

INTELLECTUAL DISABILITY: A CONCEPT IN NEED OF REVISION?

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Introduction

I have been a clinical psychologist working in what we now call intellectual disability (ID) for the past 25 years. Over this time I have become increasingly concerned about how the concept of ID is defined and understood by others. It seems to me that ID is often seen as a discrete entity that can be easily identified. This, together with an increasing trend towards specifying criteria for services, has led to many people who are in need of a service being refused one on the grounds that they do not have an ID. My aim in this paper is to raise these concerns and suggest how we could redefine ID in a way that would make misdiagnosis less likely.

There are a number of human conditions that are discrete entities, where it is clear that an individual either has the condition or does not have it and there are no shades of grey. Obvious examples are a person's sex, which, with very few exceptions, is unambiguous; one is either male or female. Another example would be pregnancy or more clinically Down's syndrome and Phenylketonuria (PKU), where it is

possible to use a blood test to confirm that a person has or has not got the condition. If one was to set up a service specifically for such conditions, one could be sure that everybody who the service was provided for had the condition and nobody who had the condition would be refused a service on the grounds of not having it.

However, many human conditions are not discrete entities but rather the extremes of a continuum. An obvious everyday example is tall and short, which are the extremes of the continuum of height. A more clinical example would be anaemia, which is dependent upon one's red blood cell count. I would like to call these "far end conditions". It seems to me that it may be possible to consider many far end conditions as discrete entities, in terms of being able to clearly identify them, provided, firstly, that there is a clear criterion as to how far along the continuum a client should be before they are considered to have the condition, and secondly one is able to accurately measure how far along the continuum they are. It would therefore be possible to define "tall" as being above 6 feet and accurately assess everybody in

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a population to see if they were “tall” by measuring their height. However, far end conditions will still differ from discrete entities in the important respect that they are concepts created by people on the basis of their opinion rather than being things that occur naturally in nature. Whether an individual can be considered to have the condition will be determined by where somebody or some group decides to place the dividing line on the continuum. It will be an important question as to whether the critical point on the continuum is in the right place. It is also likely that individuals who just reach the criteria and those who just fail to reach the criteria will not differ from each other in any practical sense.

There is, I think, a third set of human conditions that are not discrete entities and cannot be regarded as being so in any sense. These are conditions where either we are unclear what should be measured, or the relevant variables do not lend themselves to measurement. For example, we all make use of the concept of beauty and ugliness, but most of us would not suggest that we could measure them objectively. Although there may be some commonly agreed factors that go towards something being beautiful, inevitably much of our judgment as to whether something is beautiful is determined by our individual history, and will vary between people. It therefore would make no sense to make counts of all the beautiful women or ugly men in a population. These conditions I would like to call “judgment conditions”.

Intellectual disability

The way we talk about ID gives the impression it is a discrete entity. For example, we speak about somebody as having an ID or not having an ID. The same impres-

sion is given in the current government White Paper on learning disability (the term previously used instead of ID) “Valuing People” (Department of Health 2001), which contains statements such as:

“All people with a learning disability to be registered with a GP by June 2004. All people with a learning disability to have a Health Action Plan by June 2005.” (Page 61).

This suggests that one can identify all the people who have an ID in the population of England and Wales.

The way ID is defined suggests that it is a far end condition. There are several diagnosis/definitions of ID. For example American Association on Mental Retardation (2002), American Psychiatric Association (2000), Department of Health (2001), British Psychological Society (2001); however, they all require both an IQ below a critical point (usually 70) and a deficit in adaptive behaviour. Valuing People (Department of Health 2001), which sets out the Government’s vision for services for people with ID, is probably most relevant in a UK context. It refers to learning disability rather than ID but the terms can be regarded as synonymous. It defines learning disability as follows:

“1.5 Learning disability includes the presence of:

- *A significant reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;*
- *A reduced ability to cope independently (impaired social functioning);*
- *Which started before adulthood, with lasting effect on development.”* (Valuing People 2001, Page 14).

It then goes on to clarify this:

“1.6 This definition encompasses people with a broad range of disabilities. The presence of a low intelligence quotient, for example an IQ below 70, is not, of itself, a sufficient reason for deciding whether an individual should be provided with additional health and social care support. An assessment of social functioning and community skills should also be taken into account when determining need.”
(Department of Health 2001, Pages 14 -15).

The implications of this definition is that the diagnosis of ID is simply a matter of determining whether an individual has impaired social functioning (adaptive behaviour) and an IQ less than 70. However, I would argue that there are some major problems in doing this.

Measurement of intelligence

Determining whether an individual has a sufficiently low intellectual ability would seem at first glance to be straightforward. We are told in the definition that the critical IQ figure is 70 and there are IQ tests to measure intelligence. The way we talk about the results of IQ tests suggests that these tests are accurate. It seems to me that any measure has an implied accuracy to the nearest unit stated. For example, if one states a distance is 8 kilometres, one understands that it will be between about 7.5 Kilometres and 8.5 Kilometres. If one says one's weight is 62 Kg then it is understood that it is between 61.5 Kg and 62.5 Kg. It would be regarded as misleading if the distance turned out to be 10 kilometres or the weight to be 66 Kg. Although when psychologists report IQ scores they will

usually indicate that the IQ figure is only accurate to within about 5 points, in day to day speech we talk about people having IQs to a single whole IQ point, for example, Fred has an IQ of 83. We would not normally say that they had an IQ between 78 and 88, and certainly not that they had an IQ of 82.7. The impression gained by non-psychologists is that IQ can be measured to an accuracy of one point, which certainly is not the case. I (Whitaker, 2003; 2006) have suggested that the accuracy of IQ tests when applied to people with low IQs is not only not to the nearest point but is also considerably less accurate than most psychologists had previously thought. To briefly go over the arguments:

A lack of reliability in IQ tests.

Even the most well standardised tests of intelligence do not claim to measure intelligence to within one IQ point. The accuracy of an assessment is usually indicated by the 95% confidence interval: the range of scores between which an individual's "true IQ" has a 95% chance of lying. For most tests the interval is usually about 10 points, for example, for IQ 70 on the Wechsler Intelligence Scale for Children fourth edition (WISC-IV) it is between IQs 74 and 84. To put it another way, the test measures to within about 5 point accuracy. However, this interval should not be taken as definitive, particularly when low IQ is being assessed. The 95% confidence interval is a function of the test reliability: the higher the reliability the smaller the 95% confidence interval. However, there are several different reliability figures that could be used to calculate the 95% confidence interval. The type of reliability used in the Wechsler tests is based on the split half reliability of the test, which is determined by the internal consistency of the test. It does not, however, give any indication of how much one would expect an individual's IQ

score to change if they were tested on two occasions on the same test, which would be given by the test re-test reliability. It seems to me that it would be far more relevant to know how much an individual's IQ is likely to change if they were re-tested, than whether the test items were consistent. Recent data on this had been produced by myself in a meta-analysis of the test re-test reliability in the low IQ range (Whitaker in press). I found that 14% of IQs changed by 10 points or more from one assessment to the next and that the 95% confidence interval was about 25 points. This suggests the degree of accuracy of IQ assessments, at least in the low range, is considerably less than had previously been thought.

The intelligence of the population as a whole is increasing.

Flynn (1984; 1985; 1987; 1998; 2000) has shown that the average IQ of the population as a whole is going up by about 3 points a decade. Therefore tests that were standardised several years ago would give higher IQ than tests standardised today. Therefore as time goes on since a test was standardised the proportion of the population who would be assessed as having an IQ less than 70 will gradually decrease. This raises the question as to whether the criterion IQ level should still be 70 on a test standardised some years ago, or whether it should be a gradually increasing figure to take account of the increase in general intellectual ability and keep the proportion of the population scoring an IQ less than 70 constant. It seems to me that to be consistent it should be the latter. The problem, however, is that we do not know exactly how many points the score on a currently used IQ test should be decreased by to be equivalent to an IQ of 70 on a newly standardised test. This adds further error and ambiguity to the assessment of IQ.

Different IQ tests give different results.

There seems to be a general assumption amongst non-psychologists that if an individual was assessed on two different IQ tests the same result would be obtained. Amongst most practising psychologists it is thought that the two tests would give approximately the same result. However, there may be a major lack of consistency between tests in the lower IQ ranges, even on the two gold standard tests: the Wechsler Adult Intelligence Scale (WAIS) and the Wechsler Intelligence Scale for Children (WISC). Both Flynn (1985) and Spitz (1986; 1989) reported the Wechsler Intelligence Scale for Children – Revised (WISC-R) gives IQ scores up to 15 points lower than the Wechsler Adult Intelligence Scale – Revised (WAIS-R) for IQs of 70 and below. It is therefore clear that either one or both of these tests is failing to produce an accurate measure of IQ. The revised versions of the Wechsler tests are not the latest standardisations and I am not aware of any published empirical comparison between the new standardisations of these tests (the WAIS-III and WISC-IV) in this IQ range. However, work currently underway by myself and colleagues on the latest standardisation of these tests suggests that the WISC-IV consistently scores less than the WAIS-III by an average of about 12 points for WISC-IV IQ less than 70.

If all these various sources of error are put together, a conservative estimate of the degree of accuracy of an IQ test when measuring low IQ is about 15 points. That means we could be reasonably sure that a client's true IQ is within 15 points of the score obtained on a modern well standardised IQ test. This would correspond to a 95% confidence interval of about 29 points. This is a far greater margin of error than has previously been thought to

apply, and, I would suggest, far too great for a specified IQ point to be used as a criterion for having an ID. Therefore, rather than being able to regard ID as a discrete entity it should be regarded as a judgment condition. However, my impression is that most people working in intellectual disability services just accept a diagnosis of ID based on an IQ < 70. Others acknowledge that there may be some error in the IQ tests and consider that an individual may have ID if they have an IQ between 70 and 74. ID is therefore regarded as effectively a discrete entity. This inevitably will result in people being either wrongly diagnosed as having an ID or not being diagnosed when they should have been. It seems to me that we need to change our definition of ID to something that reflects our ability to assess a client.

Measurement of adaptive behaviour

There are scales of adaptive behaviour which are reported to have moderate agreement with each other and moderate reliability (see Harrison, 1987; MacMillan and Reschly 1997 for reviews), however, there are relatively few studies that have examined their psychometric properties and it is unclear how much error they are subject to or to what extent a measure of adaptive behaviour can predict if an individual is able to cope or not. A further concern in the UK is that the definition of ID in *Valuing People* talks about a deficit in social functioning but does not give any clear indication as to what exactly is meant by "social function", what the critical degree of deficit should be before a client could be regarded as having an ID, or how to measure it. One therefore can only rely on clinical judgment as to whether an in-

dividual has a sufficient deficit in social functioning to be regarded as having an ID.

Re-conceptualising intellectual disability

The reason we are concerned about people with ID is not because they have low IQ as such but rather because many people with low IQs cannot cope without additional support. The concept of ID was therefore developed to identify these people. However, I would argue, it fails to do this adequately. In part this is because we cannot accurately measure either adaptive behaviour or IQ; however, there is also the additional reason that IQs in the 60s and 70s are not good predictors of a person's ability to cope. Over the years I have come across a lot of people with IQs in the upper 70s who clearly were not able to cope. Some of them had autistic spectrum disorders and were not able to cope as they could not relate to people socially. Others had a combination of disabilities, for example IQ in the 70s, a mild mental illness or challenging behaviour, none of which, on their own, would have been sufficient to prevent them from coping. However, when an individual has all of them together they are not able to cope. Similarly it is likely that many people with IQs less than 70 are able to cope adequately. I have found (Whitaker, 2004) that only a small proportion of people with IQs less than 70 had an ID label and were known to services, the implication being that many of them were coping. So ability to cope is probably only weakly related to IQ: some people who have relatively high IQs are not able to cope, and many with low IQs are able to cope. It therefore makes little sense to have

a specified IQ point below which an individual may be considered to have an ID. I would suggest that we need a new definition of ID that is designed to ensure that those people who require a service get one, and that we acknowledge that we are not able to measure either adaptive behaviour or IQ with any accuracy.

I would suggest the following:

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

This definition of ID is based on a definition of a Vulnerable Adult (Lord Chancellor's Department 1997), which specifies a client's assessed need. It does acknowledge that low intellectual ability is at the root of an individual's problems but it does not specify an IQ figure. The diagnosis instead is explicitly based on clinical judgment which is clearly a professional opinion based on an assessment of all the relevant information. In order to be regarded as having an ID an individual should be assessed as having a sufficient degree of need and that this need is in part due to a failure to cope with intellectual demands, which could only be determined by clinical judgment. This definition is considerably less precise than previous definitions of ID. However, as I argue above, these definitions give a false impression of the accuracy with which we can measure IQ and adaptive behaviour.

I am not suggesting that we should never use IQ tests, only that we should not

base our definition of ID on an explicit IQ figure. IQ scores may well be clinically useful as part of a more general assessment of an individual. They may provide evidence that an individual's failure to cope is due to intellectual problems. For example, if a woman is referred to services as she is failing to cope with her new born baby, it may be appropriate to use an IQ test as part of the assessment to find out why she is failing to cope. If she is found to have an IQ of 93, then it is unlikely that low IQ is a major factor as we can have more confidence in IQ scores in the 90s and most people with that level of IQ are able to bring up children. If she has a measured IQ of 75, then it is likely that she has a true IQ below 85 and may well have one below 70. It may therefore be appropriate to investigate further as to whether her failure to cope centres around skills that are intellectually demanding, such as reading complex instructions, organising time to cope with changing demands or budgeting her money. The essential point, however, is that the IQ score is interpreted with due regard to the limited accuracy with which it can be measured.

It was the aim of this paper to clarify the position with regard to our ability to measure IQ and adaptive behaviour and to consider the implications of this for the diagnosis of ID. Throughout the paper I have stated what I think other psychologists and other service providers think about the accuracy of IQ tests and the nature of ID. I don't have any empirical evidence for my views on this, they are just the impression I have gained in my clinical work over the past 25 years. However, if I am right, then there is a major incompatibility between the accuracy which service providers assume occurs in the diagnosis of ID and that which actually exists. I hope that this paper will go some way to correcting this and

will persuade service providers to adopt a more flexible, needs-driven approach when deciding who should be provided with a service.

Summary

It is suggested that the way the term intellectual disability is used gives the impression that it is a discrete entity which can be diagnosed simply by assessing an individual's level of adaptive behaviour and IQ. It is argued that we are not able to measure either adaptive behaviour or IQ with sufficient accuracy. A looser definition of intellectual disability is suggested, acknowledging the problems in measurement and emphasising the need for clinical judgment.

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