one key idea at a time
- Facial expression and posture matches the spoken message
Strategies that help

Use inclusive communication

- Not aimed at children
- Not about changing the meaning of your message
- Not an amateur’s method of communication
- It is about being clear and inclusive without being patronising
Strategies that don’t help!

- Speaking loudly
- Speaking slowly
- Over articulating each word – speaking extra clearly
- Using formal sign language without first establishing the person uses this language
Issues for participation in child protection procedures

Inaccessibility of:

- Reports sent out in advance & lack of support to understand them
- Communication during meetings
- Understanding the right to participate, and the ‘how’ to participate
- Understanding the consequences of meetings
- Effective independent advocacy
Challenges in getting the right support

There are various difficulties in getting the right support in place:

- Eligibility
- Resources
- Assessment
- Commissioning
- Provider expertise
- Joint budgets
Issues in supporting parents

Day to day support might come from support workers/ personal assistants who lack knowledge of child protection issues, procedures and/ or legislation.

The concept of “supported living” is now well established – so why can’t we start to think of “supported parenting”?
What should help

- *Scottish Good Practice Guidelines for Supporting Parents With Learning Disabilities*
- *National Guidance for Child Protection in Scotland, 2014*
- GIRFEC (early intervention, joint working)
- Children and Young People Act 2014
- *National Parenting Strategy: Making a positive difference to children and young people through parenting, 2012*

Additional Notes for Practitioners: *Protecting Disabled Children from Abuse & Neglect*
# Reflection

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<tr>
<th>Has this part of the course met the learning objectives?</th>
<th>Has the course overall (all three parts) met its objectives?</th>
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<td>How could it be improved?</td>
<td>What further information/study might you want?</td>
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Scottish Consortium for Learning Disabilities

Glasgow Centre for Inclusive Living

People First Scotland
Further reading


Further reading
Continued


- Social Care Institute for Excellence, 2005. *Helping parents with learning disabilities in their role as parents*, www.scie.org.uk


Further reading
Continued


Further reading
Continued


• Healthy Start, A National Strategy for Parents with Learning Disabilities (Australia) [http://www.healthystart.net.au/](http://www.healthystart.net.au/)

• Beresford, B (2009) Seeking the views of children who do not use speech to communicate: cumulative experiences. Paper, Children as Experts in their own lives. Univ of Western Sydney