

Case Studies/Activities

Chapter 34: Working with adults: learning disability

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Additional challenges: There are emotional and practical challenges in adjusting to the fact of having a baby with a disability. At the birth of a disabled child many parents experience something akin to grief for the perfect child who was expected. Some parents may find it difficult to accept the reality of their child's condition. For some families there is a tension around who is to blame for the disability. Feelings are often very mixed with parents reporting feelings of guilt, anger, resentment, fatigue, fear, frustration, negativity, depression, feeling out of control, disempowerment and feeling unsupported (Brett, 2010: 11).

This does not mean that the vast majority of parents don't also feel love for and want to meet the needs of their baby and that the majority manage to do so. However many parents struggle with their emotional adjustment to a reality which was not what they had planned for. This adjustment can be long-term with each developmental milestone missed reawakening feelings about the loss of the perfect child that never was.

Parents for whom the learning disability is not obvious at birth face the additional stress of beginning to realise a child is not hitting expected developmental milestones and often a long process of having their anxieties confirmed (James, 2012).

In many cases the practical demands of having a child with a disability can be as demanding as the emotional adjustment particularly where there are complex additional needs. For some babies and young children with learning disabilities there are associated sleep and feeding problems. In addition the slower development of children with learning disabilities means that they may remain in nappies for longer, and for children and adults with additional disabilities or profound cognitive impairment they may remain incontinent lifelong. For those with mobility difficulties there is often the need for aids and potentially adaptations to the house they live in to accommodate a wheelchair, hoists and suitable bathrooms.

Supporting parents: It is important to provide appropriate emotional and practical support for parents with a child who has a learning disability as soon as possible. In fact the way in which parents are informed about their child's disability and the support offered in the child's early years can have a lasting impact on the parent-child relationship. Where it is clear early in a child's life that they have a learning disability it is important that parents are told as soon as possible. They should be given as much information as possible about the learning disability and time to ask any questions they wish to. However as they are unlikely to take it all in initially another time should be made for them to come back and discuss the information. Where possible links to support groups should be provided. Though it can be very difficult for parents to hear that their child has a learning disability they are more likely to feel supported if the disclosure is direct and clear and where they have time to express their concerns (Hasnat and Graves, 2001).

In addition, Howe (2006) stressed the needs to support parents both practically and emotionally in order to ensure the best outcomes for parents and the child with learning disabilities. He noted the need to improve the material and economic circumstances of parents with children with learning

disabilities while also providing information, and helping parents reflect on and process their own reactions.

Potential impact on the development of attachment: For a general discussion of attachment see chapter 7 of this text – Human growth and development.

As attachment develops from a relational interactional process between the parent and the baby it is important to think not only what the baby may bring to the process but also what the parent brings. For some parents their own emotional responses and struggle with adjustment to the fact that the child has a disability can make it more difficult for them to tune into the child. The preoccupation with their own concerns can interfere with the process, though it needs to be remembered that many parents take some time to develop their attunement to their child.

The other difficulty a parent may have is that their responses may become out of phase with the development of their child. As the child's development is slower than average the parent may be ready to respond to the next stage of their child's development before the child has reached this. As some older children and adults can remain at an early interactional stage this can challenge parents and workers to tune their responses to the needs of the person.

On the other side of the relational dyad babies with learning disability may have their own difficulties in responding to the care that is offered. For some babies with learning disability there is some impact on their ability to respond to the attention of the parent and this may be compounded by periods of separation in special care baby units. Some babies may have problems with feeding for example with sucking or digesting food. Much positive contact is made with babies when feeding them and instead of a pleasurable experience feeding may become frustrating and upsetting to both the mother and the child.

In addition where there are additional physical disabilities a baby may be in pain and experience touch and being held at least sometimes as unpleasant. The experience of medically intrusive procedures can leave the baby resistant to being cuddled and held. Where babies have hearing and/or sight impairments in addition to learning disabilities this can make the development of attachment more difficult as visual and auditory cues can be missed.

This may account for the fact that there are a higher proportion of insecure attachment in those with a learning disability (Janssen et al., 2002). This is not because parents are uncaring but that despite their best efforts it can be extremely difficult to meet the needs of some individuals with a learning difficulty. This may make parents become either over-engaged with their child or manage the difficulties in relating by separating off to some degree. Though this may relate to a parent's own attachment style it can be the only way the parent has found to respond to the child and manage their own responses to the learning disability. For workers it is important to have an awareness of that and recognise that the neediness and anxiety of some individuals with learning disability and the detachment of others may indicate their difficulties with managing relationships.

However though there is a tendency to emotional strain and isolation related to having a child with learning disabilities parents also note the positive social and family experiences they have with their child. Scorgie and Sobsey (2000) note that most parents reported many positive changes in their lives as a result of parenting a child with a disability. These included personal growth, improved

relations with others, and changes in philosophical or spiritual values. Positive perceptions helped families adapt to and cope with the experiences of raising a child with disabilities.

References

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