

## Practice Point

### ***What is intellectual disability anyway?***

Interview with Hanna Björg Sigurjónsdóttir, associate professor and chair of disability studies, Faculty of Social Sciences, University of Iceland

### **What does the term intellectual disability mean?**

Intellectual disability is not an absolute condition. There's no universal agreement on how to define intellectual disability. Over the years definitions and criteria have changed as specialists from various fields have used their own terminology, explanatory models or points of view to describe and explain intellectual disabilities<sup>i</sup>. For example, since the 1930s, the cut-off point in the Nordic countries has in practice varied between IQ 50 and IQ 85. Using IQ 50, less than 0.5 per cent of the population would be defined as intellectually disabled, whereas using IQ 85 more than 15 per cent would be given this label<sup>ii</sup>. The cut-off point of who does and who doesn't have intellectual disability is of political interest because it defines who gets access to welfare services and financial support and who doesn't.

Even though intellectual disability can be described and examined from many perspectives, medical definitions have dominated. From this viewpoint intellectual disability is defined using two main criteria. Firstly, reduced intellectual functioning, or IQ, and secondly, reduced ability to manage daily life. Using this definition the 'problem' is within the individual and intellectual disability is understood in terms of limitations and inabilities. This narrow view of people with intellectual disabilities has been challenged for over 30 years, and increasingly so more recently, for not taking into account the environmental and the social context in which people live.<sup>iii</sup>

Over the last couple of decades new understandings have gradually been incorporated into public policy at an international level. According to this new perspective, how people with intellectual disabilities manage in life is understood as a fit between their ability in different areas and what the situation or environment demands.<sup>iv</sup>

### **Why is an IQ test not enough to use as a guide? What is the limitation of using these tests in parenting assessment?**

An IQ test only tells a small part of the story. Linking intellectual ability to social ability ignores the complexities of living with impairment. Everyone has their own strengths and weaknesses. There are people assessed as having an IQ of less than 70 who can nevertheless manage the demands of their daily lives. There are also people who's IQ is difficult to calculate because their verbal and practical skills are very different. But most importantly in this context these tests are not designed to assess parenting skills. There's no clear relationship between parental competency and intelligence and there are also parents with high IQs who are not fit to raise their children.

People, including those working in the service system, have a tendency to view people with disabilities in terms of their impairment and diagnosis. The label intellectual disability is loaded with meaning and people with intellectual disabilities are commonly portrayed as incompetent, asexual and childish. It's assumed that people with intellectual disabilities won't be able to carry out the same roles as other people. This includes parenting, and when people with intellectual disability have children it is often assumed that their children will be in danger. This can have harmful consequences for these families.

I think the best way to illustrate this is to tell a story:

A young couple with intellectual disability were expecting a child. The parents to be had support from social services and lived in secure housing with access to services. Their baby was born three weeks early while their social worker was away on holiday.

The staff at the hospital had been asked to assess the parents and teach them parenting skills. This was beyond their scope of responsibility, knowledge, experience or qualification. Most of the staff had no disability awareness or knowledge of training methods and learning processes for people with intellectual disabilities. They couldn't get hold of the social worker and the only thing they knew about the parents that had any meaning to them was the label intellectual disability.

Later the staff said that knowing about the parents' intellectual disability made them feel more anxious and act more aggressively than they would otherwise have done. They felt responsible for the baby's wellbeing and were worried that they would be held accountable for any unforeseen tragedies. So they contacted child protection services who told them they would have to notify the family in writing before they could act.

The staff felt they had to do something to safeguard themselves and the baby. Not realising the weight of their arguments, they wrote in the notification that they were concerned that the parents wouldn't be able to make the baby's bottle using dry milk powder and that this could be dangerous if it's done wrong. They also wrote that they worried that the parents might drop the baby onto the floor. They didn't mention that they hadn't had the opportunity to teach the parents how to make up a bottle in the hospital as the milk came ready-made.

Mistakes were made and the parents were not told that they had been notified to child protection services. It therefore came as a big shock to them when they were discharged on their own and their child was removed temporarily by child protection.

A few weeks later decisions were made about who would be the child's future legal guardians without the natural parents being given a fair chance to prove their ability to care for their child.

Two years later the same couple had twins. By this time their story of what had happened when they had their first child was well known as the parents had spoken to TV, radio and newspapers reporters. This time they kept their children, who are now 11 years old and doing well. Earlier this year the mother, and her new husband, had her fourth child, this time no one questioned her ability – she had had the opportunity to prove herself.

### **What are possible negative effects if a parent is labelled 'ID'?**

I believe the story told above is a good example of how the term intellectual disability can have a negative impact on how a person is seen and treated as a parent. The label leads to assumptions being made that can determine what action is taken or what support is provided.

There are many things that impact parents with intellectual disability that have nothing to do with their impairment. But if practitioners view the parents as the problem the support will become problem-centered and key aspects of the environmental situation might be ignored. With problem-centered support parents don't get a chance to take care of their child with good and appropriate support or to prove themselves as parents.

Parents labelled as intellectually disabled are often aware that others doubt their ability to care for their children and they realise that they're at risk of having their children removed. This can affect how they relate to the service system and some parents might refuse all support because they don't trust the system and worry that their child will be taken away. As a result these parents could be labelled as non-compliant which will further reduce the opportunities for good support to raise their child.

### **Why is it important to regard each parent as an individual – not as a member of a category?**

Parents with intellectual disability have been subjected to negative stereotypes and assumptions. But they are individuals. They've grown up in different families, have different abilities, strengths and weaknesses and their support needs differ. Respecting each parent and working with them in a way that suits their needs will allow them to blossom and take good care of their children.

### **What do we mean by the 'social construction of disability'?**

The concept of disability is man-made. It exists within the framework of the norms and rules in our society. We base our interpretation on the meaning this label has for us.

The label is associated with stigma. From early childhood we learn about our own and other people's social status through socialisation and we grow up believing that these ideas are both appropriate and right. These ideas don't teach us to understand disability as a natural part of human diversity but as something that should be avoided or fixed. Our ideas are supported by the fact that historically people with intellectual disabilities have spent their lives marginalised and often in segregated settings. Parents with intellectual disabilities have had limited access to education and employment, they have been kept close to poverty through social benefits and made to live in social housing that is usually in poor and sometimes dangerous neighbourhoods.

This dominant social and cultural view of people with intellectual disabilities affects how they are seen and treated. Women with intellectual disability have been sterilised and institutionalised to prevent them from having children and those women who have become pregnant have either been encouraged to go through abortion or have had difficulties keeping their children. If the

professionals involved in their lives have received any education at all about disability it has usually focused on abnormality, risk and problems.

### **What do we advise support workers to do in relation to this social construction?**

Support workers need to be aware that their relationship with parents is very important and that parents can find it hard to trust their support workers because of the negative assumptions and stereotypes that are associated with the label intellectual disability.

Instead of focusing on the perceived inadequacies of the parents support workers should look at what is shaping the parents' lives to be able to understand the origin of their behaviour and attitudes.

A positive self-image and good self-esteem are important for successful parenting. Support workers can help parents boost their self-determination and positive feelings about themselves by using an inclusive approach with co-operation, flexibility, kindness, responsiveness, and respect.

### **What does this all mean for assessment when it comes to parents with intellectual disability?**

IQ tests and assessments are often wrongly used to understand if parents can or can't keep a child. We have to remember that IQ tests don't tell us anything about parenting abilities.

I believe parenting assessments are important to understand what type of support and training parents might need.

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<sup>i</sup> Sonnander, K. (2005). Biological and social aspects of intellectual disability. In A. Gustavsson, J. Sandvin, R. Traustadóttir and J. Tøssebro (Eds.), *Resistance, reflection and change: Nordic disability research*. Lund: Studentlitteratur.

<sup>ii</sup> Tøssebro, J. and Kittelsaa, A. (2004). Studying the living conditions of disabled people: Approaches and problems. In J. Tøssebro and A. Kittelsaa (Eds.), *Exploring the living conditions of disabled people*. Lund: Studentlitteratur.

<sup>iii</sup> Atkinson, D. (1997). *An auto/biographical approach to learning disability research*. Aldershot: Ashgate.

<sup>iv</sup> World Health Organization, (2001). [http://www.who.int/classifications/icf/icf\\_more/en/](http://www.who.int/classifications/icf/icf_more/en/)