Adult Clients With Mild 'Intellectual Disability':
Rethinking Our Assumptions

Eddie Gallagher

There is considerable confusion surrounding the concept of 'intellectual disability' and great stigma attached to this label. This paper questions whether the concept is a useful one when applied to adults with mild learning difficulties and encourages less rigidity in categorisation. Some implications of a pseudo-medical model are examined. Counselling for adults with mild intellectual disabilities has been much neglected. Some aspects of counselling these individuals are briefly discussed: expectations; communication style; exploring the client's idea of 'disability'; accepting versus challenging 'disability'; importance of relationships; exploring discrimination and abuse: depression and anxiety; and the danger of assuming a lack of understanding.

I set out to write specifically about solution-focused counselling with adults who have a 'mild intellectual disability' but this is such a neglected area that I felt compelled to write a more general article. Firstly, there is such confusion surrounding 'intellectual disability' that I felt it was wrong to discuss this group of people without stating my reservations about the concept. Secondly, I realised there had been remarkably little written about counselling adults with learning difficulties from any perspective and felt the need to make some general points. I will touch on the following:

- the social construction of disability; the meaning of 'intellectual disability'; what is different about 'mild' intellectual disability; common problems caused by a traditional, pseudo medical model; counselling people with learning difficulties; communication issues; exploring the individual's attitude to his or her disability; accepting vs. defying the disability; relationships; depression; and risk.

I will use the abbreviation 'ID' when referring to the label but when referring to individuals, who may or may not be labelled, I refer to people with learning difficulties', which they consider a less insulting alternative (Simons, 1992). Names and details of case studies have been changed.

The Social Construction of Disability vs. the 'Medical' Model

When I first became interested in intellectual disability, in the UK in the 1970s, the social construction of disability was a novel, rather radical idea, as was constructivism itself. Today constructivism is almost mainstream, and in the disability field hardly anyone admits to using a medical model that assumes a clearly defined and diagnosable syndrome. Yet sadly, despite big improvements in some services, attitudes of individuals and organisations towards those labelled 'intellectually disabled' have shifted very little over the last two decades.

David Pfeiffer, a physically disabled activist, recently wrote that the 'medical model is alive and well' and seen if you 'probe beneath the statements of colleagues and listen to what is said in times of stress (Pfeiffer, 2000: 98). I would go further and maintain that the medical model still clearly informs much practice with those labelled intellectually disabled — no probing necessary. Importantly, the widespread practice of registering individuals as 'intellectually disabled' is firmly based on a pseudo-medical model. Mercer, 1965, used the term 'the clinical perspective' rather than the medical model'. It has been suggested that 'bureaucratic model' might be more accurate, but the unstated assumption that there is an underlying syndrome or condition remains a fundamental justification for categorisation. The vague idea of dichotomies of health/normality vs. illness/disease/disability is bound up with common conceptions of disability.

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Individuals on the boundary between 'normal' and intellectually disabled serve as a good example of the relative, arbitrary and discriminatory nature of such labels.

In working with any disadvantaged group — and they don't come much more disadvantaged — worker attitudes are crucially important. Even a worker with extensive knowledge and experience will not have a positive impact if s/he has negative attitudes. Negative attitudes may reflect discrimination, dehumanisation and rejection of the disadvantaged group, or (more well meaning, but still dangerous) paternalism, overprotection and infantilisation.

**What is 'Intellectual Disability'?**

'Intellectual disability', the term used in Australia, was once 'feeblemindedness', with distinctions between 'imbeciles' and 'morons'. In the US, intellectual disability is still known by the ugly term 'mental retardation', while in the UK, 'learning disability' (or 'learning difficulty') has recently replaced 'mental handicap'. Though roughly equivalent, we can never assume that such concepts are identical, as their meaning changes over time and from place to place.

The changing labels, differing widely in emotional intensity, define a 'fuzzy set' (Zadeh, 1965, definitely nothing to do with 'warm-fuzzies'!). This category of people cannot be defined in a precise way without arbitrary distinctions being made. Nor can it be defined (even in an imprecise way) without taking societal context into account. Edgerton observed that 'a child born in an urban ghetto or an impoverished rural environment is 15 times more likely to be labelled mentally retarded than a child of the same age from suburbia' (Edgerton, 1979: 49). As Barnett clearly stated:

> Mental retardation cannot be understood simply as an individual characteristic, rather, the judgment that someone is mentally retarded reflects the interaction between the cognitive abilities of the individual and those required by the society at a given historical moment.

Barnett (1986: 112; emphasis added).

Most definitions of 'intellectual disability' in recent decades do acknowledge its social relativity. Recent official definitions have three parts: a) a condition existing since childhood with b) 'serious adaptive deficits' and c) sub-normal 'intelligence'. The prohibition (a) on those with intellectual limitations starting after age eighteen is an arbitrary exclusion of adults with acquired brain injury or dementia. This not only serves an administrative convenience but also helps maintain a firm them and us distinction as any of us may become physically disabled but we cannot become intellectually disabled.

**Adaptive Deficits**

It should be obvious that 'adaptive deficits' are socially prescribed, value-based and change over time. People are handicapped by the way society is structured. As a society, we exclude a percentage of people as too troublesome to cater for in designing generic services, structures and materials. If a tap is too tight for 25% of the population to turn, we consider the design to be at fault. If only 5% of the population have trouble turning taps we consider them to be at fault. Similarly, written instructions that most people cannot understand are considered badly written, but if a small percentage of people cannot understand or read them, they are seen as the problem. A wheelchair user is handicapped by stairs, narrow doors, high kerbs, and poorly designed wheelchairs. Someone with an intellectual limitation is handicapped by the complexity of society. Both groups are further greatly handicapped by prejudice. How many individuals are potentially intellectually disabled is largely a question of how user-friendly we choose to make our society to disadvantaged minorities. How far have we advanced since Terman wrote: 'The least intelligent 15 or 20% of our population ... are democracy's ballast, not always useless, but always a potential liability' (1922: 658)?

Officially, those labelled ID should show 'adaptive deficits' in addition to 'subnormal intelligence'. In practice, IQ scores are the main criteria used in classifying those with mild learning difficulties (Wen, 1997, Switzky, Greenspan & Granfield, 1996). It is always possible to find some adaptive deficit to justify classifying someone with a low IQ as 'intellectually disabled'. Deficits can be in 'communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work' (Luckasson, 1992). Attempts have been made to devise standardised tests of adaptive deficits, but these are so subjective, so culture-, age- and gender-specific, and so rapidly out of date, that they are often quite silly.

**'Sub-normal' Intelligence**

Alfred Binet devised the first standardised IQ test for the purpose of selecting children thought incapable of benefiting from a standard education because they were of sub-normal intelligence. Binet clearly stated that he was not measuring a unitary concept and warned of the 'brutal pessimism' of those who believed that intelligence was fixed (1905). The American adaptation of Binet's test, the Stanford-Binet (and later the WAIS), became the standard against which all other measures of IQ are evaluated. It may seem unlikely that Binet, by combining a diverse group of measures correlated with school attainment and without intent or realisation, happened to hit on a measure of something fixed, unitary and important. The idea of the fixed and unitary nature of IQ had great appeal to racists and eugenacists (Gould, 1981) and is still widely accepted, despite the continuing lack of agreement as to what intelligence actually is (Ceci, 1996), and despite the lack of any real evidence that "some crude consumer index like IQ" (Pinker, 1997: 34) is measuring a fundamental ability. If IQ is really measuring what is normally meant by intelligence, then shouldn't teenagers, who score highest on IQ tests, be running the country?

Even if IQs were lining people up in a meaningful order, where one draws a line to separate 'subnormal' from 'normal' must still be arbitrary. This 'cut-off point' has varied from 65 to 85 in different times and places. Common practice today gives the cut-off at 70 points (two
... and deviations from the mean). Cyril Burt, the educational psychologist who devised this cut off \([IQ = 70]\) did by working out the numbers of pupils who could be accommodated within special education (Marks, 1998: 44). Those falling between 55 (three standard deviations) and 70 can be considered to have a "mild" intellectual disability. However, only a small minority of adults with IQs in this range actually will be so labelled. We thus have the paradoxical situation that while IQ is used as the main criteria for assessing ID, other factors (with adaptive deficit being only one of many) are actually more important in determining who gets the label. This situation leads to discrimination and anomalies. Harris' conclusion was that:

Abandoning the IQ criterion will assist the move towards integration by softening boundaries between disabled and non-disabled people. This may be further facilitated by the use of fuzzy or continuous terms like learning or disability (1995: 349).

**Why 'Mild' is Important**

There has been an admirable move away from grading individuals in facilities for the intellectually disabled (and in legislation and definitions, Luckasson, 1992). To have some individuals referred to as 'low grade' or worse (e.g. vegetating, 'animal' and 'child-like', Ryan & Thomas, 1980) is highly distasteful. The labels 'mild', 'moderate' and 'severe' are also best avoided in training and residential facilities, as people should be treated as individuals in their own right. Within any kind of institution, this is an ethical approach but for adults with mild learning difficulties living in the community (as the vast majority always have) the addition of 'mild' to their label (if they have to have one) is both accurate and ethical.

Theorists and writers on intellectual disability have always recognised the fundamental difference between (most) individuals labelled as mildly ID and those with severe or moderate intellectual disabilities deriving from genetic or medical causes. The first group has been called sociocultural or 'familial' intellectual disability, in recognition of the clear social origin of their limitations. Unlike the biomedically disabled group, only a few people with mild intellectual disabilities have any kind of genetic disorder or recognisable brain injury or trauma. They mainly come from the bottom rung of the socioeconomic ladder (whereas the biomedically disabled come from all social groups). Though they may need help and support at times, they are not usually dependent on a day-to-day basis. They often partner and have children (both extremely rare among the biomedical group). They often 'pass' as non-disabled in the general population (very few of the biomedically disabled can ever do so). Their 'disability' is usually not apparent until they are past infancy and often not until after they start school (for most biomedically disabled individuals, problems are apparent in infancy). Many of those considered mildly ID as children are not disabled as adults (Ross et al., 1985).

The idea that this group of people, *as a whole*, have some kind of syndrome is a historically recent idea, with no medical basis whatsoever. The idea was initially clearly linked to the racist eugenics movement. Goddard (1916) is credited with popularising the idea and with coining the term 'moron' to mean mild ID. He was concerned with this group of people as a threat to society and, among other racist and elitist views suggested that all the feebleminded should be castrated or have their ovaries removed! He bemoaned the fact that the public had an irrational aversion to this! (1912: d5).

The inclusion of those with mild learning difficulties in the category of intellectual disability has occasionally been challenged (e.g. Zigler, Hodapp & Balla, 1984; MacMillan, Siperstein, & Gresham, 1996) but most writing on intellectual disability tends to virtually ignore this group of people, despite the acknowledged fact that they make up over three-quarters of all those labelled ID at some point in their life (Grossman & Tarjan, 1987).

**Taller and Taller Dwarves!**

I won't get into the many criticisms of IQ tests (much has been written, e.g. Ceci, 1996) but an interesting, and seldom-discussed issue nicely illustrates their arbitrary nature and is relevant to counsellors and therapists.

Overall IQs in Western society have been increasing at a rate of approximately three points per decade for the last 50 to 100 years. This is known as the Flynn effect (not Errol but James Flynn, 1987). As IQ tests are recalibrated, so that the mean IQ equals 100, those scoring 70 or below are a changing group, including some brighter, more capable people each time IQ tests are renormed. An appropriate analogy would be to define dwarfism as the shortest 2% of the population (such a definition has sometimes been used). As heights have increased over the last century we would have taller and taller dwarfs! Of course if society designs for the norm, and moves things out of short people's reach, they may indeed be handicapped.

This inflation of IQs is not merely of theoretical interest. I have been struck by how much more capable some of those now receiving the ID label are, compared to 20 years ago. The main IQ test used, the WAIS III (1997) is eleven points different in its present version to the one used until 1981! Thus someone scoring 70 today could have scored 81 in 1981, well above the cut-off point.

**Category Creep**

Additionally, it has become common in some areas to register people as intellectually disabled if they have IQs up to five points higher than the official cut-off — at a stroke doubling the potential population! The rationalisation for this practice is that there is a 5-point statistical error in IQ tests (this is overall error rate, in reality greater for those scoring lower). However, someone scoring low on an IQ test is statistically far more likely to have a higher IQ than a...
lower one. Think of adults measuring four foot on a highly inaccurate rubber ruler: on average they will be found to be taller than four foot far more often than shorter. Thus many individuals with a 'true IQ of 5 to 80 will also be registered as ID. This assumes only normal statistical errors, but there are many ways that someone can score lower on an IQ test besides random errors. Cultural differences, communication problems, depression, anxiety, other psychiatric problems, extremely low self-esteem and abnormally low motivation all reduce IQ. All of these factors are far more likely to affect individuals from the lower social classes, from minority groups, and from multi-problem families.

The issue of low motivation is an interesting one, as most adults are being assessed and registered either to receive a specific service or to reduce criminal sentences. I once counselled a young man who, although he had attended a special school for a few years, had, while still in his teens, worked consistently in open employment and started a family, as well as finding time for some serious crime. He was being assessed to be registered as ID, having been told by his solicitor that otherwise he might face a prison sentence! I casually asked if he would do his best on the IQ test. ‘Do you think I’m stupid?’ he replied cheerfully. How easy it is to fake mild ID was shown by the farce of the Spanish relay team at the Para Olympics in Sydney, 2000, none of whom apparently had learning difficulties!

The trend for brighter individuals to be given the ID label has no clear implications for the numbers of those being labelled. This may seem strange but it merely illustrates the extent to which gaining or not gaining the label is a lottery. Reported rates of mild ID vary wildly (e.g. 0.17%; Baird & Sudovik, 1985; 0.59%; Frost, 1999) but are consistently only a small proportion of those adults expected to have IQs below 0 on normal distribution estimates. Only a tenth to a quarter of those potentially eligible are labelled (less if some people with IQs over 0 are labelled). The numbers of those being labelled ID in the US have recently been steadily falling as the label ‘Learning Disorder’ has dramatically increased (Sternberg & Grigorenko, 1999). The term ‘Learning Disorder’ is used in the US to indicate significant differences between IQ and skills such as reading.

This trend for brighter people with the ID label is also not likely to be apparent to most people working with the intellectually disabled. Residential and training facilities cater predominantly for the more severely disabled. Changes in this population are quite separate, having to do with factors like birthing techniques, infant diseases, genetic counselling, survival rates, etc.

People with Severe Learning Difficulties

It is undeniable that within those with the ID label there is a group of individuals who are obviously seriously disabled, often physically as well as mentally. Some of these individuals would be considered disabled in any existing society, or any past society (had they survived). The fact that this group of people exists obscures the fact that the majority of individuals who are given the ID label (at some point in their lives) only resemble the more severely disabled group by analogy.

I am on dodgy political and moral ground! I do not wish to be seen as denigrating those with severe learning difficulties by stressing the difference between them and those whose learning difficulties are mild. Nor are all people with real biomedical conditions moderately or severely disabled; a few have mild disabilities (see Count Us In, by two remarkable young men with Down’s Syndrome, Kingsley & Levitz, 1994). However, not to stress this difference is to accept that the currently defined category of intellectual disability’ is a meaningful and useful one. I no longer believe that it is logical or helpful!

Images of Intellectual Disability

Unfortunately the term ‘intellectual disability’ conjures up an image in most people’s minds of someone who is somewhat deformed, with little or no speech, and highly dependent. This image affects how people react to all those labelled ID. Thus we tend to treat individuals with mild learning difficulties as being less capable than they are (Bromfield, Weisz & Messer, 1986). The image also affects how they themselves react to being labelled, usually distancing themselves from a label that they associate with physical disability (Booth & Simons, 1989; Fine & Asch, 1998). The ID label is one of the most powerful and most stigmatising there is (Wolfenberger, 1975). It creates strong expectations and stereotypes and leads to a great deal of prejudice. Prejudice is easy to find even in print, for example: ‘By virtue of their disabilities, they think, feel and act differently from others’ (Burkhardt, 1998: 102).

Problems Arising from the Traditional View of Disability

Failure to appreciate the socially constructed nature of ‘disability’ leads to a number of common errors:

• Disability is seen as permanent. Yet many individuals who are intellectually disabled in childhood (at least in school) cope without help as adults and should not be considered disabled.

• The label dominates our view of the individual. Personality, motivation, gender, victim status, social situation, relationships, culture are all played down.

• As the core issue is seen as the disability, and this is by definition untreatable, hopelessness and negativity are likely consequences.

• Similarities between disabled people and ourselves are masked and they are seen as inherently unknowable. Few attempt to see things through their eyes. Instead of empathy we settle for sympathy or rejection (or both).

• Disability is seen as all-pervading but so taken for granted that it is seldom discussed.
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• Whyn the disability? This focused on it as often in term of 'loss. assuming that disabled people mourn an ideal non-disabled self.

• It is assumed that the 'tragic nature of disability makes emotional problems inevitable (Oliver, 1996). Of course discrimination and rejection may make emotional problems likely, but not inevitable.

• Expectations of failure and inadequacy are subtly, and unsubtly. communicated to the disabled person and his/her family on a continuous basis.

• Emphasis is more on acceptance of the disability than on overcoming it.

• The many ways that individuals challenge their disability are often overlooked. Strength in battling against, or rising above, disability is not celebrated.

• Assessments are seen as something done to individuals rather than with them, with the individual being fitted to the best 'diagnostic' label.

• Some social roles are seen as inconsistent with the disability: if an individual is ID, she/he cannot also be a sexual being, a parent, a helper.

• An emphasis on the individual's limitations can result in an over-emphasis on skills training. This may be limiting, sometimes inefficient, and sometimes insulting. To what extent is your own performance on. say, ironing, running or hang-gliding a reflection of your skill as opposed to your motivation, confidence. anxiety. time. etc.

• The focus on the disability often equates to a focus on the individual, not on the individual's social context or system.

Counselling Adults with Mild Learning Difficulties

There is a remarkable lack of literature on counselling adults with learning difficulties. In books on intellectual disability, there is often no mention of counselling. If there is, it is assumed to be for parents rather than the intellectually disabled person. Twenty years ago it was noted that counselling was 'exclusively from the family's viewpoint ... there is a need to develop counselling for [mentally] handicapped people themselves' (Hanvey, 1981: 46). Today, this is still largely true. Disability generally is neglected in the counselling field (Hastings, 1997) and intellectual disability is on the margins of the marginalised. There are counsellors around doing good work with this client group but it is a fringe activity, and often only made available to individuals with seriously deviant behaviour or in specific counselling for careers or sex education.

Starting in the 1970s (but since then making much slower progress than many of us hoped) disabled people's advocacy groups have shown that adults with learning difficulties can have a voice, can understand their situation, and can communicate. As we have noted, there are now more intelligent 'intellectually disabled' people around than there were 20 years ago. Yet still it is often assumed that they will not be able to make use of counselling, or that special techniques or superhuman skills are necessary from the counsellor.

In fact, there is nothing unique to counselling those with mild learning difficulties. Nonetheless many people shy away from counselling those with this label (when in actuality they may be counselling other individuals, of equal ability, who simply do not bear the label). These adults may have lots of contact with professionals over behaviour, relationships, trauma, anxiety or depression without ever being offered counselling. Many have had children removed without counselling being suggested either for the behaviours that led to their loss or for the grief that follows.

Expect the Unexpected

I recently read a report stating that a woman was incapable, due to her intellectual disability, of abstract reasoning and therefore incapable of being a good parent! Coincidentally, on the very same day I read in a New Scientist magazine that evidence of abstract reasoning had been demonstrated in gibbons! A further irony is that the woman in question is fairly clearly mislabelled (she was assessed in adolescence following a highly abusive childhood and should not be considered ID.

People often express the belief that work with 'intellectually disabled' people will be slow and need great patience. I don't have great patience, so it is just as well that this is not necessarily the case! We need to see beyond the labels and not make assumptions based on preconceived ideas. Challenging limiting ideas and attitudes can sometimes produce dramatic change.

It should not be assumed that counselling must be long term; even single sessions can sometimes be productive. As adults with learning difficulties have often encountered massive doses of negativity, approaches that emphasise strengths, positives and potential are particularly suitable and less likely to do further harm to their self-esteem (Russo, 1999). Having been so thoroughly disempowered, empowerment and respect are crucial for this client group (Oliver, 1995), particularly as they 'cannot easily defend themselves against unwelcome or intrusive questioning (Booth & Booth, 1998).

Sue had been labelled ID since childhood. Her husband, Peter, also attended a special school but was not labelled ID. This family had had years of service involvement, were definitely seen as a multi-problem 'family', and had had one child removed for alleged neglect. Protective Services reports, and a psychologist's report, said clearly that the mother could not learn to alter her parenting in any significant way. In seeing this family, it was important that I did not believe these highly negative assumptions.

A major issue in counselling this family was lack of consistent boundaries and discipline (a common problem in parents with learning difficulties). Both parents, after much discussion, concluded that Sue gave in about 50% of the time to her children's tantrums and demanding behaviour, while Peter gave in about 10% of the time (without the dialogue between them neither would admit
to giving in at all). Over the next three months (of fortnightly sessions along with a support worker) the couples’ estimates of how often Sue gave in steadily decreased until Peter shamefacedly admitted that he was giving in more than she was — and their daughter complained that she was not getting her own way! Their daughter’s tantrums decreased from daily to fortnightly.

We need constantly to beware of the assumption that behaviour, attitudes or feelings are caused by disability. Disabilities influence but do not cause behaviour. There is a strong tendency to assume a lack of skill or understanding, when a lack of motivation, lack of experience, or emotional factors may be the cause of difficulties. This is good news for counsellors, as it is often easier to change motivation and remove emotional blocks than it is to teach skills or improve problem solving ability.

Communication and Style of Counselling

The communication style of those with mild learning difficulties, whether labelled or not, varies from articulate to monosyllabic and from those who have verbal diarrhoea to those who are virtually mute! In most cases, IQs tell us nothing useful about an individual’s capacities, as two individuals with the same measured IQ can vary greatly in any practical ability, including verbal fluency. Vocabulary can also be a misleading guide to an individual’s level of understanding (Booth & Booth, 1998). We need constantly to check our language and how well the other person is understanding us. It is not sufficient just to simplify. Sensitivity is the key, and aiming too low or treating the other as a child is probably more damaging in a counselling session than sometimes saying things clients don’t understand.

In counselling those with learning difficulties, we will usually need to slow down, both in our communication and in the speed with which therapy proceeds. This should be wholly dependent on the individual client and will apply equally to some individuals without learning difficulties. We will usually need to be more active in our counselling approach (though most family therapists tend to be fairly active). A passive, reflective style is unlikely to get very far (Trotter, 1993; Goor, McKnab & Davison-Aviles, 1995). We probably need to talk more overall, to make more statements than usual, to give more suggestions, to prompt more, to use many more rephrasings of the other person’s words and ideas — ‘to loan them the words’ (Booth & Booth, 1996). We may need to ask fewer open questions and more specific, direct questions (Sigelman et. al., 1982). Styles of counselling that rely on complex questions or indirect statements may be confusing, though I doubt there is any counselling approach that cannot be adapted. On occasions we may need to give more direct advice and guidance than we usually do. All this carries the danger that we can become more directive and controlling than usual.

We may need to supply words to help a client explain herself. Words such as ‘stress’, ‘depression’, ‘frustration’ can be introduced and explained. This not only assists communication but also can be powerfully normalising. Besides the danger of putting our words in their mouths, there also exists the danger of suggesting another stigmatising label (such as ‘depressed’). However, as the ID label is so negative, almost any other problem label can be de-stigmatising!

Although adults with learning difficulties may be more concrete minded and present-focused than other adults, this does not mean that they are incapable of abstract thought, of appreciating analogies or of having philosophical discussions. It is sad that we often expect less of adults with mild intellectual disabilities than we do from quite young children. We do, however, need to beware of response sets, such as when individuals say ‘yes’ to most questions they don’t understand (Sigelman, Budd, Spenhel & Schoenrock, 1981). This may be a strategy that helps them hide their limitations and pass in society (Edgerton, 1967).

Exploring the Client’s Ideas of ‘Disability’

The fact that the ‘disability’ is seldom openly discussed, while greatly influencing the person’s life, suggests that it is somehow unspeakable! I am amazed how often quite articulate adults with learning difficulties say that no one has ever talked to them about what it means to be ‘disabled’. Surprisingly, some of them nevertheless have quite clear and sensible ideas about their limitations and what being disabled means. Considering the contradictory messages they are often surrounded by, it is not surprising that others are thoroughly confused, though most have a keen awareness of stigma (Dudley, 1997). Sometimes they are even more confused about their ‘disability’ than the professionals dealing with them!

When appropriate, I am interested in exploring what terms, if any, clients themselves use for their learning difficulties. They seldom use a formal definition. They may say: ‘I’m a slow learner’ or ‘I can’t read and write’, or ‘I have trouble understanding some things’. If the term ‘slow’ is used, I may make a comment along the lines of: ‘So learning takes longer, but you can get there in the end’.

Labels vary greatly in how negatively they are perceived (Hastings & Remington, 1993). If individuals are using a highly negative or unhelpful term, such as ‘stupid’, ‘retarded’ or ‘mentally challenged’, I encourage them to use more positive terms. The ID label is so negative, that I encourage the use of terms such as ‘slow learner’ or ‘learning difficulties’. If the term ‘slow learner’ is used, I may make a comment along the lines of: ‘Some people say you learn things slower than other people’.

So what do you say is that you have difficulty learning? I encourage the use of terms such as ‘slow learner’ or ‘learning difficulties’, which are not only less stigmatising, but more accurate. As noted earlier, I also believe that the term ‘mild’ is very important, and encourage people to stress this when they tell others about their disability. People, including professionals, respond differently when someone’s intellectual disability is described as ‘mild’.

Externalising the Disability

Once we have explored what the ‘disability’ means to the client we can explore its influence: How has your learning
difficulty affected your life? Such questions will sound quite familiar to those with even passing knowledge of Solution Focused and Narrative approaches. Is it the learning difficulty that stopped you doing things, or is it what people think about you? ‘In what ways have you managed to overcome your learning difficulties?’

Questions such as these and of course wording, phrasing and timing should depend on the client may produce a flood of achievements or alternatively, may highlight the client’s feelings of hopelessness and despair. She may need much prompting to identify her strengths and successes. She may take her achievements for granted or be very present-focused. Joint sessions with a supportive support worker, family member or friend can allow us to question them about the client’s strengths. Have you seen other ways that Anne rises above her slowness?

Many (though not all) individuals with the mild ID label are capable of understanding that such labels are not absolute, fixed or all encompassing. It is helpful to reinforce that they are only ‘disabled’ in some ways, in some situations, and only ‘handicapped’ by society’s treatment of them. Involvement in self-advocacy is one way in which those labelled ID can improve their self-esteem without having to abandon all identification with individuals in similar situations (Harris, 1995).

‘Accepting’ or ‘Defying’ Disability

Why should it be a good thing to accept one’s disability? History is full of examples of individuals who refused to accept their limitations and went on to achieve great things. What does it really mean for someone to accept that they have learning difficulties? Not long ago, accepting one’s intellectual disability would have meant accepting illiteracy, segregation, uselessness and hopelessness! I have seen client files from the fifties with ‘ineducable moron’ written across the top. No doubt their parents were then urged to accept the disability and not push that their child be educated. It has often struck me in working with parents with disabled children that there are more success stories among the families who failed to accept fully their child’s disability.

I am not denying that lack of acceptance is sometimes a valid concern, but I feel that the emphasis has been too much on the need for acceptance. Accepting one’s disability can be similar to the old idea of ‘knowing one’s place’, and individuals are discouraged from aiming too high (e.g. Pfeiffer, 2000). Should an adult with the ID label not try to learn to read, drive a car, get a job, find a partner, be a parent? Who decides?

In reality there may be a ceiling of achievement above which someone with learning difficulties will never reach, though their ambitions are often modest and achievable. This is no different to the rest of us. Someone with an IQ of 80 or 120 is intellectually limited (as opposed to socially limited) in the same way as someone with an IQ of 60. Personally, I regret that I will never really understand Einstein’s theory but I don’t need anyone trying to help me accept my intellectual limitations, thanks very much!

Relationships

There are more adults with learning difficulties who feel lonely and isolated than there are people who feel this way in the general population. This does not make relationships less important to them, but arguably more important. The concept of a ‘syndrome’, combined with the fact that services are individually focused, often means the influence of partners, parents and friends is neglected. Working conjointly with other family members (or support workers) may be particularly important for individuals with poor memories or limited understanding. Conjunct work may be essential for us to gain an understanding of what is going on, and behavioural and attitudinal changes worked towards in therapy may need to be reinforced by those in daily contact.

It is not unusual for professionals to work with mothers who have an intellectual disability without any contact with their partners (Booth & Booth, 2002). In working with mothers with the ID label, I found that getting their partners more involved with the children sometimes worked wonders, and also that training and instruction of these mothers could be effectively undone by the influence of some grandmothers unless they too were involved in the therapeutic or training process.

Most adults with mild learning difficulties will partner at some point. This is probably the norm, not the exception (though we don’t have any reliable data). Yet because of our assumptions about people with intellectual disabilities, we tend to be surprised, even shocked by this and often see it as a cause for alarm rather than celebration. Women with mild intellectual disabilities are vulnerable to abuse, exploitation and violence, and those working with them need to be alert to these possibilities. However, this alertness often appears to become an expectation that abuse and exploitation are inevitable. Not all men who partner women with learning difficulties are abusers, and for many adults with learning difficulties, their greatest hope of a happy and fulfilling life may lie in finding a loving, supportive partner of the opposite, or the same, sex.

Supportive partners do exist (though they are much less likely to come to our attention). Studies have found that many partners function as benevolent beneficiaries (Edgerton, 1967; Ross et al., 1985, Booth & Booth, 2002). Women in our society tend to marry men who are better educated than themselves (also older, taller, richer: all serving to bolster the male’s power). We should not be surprised, then, that women with mild learning difficulties often marry men without learning difficulties and that men with learning difficulties are less likely to marry.

Some adults with learning difficulties continue to have close, partly dependent relationships with their parents and other relatives. What is perhaps remarkable, given the lack of social norms for such relationships and the potential for conflicts, is that these relationships often function well. It is easy to be negative about non-standard relationships and terms such as ‘over-protective’ and ‘over-involved’ are overused.
There are potential dangers for workers in deciding how and when to involve other people in counselling or support of the mildly intellectually disabled. On the one hand, parents (and adult sibs) of adults with learning difficulties are sometimes assumed to be in a similar role to carers of young children, and may be over-involved. At other times, parents, partners and important others are excluded when their involvement would be logical and useful. Too few services for the intellectually disabled are truly family-focused: some are individual-focused, some are mother-focused (and a few are corporate focused).

Discrimination, Harassment and Abuse

We need to be sensitive to experiences of victimhood. A great many mildly intellectually disabled individuals have been abused or harassed at some point in their lives (e.g. McCarthy, 2000). This may have been within the family, in institutions (by staff or other clients) or in the wider community. A strengths/solutions approach can do much to challenge the shame and guilt that often accompany such experiences and can help restore dignity to people who have been dehumanised in many ways.

Bullying and teasing can be serious problems for adults with intellectual disabilities, either in the wider community (Booth & Booth, 1998, give horrific accounts of systematic community harassment) or else between themselves in sheltered workshops and residential facilities. I helped a woman who was being teased at a sheltered workshop rehearse lines such as: ‘You aren’t very good at insulting people, shall I bring you a book of insults?’ The fact that both individuals were illiterate probably added to the humour and shock value of this rejoinder, which defused the situation quite effectively.

Depression and Anxiety

Related to discrimination and abuse, and to stigma and low self-esteem, is the fact that many individuals with mild learning difficulties suffer from depression, anxiety or other emotional and psychiatric problems. (I dislike the trendy term ‘dual diagnosis’, as it seems to imply that there is such a thing as ‘sole diagnosis’.) Depression and anxiety may be masked by behavioural and subcultural differences, or simply obscured by the power of the label. Long-term depression is common and often plays a part when an individual neglects health, appearance, children or environment. The same factors which cause depression in others are responsible for depression in those with learning difficulties (e.g. lack of social support (Reiss & Benson, 1985); and negative self-concept (Benson & Ivins, 1992). Individuals with learning difficulties also appear to have a high rate of anxiety symptoms, which often remain untreated.

The Dignity of Risk

Life can be risky for individuals with an intellectual disability. A few create minor practical or social crises on a fairly regular basis. They get beaten up, harassed and raped more often than the norm. They are more likely to be abused by partners, friends and relatives. They may be targeted by con men, control freaks and paedophiles. The level of risk varies greatly but is often real. Some workers, and many organisations, find this difficult to deal with and may react either by continual overprotection, or by minimising or denying risk until it reaches a threshold, and then over-reacting. It is important that we allow adults to take risks and, in most cases, provide support and guidance rather than any form, however subtle, of coercion. Unfortunately patterns of official neglect followed by coercion are common for some adults with intellectual disabilities. This is dramatically so for many parents with an intellectual disability, who receive little or no support until their children are removed from them (personal experience, correspondence and McConnel Llewellyn & Ferronato, 2000).

The Danger of Assuming Lack of Understanding

Julie was the sole parent of a ten-year-old boy who had been hitting and verbally abusing her when at home. He had recently been placed in foster care and on access visits their relationship was steadily improving. Both she and her son had agreed on several occasions that they were not ready for him to return home full time. I gave her a lift to the Children’s Court and sat in on the interview with her barrister. When asked if she wanted her son home, she immediately replied ‘Yes’. The barrister asked if she wanted to contest the matter. Julie again answered ‘Yes’. The barrister suggested we take some time to think and talk about it. Julie was less articulate and socially competent (partly due to anxiety and depression) than many of the adults with mild learning difficulties I have worked with. My immediate reaction was that she was confused and had not understood the barrister’s language. I think most of us would probably have made the same prejudiced assumption.

On discussion Julie seemed to understand the implications of a three-day contested hearing, though she was terrified of courts. On a hunch (based on experience of mainly non-disabled women who had lost custody of their children) I asked, ‘Would you feel guilty about not fighting to get Sam home?’ She nodded vigorously. I acknowledged that I understood this and that it was a normal, admirable reaction. She asked for time to think by herself and ten minutes later had decided that her son could stay in foster care as long as it was not for more than six months. People with learning difficulties have the same emotions as the rest of us.

It should be a general principle to assume that all people (especially children, the elderly, the less educated, non-English speakers, and those with mental illness or disabilities) understand more than they are able to communicate or demonstrate.

References


