

Intellectual disability

Case 5.1

Ranjit was brought by his father to the clinic because Ranjit was very slow to learn. At 5 years most of his skills were more like those of a boy half his age. He had only just learned to feed himself with a spoon. He still soiled and wet himself day and night. His language was more like that of a 2-year-old. He could say single words but had no sentences. He had been able to walk by 18 months and, although he was a bit floppy, his leg and arm movements were more or less up to his age level. No one else in the family had been slow to learn. His father was a junior clerk in the civil service. Ranjit's behaviour was generally good. He was an obedient, rather passive boy. What should the health professional do?

5.1 Information about intellectual disability¹

In Chapter 4 we described children whose development was slow in just one or two areas. In this chapter we describe children whose development is slow or very slow in all or nearly all areas.

As children grow older, they develop a range of abilities, skills and capacities, and become more adapted to their environments. The main skills acquired are to do with movement, language and social relationships. Some are slower to acquire these skills than others and some children never acquire skills at an adult level.

Children whose abilities are at or below the level of children half their age have severe intellectual disability. Children who are more intelligent than this but are only at or below the level of children about three-quarters of their age have mild intellectual disability. For example, a 12-year-old child who is functioning at or below the level of a 6-year-old has severe intellectual disability. A 12-year-old child who is at a level between 6 and 9 years old has mild intellectual disability. A child of 12 years who is at a 9- to 11-year level may be a little slow but is within the normal range. Severe and, to a lesser degree, mild intellectual disability affect the way children function in a variety of ways:

- ability to walk and use hands
- self-care, such as feeding, washing, using the toilet independently
- talking and understanding language
- social functioning, such as playing with other children.

The more severe the intellectual disability, the more difficult it will be for the child to carry out these various functions.

1. The terms mental retardation/learning difficulties/intellectual disability are used interchangeably in different regions of the world.

5.1.1 Causes

In children with severe and mild intellectual disability the brain is not working as well as it should. There are various reasons why the brain does not develop and work properly.

Most children with severe intellectual disability have abnormal genes or chromosomes affecting the brain, a very large number of which have been identified. Most common is an abnormality on chromosome 21 causing Down syndrome, which is responsible for causing about a third of severe intellectual disability in high-income countries, although less than this in LAMI countries, where other causes (listed below) are more prevalent. Women over the age of 35 years are at higher risk of giving birth to babies with Down syndrome. Some children with Down syndrome fall into the mild intellectual disability category. There are many other genetic causes, most of which are uncommon or rare.

Brain damage before, during or after birth may also be responsible. While the baby is in the womb, damage to the brain can occur if the mother is poorly nourished, drinks an excessive amount of alcohol, has a diet deficient in iodine or, because of damage to the placenta, the blood supply to the fetus is inadequate. The brain may be damaged at birth during the passage of the baby through the birth canal, or if immediately after birth the baby's breathing is delayed for some reason, or by an illness after birth. If the baby is very premature, there may be a bleed (haemorrhage) into the brain. Severe jaundice or meningitis may also damage the brain. If the child is neglected after birth, understimulated, undernourished or abused in other ways, the brain will not develop properly. This is a common cause of mild intellectual disability. Note that often there is more than one cause.

In most cases there is an identifiable cause for severe intellectual disability, although this is less often the case for mild intellectual disability. However, identifying a cause may require expensive equipment. Most of the causes identified by the use of such equipment are not treatable, so lack of such equipment does not mean that children with intellectual disability are deprived of a cure.

Children with severe intellectual disability and, to a lesser extent, mild intellectual disability have an increased likelihood of developing an emotional or behaviour problem. Difficulties with attention and concentration are especially common, but these children are also more likely to have anxiety and depressive states and aggressive behaviour. There is a small number of behaviour problems such as self-injury which virtually only occur in children with severe intellectual disability. Children with severe intellectual disability and, to a lesser extent, mild intellectual disability are at greater risk of epilepsy (see Section 12.6). They are also at greater risk of other physical problems such as hearing and visual impairment.

5.1.2 Impact of severe intellectual disability on the child and family

- Children with severe intellectual disability will remain dependent on their parents for much longer than 'normal' children, quite possibly for the whole of their lives.
- There will be an economic impact on the family. The child will not be able to contribute to the family income. One parent may have to stay at home and, in the absence of a member of the extended family who can look after the child, not be able to go out to work.
- In many localities, children with severe intellectual disability will not be allowed to go to school, thus restricting the child's ability to learn.
- Parents may experience guilt and shame at the presence of a child with severe intellectual disability who will or may look different from other children. Sometimes parents may 'hide' such children from society.

- The child may be stigmatised in the neighbourhood, teased and bullied. If the child does go to school, he may be similarly picked on and called names.
- The life expectancy of children with severe intellectual disability is significantly reduced.

5.1.3 *Impact of mild intellectual disability on the child and family*

- The child will gradually be able to achieve independence, although more slowly than other children.
- In most areas the child will be able to go to school and, after leaving school, will be able to find employment in an unskilled job.
- This means that the impact on the family will be much less than with children with severe intellectual disability.
- Children with mild intellectual disability will probably be able to hold down an unskilled job, marry and have children. They will probably have normal or near normal life expectancy.

5.2 Finding out more about children with intellectual disability

You should suspect the presence of intellectual disability when a child:

- is slow to pass most or all of the milestones at the usual ages (see Section 4.1)
- is having difficulty in schoolwork
- is not as independent or as capable of self-help as other children.

If you suspect intellectual disability you should try and work out at what age level the child is functioning in different areas, such as movement, language and social relationships. Then find out at what ages the child passed the various milestones.

Remember that the child may not be functioning at an age-appropriate level because his parents are overprotective and do not allow him to do various things. Try to establish at what age level the child is functioning in movement (including coordination of hands and fingers), language and social relationships (see Section 4.1), as well as in self-care. If the child is at school, ask the teacher what level he thinks the child is at, or get a school report. In some situations, children do not achieve as well as parents think they should. Parents may be right to worry about this, but sometimes their children are not as intelligent as they think they are. Information from both the parents and the teacher about the child's functioning in different settings and for different tasks would be helpful in determining what is causing the child to underachieve.

Assuming the child is showing severe or mild intellectual disability, try to establish a cause, first by taking a history.

- Ask the parents whether anyone else in the family has been slow to learn.
- Ask whether the pregnancy was normal. Was there any bleeding during the pregnancy? Did the mother have an adequate diet? Did she drink alcohol, and if so, how much?
- What was the birth like? How long did it last? Was it necessary to use forceps or to deliver by Caesarean section? Were there any other complications? How much did the baby weigh at birth? Did the baby cry and breathe straight away or was there a delay?
- Has the child had any illnesses after birth? In particular, did the child have any brain infections?
- Is there any history of trauma to the brain? Has the child had any accidents, been dropped, etc?
- Has the child had any fits/seizures?

Then examine the child to see whether this can give a clue to the cause of the intellectual disability. Most children with mild intellectual disability look normal. Some children with severe intellectual disability may have an unusual appearance which can provide clues; for example, children with Down syndrome have slanting eyes, low ears, a short neck, a small mouth so that the tongue looks large and may stick out, and a single crease across the palms of their hands. Examine the child fully for evidence of other health problems. In particular, test the child for deafness and for eyesight problems (see Sections 12.3 and 12.4).

If the child's language and social development are well behind his ability to draw, and he is very sensitive to noise and has unusual habits, such as flapping of the hands, think of the possibility that he has ASD (see pp. 25–28). Of course, he may have intellectual disability as well. If the child is generally at the level of other children of his age but is very behind in language, he may have a specific language delay (see pp. 16–18). Also, if the child is underachieving in school-related skills but on par with other areas of development, it may be a specific reading disability/dyslexia or other learning problems and not intellectual disability. Similarly, if the child is generally at the level of other children but has very poor movement coordination, this may require further physical and neurological assessments.

It is worth looking for bruising of the skin or other signs of maltreatment, as children with severe intellectual disability are at particular risk of being abused.

Note that if there is one available, you should refer to a child health specialist to confirm your view and to carry out investigations, especially biochemical studies, neuroimaging and chromosome analysis that will not be possible in a health clinic. The results will not lead to a cure, but will mean that the parents have a better idea of the cause of their child's problem. This may help to give a better idea of the risk of abnormality if they are planning further children.

Now using the information you have obtained from your observations of the child with intellectual disability and from talking with the family member(s) you have seen, try to understand what has caused the problem, how it is affecting the lives of the child and family members, and decide what is the best course of action.

5.3 Helping children with intellectual disability

First, it is important to be sure that the child has an intellectual disability. Then, using the above criteria you should try to decide what level of disability the child has – mild or severe. Below the age of 5 years, although you can be sure of the presence of severe intellectual disability, it may be more difficult to decide whether the child has mild intellectual disability.

If the child has severe intellectual disability, you will first need to break the news to the parents. Remember to ask them first what they think the matter is with the child. They may well have realised their child is very slow to develop. You will need to explain to the parents that their child has an intellectual disability. If the child has severe intellectual disability, it is very likely he will continue to be very slow to develop. The child will do more every year but will remain slow and behind other children of the same age. Explain that there is no cure for intellectual disability but that there is a great deal that parents can do to improve the child's quality of life. The following are useful tips for parents of children with intellectual disability.

- Treat the child according to the child's mental age, not according to the actual age. So if the child is 4 years old but is behaving like a 2-year-old and has only developed to a 2-year level, talk to and play with the child as if he were 2 years old.
- Use praise and rewards for very small progress. Punishment is not likely to be effective.
- Always expect the child to do just a little bit more than he is doing at the present time, in self-help, in language and in achieving control of his bladder and bowel.

- Teach the child how to do things in small steps. For example, if you are teaching the child how to use a spoon to feed, first get the child used to the feel of a spoon, then get the child to scoop food up with a spoon, and finally encourage the child to move the spoon with food on it towards his mouth.
- Try to persuade the teachers to take the child into school. With a child with mild intellectual disability, this will not usually be a problem, but teachers may not like to have a child with severe intellectual disability in the classroom. All the same, it is helpful even for children with severe intellectual disability to attend school. If by chance there is a special school for children with severe intellectual disability, this will be ideal, but this is not likely to be the case in most localities.
- Encourage parents not to neglect their other children. It is easy for parents to give all their attention to the child with intellectual disability. This is not helpful for the other children, who may develop emotional or behaviour problems if they are neglected.
- Brothers and sisters can be encouraged to help so that all the burden does not fall on the parents. Conversely, in some families, the brothers and sisters may feel left out as all the care seems to be given to the child with intellectual disability.
- Encourage parents also not to neglect their own needs. Parents who sacrifice everything for their child with a disability may become angry and frustrated. They should try to find some time for themselves.
- If the child has a behaviour or emotional problem, assess and manage the child as described in other sections of this manual.
- As far as possible, the child should be encouraged to mix with other children. This will be more difficult as the child gets older unless there are other children with intellectual disability in the locality.

As children with severe intellectual disability move into adolescence, they may develop other problems.

- They are at increased risk of psychosis (see p. 107) and epilepsy (see p. 123).
- There may be problems associated with their sexual development. If they start to masturbate in public they should not be punished, but be gently encouraged to do this only in private.
- If they start to make sexual advances to other children or adults it should be made clear to them that this is not acceptable.
- As their formal education is likely to have finished by now, they should be given simple and, if possible, useful tasks to perform to keep them busy, and made to feel they are contributing to the family.

When talking with the parents, always remember to keep the child in the picture and try to talk to the child as well. Remember children with mild and even severe intellectual disability can often understand or communicate their needs more than you think, so listen and talk with the child as much as is possible. Finally, remember that the parents will most likely experience shame and guilt about the fact that they have a child with intellectual disability. They should be given the opportunity to express their feelings.

Now make a list of the ways in which the health professional might be able to help Ranjit.