

Defining learning disability

Jenny Webb and Simon Whitaker question whether the right people are being labelled and subsequently supported

Diagnoses of learning disability have real-life impact, in terms of service delivery. Currently, whether or not a person meets the diagnostic criteria depends on having an impairment of intellectual functioning, typically measured as an IQ below 70, along with a significant impairment of adaptive or social functioning. If over this IQ threshold, an individual may not get access to the resources they need even if it is abundantly clear that cannot cope without help. How reliable and valid is the current cut-off point? Do we need to move to a definition of learning disability based on clinical judgement rather than IQ score?

Sophie is a young woman aged 21 who, since leaving her special school, has survived below the radar of specialist learning disability services. She lived with her mother and worked in the small local supermarket. She attended the Gateway club, where she met her partner, Gary. When she became pregnant, her GP referred her to the community team for people with learning disabilities for 'support'. By this time she had given up her job and planned to move into Gary's flat. She had never lived independently, cooked, cleaned, budgeted or shopped for herself. The clinical psychologist carried out a cognitive assessment, and Sophie was found to have an IQ of 70–75. The social services learning disability service decided that, since her IQ was over 70, and she had once been in employment, she was 'too able' to be eligible for support. The clinical psychologist argued unsuccessfully that Sophie had cognitive deficits in areas of memory and executive function, particularly in planning, organisation, working memory and holistic processing. She therefore did need specialist support. By the time the social services children's team carried out its assessment, Sophie was seven months pregnant. The children's team concluded that, for Sophie and Gary to keep the baby, the level of support they would require long term was unsustainable.

As we write, the future for Sophie, Gary and their unborn baby hangs in the balance. This sad story illustrates the pivotal role that IQ plays in decisions relating to service delivery and the allocation of scarce resources. Is it

right that Sophie and others like her should be denied access to services, not because she can cope but because she fails to meet a criterion of the definition of learning disability?

This issue is particularly salient at present for two reasons. First, the diagnostic manuals *Diagnostic and Statistical Manual of Mental Disorders* (DSM) and *International Classification of Mental and Behavioural Disorders* (ICD) are currently being revised, and with that revision comes the possibility of review of the definition of learning disability. In the UK, the British Psychological Society document giving guidance on assessment of learning disability (BPS, 2001) is also being reviewed. And second, with the current draconian squeeze on local authority finances, eligibility criteria are being interpreted in increasingly rigid ways.

The BPS follows the diagnostic manuals in defining learning disability in terms of three core criteria, namely:

- | significant impairment of intellectual functioning (usually taken as IQ < 70);
- | significant impairment of adaptive/social functioning; and
- | age of onset before adulthood.

For an individual to be given the diagnosis they must meet all the criteria. These criteria are also those used in the White Paper *Valuing People* (Department of Health, 2001).

'Significant impairment of intellectual functioning' is always interpreted in terms of IQ score. Is this an adequate definition? We consider this question in terms of three issues: the validity of the test generally used to measure IQ; the reliability of its measurement; and its utility. We then discuss the BPS response to this issue, and suggest a possible way forward.

Validity

The test used in the UK to measure IQ in adults is generally the Wechsler Adult Intelligence Scale fourth edition (WAIS-IV). However, this test is not based on a

question

Should clinical judgement and practical considerations trump IQ when it comes to the diagnosis of learning disability?

resources

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generally accepted theory or definition of intelligence. Indeed, the manual for the WAIS-IV seems at one point to abandon the concept of validity altogether, speaking instead of 'the degree to which the evidence supports the interpretation of test scores for their intended purpose (which) requires an evaluative judgment by the test user' (Wechsler et al., 2008).

So the construct of learning disability is grounded in the construct of intelligence, which is not clearly defined, and also is not embedded in an agreed, coherent theory. It is also understood very differently in different times and cultures (Sternberg et al., 2001). Yet in the diagnostic manuals learning disability is treated as a medical condition that exists as a discrete entity that one either has or has not got, much in the same way as pregnancy. From this point of view, successive revisions in the definition of learning disability represent an attempt to get closer to the 'true' nature of the condition.

There seems to be little scientific rationale for such revisions. To take just one example, from 1961 to 1972 the definition of learning disability given by the American Association on Mental Retardation (AAMR) specified an IQ of one standard deviation below the mean (i.e. IQ 85). In 1973 this was revised to raise the cut-off point to two standard deviations below the mean (i.e. IQ 70). This revision overnight changed the status and eligibility for services for huge numbers of people.

The cut-off point of 70, which is still in general use, is an arbitrary one. There is no evidence to suggest that people with IQs of less than 70 are significantly less able to cope than those with IQs above 70. In fact Whitaker (2004) has suggested that the majority of people with IQs of less than 70

can cope without specialist services. On the other hand, our clinical experience suggests that there are also a significant number of people with measured IQs over 70 who cannot cope without the support of specialist services.

Reliability

Since learning disability is defined in terms of an IQ score cut-off point, the issue of how accurately IQ can be measured in the low range is of critical importance. It is well known that IQ tests are not accurate to one point and therefore when the results of an IQ test are reported a 95 per cent confidence interval is usually given. This indicates



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the range of scores where the individual's 'true IQ' has a 95 per cent chance of falling. On modern tests such as the Wechsler Intelligence Scale for Children (WISC-IV) and WAIS-IV this is about four points either side of the measured IQ.

However, recent work by the second author has suggested that the error, at least in the low range, is much greater than four points. The major points of this work are

as follows.

First, there is much greater change in scores from one assessment to the next. A meta-analysis (Whitaker, 2008) of the test-retest reliability of IQ assessments in the low IQ range (IQ < 80) found that although 57 per cent of IQ changed by less than six points between assessments, 14 per cent changed by 10 points or more. The 95 per cent confidence interval

calculated on the basis of the test-retest reliability figure was about 13 points.

Second, there is good evidence that the intellectual ability of the population as a whole has increased from one generation to the next at about 0.3 of an IQ point a year over the last 100 years. This is known as the Flynn effect. Not only has this occurred for the population in general (e.g. Flynn, 1987), but also for those with low intellectual ability (e.g. Flynn, 1985). The implication of this is that IQ tests will become less accurate the longer it is since they were standardised. On average, a test will overestimate an individual's IQ by about 0.3 points for each year since it was standardised. It therefore may be possible to compensate for this error by subtracting 0.3 of an IQ point from the measured IQ for each year between the test being standardised and given. However, although it has been argued that it is still a valid correction in the US (Flynn, 2009), the rate of increase in intellectual ability is not consistent over time or between tests (Flynn, 2006). There is now evidence that in Scandinavia (Teasdale & Owen, 2005) and in the UK (Whitaker, 2010a, 2011) the Flynn effect may have gone into reverse in the low IQ range. This would mean that in order to correct for the Flynn effect points would have to be added to the obtained score. This uncertainty of the degree of the Flynn effect means that IQ scores cannot be corrected with confidence and that in effect there is additional chance error in the scores of the order of about 0.3 of a point per year (c.f. Whitaker, 2010b).

Third, there seems to be major disparity between the two gold standard IQ tests when they are used at the low levels. It is accepted that different IQ tests will give slightly different results (Floyd et al., 2008). It is also possible that these differences between tests may be greater at the low IQ range, as the tests were standardised in the main using subjects in the average intellectual ability range. An important indicator as to how much this is a problem would be given by the degree to which the two gold standard IQ tests, the WISC and the WAIS, agree with each

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other. This would have to be done with 16-year-olds as either test can be given at this age.

Gordon et al. (2010) compared the WISC-IV (UK) and the WAIS-III (UK) with 16-year-olds in special education. It was found that although there was a high correlation between the two assessments ($r = .93$), in each case the Full Scale IQ (FS IQ) on the WISC-IV (UK) was lower than that on the WAIS-III (UK). A mean FS IQ of 53.00 was found on the WISC-IV (UK), which compared to a mean of 64.82 on the WAIS-III (UK), a difference of nearly 12 IQ points.

As the degree to which either assessment is in error is largely not known, it is clearly possible that either the WISC-IV (UK) is

systematically underestimating true IQ by up to the order of 12 points, or the WAIS-III (UK) is systematically overestimating true IQ by the order of 12 points, or both assessments are making systematic errors of less than about 12 points.

Although the WAIS-III has now been superseded by the WAIS-IV there is evidence that the same problem still occurs. Whitaker (2012) compared the subtests that the WISC-IV and WAIS-IV have in common and noted that it was likely that an individual with low intellectual ability would still score higher on the WAIS-IV than on the WISC-IV.

Utility

How helpful is intelligence testing in enabling us to make judgements or predictions about the nature or degree of the supports people need to achieve a good quality of life? This predictive function of a test is described as its ecological validity (Chaytor & Schmitter-Edgecombe, 2003). Though IQ score is known to predict academic achievement, there is little evidence that it can be used to predict performance in other areas of life (Sternberg et al., 2001).

In the case of Sophie, in our scenario at the start of the article, her IQ score was not helpful in predicting her likely parenting ability. A more comprehensive cognitive assessment revealed she had serious impairments in memory and executive function, which were not revealed by assessment on the WAIS-III. Indeed, it has been found that the IQ score is only weakly related to memory and executive function in people with learning disability (Willner et al., 2010)

Sophie's reported IQ of 70–75 is just outside the learning disability cut-off point

of IQ 70. However, if she had been assessed on the WISC-IV five years earlier when she was 16, everything else being equal, she would have achieved a score of 12 points less. Her estimated IQ would then have

been in the range 58 to 53, well below the cut-off point for a diagnosis of learning disability. As the WISC-IV and WAIS-III are both well standardised and respected IQ tests it is not possible to say which one is correct, or if they are both in error to some extent. So what is Sophie's true IQ? The answer must be that we do not know. It may be somewhere between the top of the range on the WAIS-III and the bottom of the range on the WISC-IV, 75 to 53. But even that much larger range is not certain as scores on any one test may well fluctuate by 10 points or more.

So if IQ does not predict real-life functioning, and we cannot accurately measure low IQ, are the right people getting labelled as learning disabled? And more specifically, should a definition of learning disability have within it the criterion that IQ should be below a specified IQ point?

What does the BPS say?

The BPS acknowledges the fact that learning disability is a social construction:

As the concept of learning disabilities may be seen as a social construction...the idea of any

permanency of the concept must be questioned...'

Nevertheless, the BPS also goes on to justify its adoption of a definition of learning disability largely based on the criteria given in the diagnostic manuals.

'However...the concept is enshrined within our social and legal systems. As such, the concept affects peoples' legal and civil rights.' (BPS, 2001)

Recently, the BPS has responded to the draft review of the DSM-V. In the DSM document, the definition of intellectual disability is largely unchanged, but it is, bizarrely, placed within a group of conditions labelled 'Neurodevelopmental Disorders', which places 'mild mental retardation' at one end of a single spectrum that includes people with autistic spectrum disorders (Andrews et al., 2009). In its response, the BPS recognises that the diagnostic systems for mental illness 'fall short of the criteria for legitimate medical diagnoses'. But as far as intellectual disability is concerned, 'the use of diagnostic labels has greater validity, both on theoretical and empirical grounds' (see tinyurl.com/bpsdsm5). The BPS thus ignores at least a decade of critical comment on the definition of learning/intellectual disability.

Is there an alternative?

We accept the fact that there is a need for the concept of learning disability to be defined, and for a criterion to be established. But this does not entail the passive acceptance of a flawed definition and unreliable measurement. The alternative to conceptualising learning disability as a 'real' medical condition, is to see it as a social construction, namely, a term that is a product of particular historical and cultural conditions. Adopting this position gives us a rationale for redefining learning disability in a way that is clinically meaningful and provides a more equitable basis for decisions on resource allocation. It has been suggested, for example, that learning disability should be redefined in terms of competence (Jenkins, 1998); impaired adaptive behaviour (Flynn, 2000); systems of supports (Leyin, 2010); and risk (Greenspan, 1994).

Whitaker (2008) has proposed a definition that links the concepts of risk, intellectual function and the person's need for support:

A person can be regarded as having a learning disability if they are judged to be in need of community care or educational services due to a failure

"...are the right people getting labelled as learning disabled?"

Developmental Disabilities, 56, 49–55.

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to cope with the intellectual demands of their environment and are suffering significant distress or are unable to take care of themselves or their dependents or unable to protect themselves or their dependents against significant harm or exploitation. (p.8)

Use of such a definition would bring to an end the situation where service allocation is based on the spurious scientific objectivity of the IQ score. Instead, it would be explicitly based on clinical judgement grounded in a broad assessment of both the individual and the environmental demands being made of them. This means that any judgement can be challenged if it appears to fall outside what society currently deems acceptable. The issue is not what somebody's IQ is, but whether they are able to cope, and this comes down to what society as a whole would accept as a minimum standard of quality of life.

Such a redefinition also raises the possibility that all adults with developmental disorders and a range of cognitive deficits may face the issues of vulnerability and risk. In the longer run it

could therefore form a basis for the reconfiguration of service structures and roles.

Conclusions

In the years since 2001, when both the White Paper *Valuing People* and the BPS guidelines on the diagnosis of learning disabilities were published, psychologists have faced, Janus-like, in two directions. Privately, they acknowledge that 'learning disability' is a socially constructed term, measured by an instrument that is seriously flawed. Publicly, they continue to use the term 'learning disability' as if it were a real, naturally occurring condition.

Janus was a god associated not just with January, but also with openings and archways: perhaps it is not stretching the analogy too far to suggest that the ability of psychologists to face in two directions gives them the opening they need to take a fresh look at their conceptual world and consider the possibility of the peaceful coexistence of two alternative paradigms. The recent change in international terminology to the term 'intellectual disability' could be helpful in this (Leyin, 2010). Whilst accepting the existence of

the construct of intellectual disability for the purposes of international conversations, psychologists could, in their clinical work, continue to use the construct of learning disability, redefined in a way that is clinically meaningful. People like Sophie and Gary should have their service provision based on need rather than IQ score. Psychologists should not continue to collude with a diagnostic system that excludes vulnerable people from accessing the support they need.



Jenny Webb

is Consultant Clinical Psychologist with Sussex Partnership NHS Trust
jenny.webb@sussexpartnership.nhs.uk



Simon Whitaker

is Senior Visiting Research Fellow at the University of Huddersfield
s.whitaker@hud.ac.uk

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