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HISTORICAL CONTEXTS, SETTINGS AND COMMON PRESENTATIONS

In this chapter I consider the political and historical contexts of people with learning disabilities, and the development of a counselling approach to this client group. The historical context is especially important as this group has traditionally been devalued, and the way in which it is viewed has important implications for the development of a therapeutic relationship with each individual client. Various contexts within which adults with learning disabilities live, work and spend their time are described, with particular emphasis on the way in which psychological distress may be manifest and recognised. These are all contexts within which a counselling approach can be utilised.

Historical approaches to people with learning disabilities

When considering a person's inner world it is important to be mindful about not only their personal history, but also their culture and the history of the groups to which they belong. When working with children of refugees or victims of torture or racism, it makes no sense to ignore how their predecessors have been treated and viewed. The past treatment of ancestors becomes integrated into families and individuals as folklore, religion, customs or accepted ways of being. This is also true of people with learning disabilities, although, just as with other minority groupings,

there is a tendency to ignore or minimise the impact of the past (Atkinson *et al.*, 1997). Brendon McCormack (1991) has described how a learning disability can be thought of as a communication difficulty in three areas: with others, oneself (thinking) and one's background or history. He points out that removing people from their homes and communities, as has been the policy over the last century, is an active removal from their historical contexts. More often than not, a person's history is not communicated to staff when they move, and files can be painfully thin for the experiences of a person's lifetime. This can negate the meanings of these experiences and the dynamic nature of experience and ability to think, or to use one's intelligence; this idea will be discussed more fully later.

Documented approaches

Early records dating back to ancient Greek and Roman times indicate that infanticide was practised on sick or deformed children (Barnes, 1994). Cruelty and mistreatment of people with learning disabilities have been documented as occurring over the centuries since then. Before the nineteenth century, the evidence available for understanding how people with learning disabilities were conceptualised tends to be laws or legal documents. Such documentation makes it hard to gain an understanding of how people with learning difficulties were thought about, what their lives would have been like, where they lived and how they were treated.

We know that during the period between medieval times and the nineteenth century there were no specific laws or guidance for treatment of people with learning disabilities, and this lack of focus has led historians to classify these times as either a 'golden age' or an 'era of neglect' (Caine *et al.*, 1998). During these times people were classified by law as either 'lunatics' (acquired and punctuated by times of lucidity) or 'idiots' (present from birth and constant) (Andrews, 1996). However people only tended to get a label of idiot if they came to the attention of the courts or poor law administrators, either through financial difficulties or extremes of behaviour.

There was a noticeable shift in treatment of people with learning disabilities at the end of the nineteenth century, when Victorian ideas about the importance of education seemed to influence policy makers. There are debates in the literature as to what exactly the precipitating factors were (Wright, 1996), but the outcome was clear; people with learning disabilities were institutionalised on a large scale. The urbanisation that occurred in the Victorian era increased the visibility of people with learning disabilities, and this led to the perception of people with learning disabilities as a social problem. The major reasons parents gave for having their children institutionalised were on the grounds of poor educational performance.

The shift in how people with learning disabilities were conceptualised was significant, and Locke's distinction between madness (right reasoning from wrong principles) and idiocy (lack of reasoning ability) was adopted. Caine *et al.* (1998) point out that as reasoning ability was considered a defining characteristic of humanity, 'idiots' were considered less than human, lacking in intelligence and qualitatively different from other people (ideas which they point out still persevere today).

Although many of the large institutions were developed with the notion of being a short-term educational facility, with the aims of training 'idiots' to become productive members of society, for economic reasons incarceration developed into a lifelong sentence.

The next major change in the conceptualisation of learning disabilities occurred around the end of the nineteenth century. People with learning disabilities started to be seen as a threat to society. This seemed to be linked to the development of the medical profession who saw idiocy as an organic and perhaps inheritable disease, which required medical treatment. Dale (1995) describes how whole families could feel guilt and blame as a family with a learning disabled member became viewed as a 'sick' or pathological family.

Further, as the eugenics movement gained momentum, there was a growing concern that social problems were being created by the reproduction of poor genetic stock. Human traits were viewed as heritable, so the next logical step was to claim that 'idiots' should be prevented from having children.

CASE EXAMPLE: Gladys

About ten years ago, I was asked to see an elderly lady who was being assessed for a move from a long stay mental handicap hospital into the community. The hospital staff were concerned that she had become very withdrawn and depressed, refusing to talk to the staff and curling up and crying for her mother. Her file was requested, and this took some time to arrive, as it was kept in the basement storage system of the hospital (meaning that none of her current care staff had any idea about her background or history). When it arrived, I was very shocked to see that the reason for Gladys's admission, sixty-five years previously, was for having had an illegitimate child, a daughter, when she was thirteen. There was no documentation about learning disabilities at all. I wondered about the possible meaning of having to leave her lifetime home, not only the loss of the familiar environment, but also the memory of her child, and her previous life. It raised questions about how she felt about the difficult separation from her child. It was then possible to think about the importance of talking with Gladys about her history, and reflecting with the staff about the importance of seeing her as a person with a valuable and relevant past. This awareness might bring anxiety and pain, but for Gladys it seemed to enable her to make sense of what she was feeling at this difficult time of transition. Sadly, such backgrounds are not uncommon, and as a result the relevance of peoples' life experiences is frequently minimised.

The development of the profession of psychology added weight to the process of segregation. Possibly in common with the medical profession's emphasis on diagnosis, psychologists and educationalists worked on refining IQ tests as a way of classifying people, basing segregation on a person's score on the test. The development of the terms 'imbecile' and 'feeble-minded' and, most importantly, 'moral imbecility' can be connected with this development. It became seen as more acceptable to incarcerate people for their behaviour, owing to the umbrella definition of 'mental deficiency' (Jackson, 1996).

The Welfare State

In 1948 the National Health Service was created and, in conjunction with Social Services, it still organises the bulk of service provision to people with learning disabilities. As the large-scale institutions fell under the administration of the NHS, there was a gradual but definite shift of emphasis in care: 'inmates' became 'patients' with health care needs.

This redefinition allowed for a shift in the perception of people with learning disabilities, the emphasis on them as a threat to society was reduced, and this allowed for a new perception to develop. For example, the civil rights of people with learning disabilities began to be questioned. In the 1970s the work of Wolfensburger highlighted the shortfalls in society that prevented people with learning disabilities having access to normal activities and services (Wolfensburger, 1972). Other factors contributing towards the most recent shifts included research evidence suggesting that skills teaching and education could be of use to people previously considered 'ineducatable'.

These changes, combined with the public scandals of mistreatment of patients within the larger institutions (Mittler and Sinason, 1996), led to the 1971 White Paper 'Better Services for the Mentally Handicapped', which strongly recommended increasing 'community care'. The emphasis of care had once again shifted from health to social needs.

Current social and political contexts

'The National Health Service and Community Care Act' 1990, came into effect in 1993. This paper promoted the services that would enable people with learning disabilities to live in their own homes. It was envisaged that people would live in local communities so that the large long stay hospitals could be gradually and completely closed down, a process which is almost entirely complete in the UK.

With housing and social needs addressed, attention has shifted to the mental health needs of people with learning disabilities. There is debate across the country as to where best these needs should be met; should services be attached to adult mental

health services, or better placed within social services, or even exist in their own right? This debate seems to reflect a wider cultural difficulty in thinking about the needs of people with learning disabilities, and the difficulty in recognising that the group itself is not homogeneous. Delays and lack of clarity in service provision can have serious implications, given the very high incidence of mental health problems for people with learning disabilities.

The power of images and representation in the media

Deborah Marks (2000) has explored in detail the impact language, images and representations in the media and western society have on people with disabilities. For example, people with disabilities are frequently portrayed in films as isolated and excluded, whereas intelligence is equated with beauty and fitness. Although it can often be the case that people with disabilities are isolated and lonely, this can only be perpetuated by the way in which disability is publicised or represented. Marks notes how disability is never presented as incidental, but is always a central topic, and that disability on television is not representative of the incidence of disability within the population. Disability is over-represented as the focus of films, but under-represented on television, for example in soap operas. Marks also explores how disabled people in films are almost always represented by 'non disabled' adults (though one could question how obtainable equity cards, the unit of qualification in acting, are to people with disabilities). She argues that the core of the difficulty in representing disability in the media is that it allows the observer the luxury of thinking that 'it's not real, it's only pretend'. This has the effect of making viewers feel once removed from the reality of disability, and the fear, fantasies of loss or dependence can be more safely experienced or explored. By representing disabled people as objects of pity, it allows us to split off and project into these images our own disabilities and weaknesses. Hostile feelings are quickly transformed into feelings of guilt or pity.

Another major source of imagery regarding disabilities is the media. Here, too, disability is depicted in a certain way, as something to be avoided and overcome. One frequent example is that of Down's syndrome. Recently there has been great media interest in new developments in Japan where it has been identified that Down's Syndrome can be identified through a maternal blood test, reducing the necessity for intrusive assessments such as amniocentesis. The implication is that it enables parents to make a choice earlier if they wish to abort the 'disabled' foetus. People with genetic syndromes are confronted with such negative messages on a regular basis. As Sinason (1992) reflected, there is a fine line between 'you should not have been born' (we are going to prevent people like you being born) and 'you should be dead'. For people with learning disabilities this focus on how to prevent disabilities in infants, as well as the drive to cure disabilities through medicine, gives a powerful message to them that they are unwanted, which can lead to an internalised sense that people would prefer it if they disappeared or died.

The importance of highlighting these issues is not to criticise the way disability is represented in western society, but to raise awareness of these issues. When working with people with disabilities, it is important to be aware of the impact of the many experiences they have on a daily basis. It is also important to be aware of one's own thoughts, beliefs and experiences of disability, and the impact that images and representations can have on one's own functioning.

Developments in theoretical approaches

There is a consensus in the literature that the field of learning disabilities is shifting. For the majority of the twentieth century it was considered that talking treatments were not appropriate for people with learning disabilities. This situation has been traced back to a comment made by Freud (1905) that a certain degree of verbal ability was required for psychoanalysis. Freud aired this view at a critical time, when the ideas about talking treatments were only just starting to catch public interest. The effect of this

early comment has been long-lasting and although there have been pockets of psychodynamic work with people with learning disabilities (for example, Clark, 1933; Mannoni, 1968) it was not really until the early 1980s that a consistent body of literature developed in which a 'talking' treatment was promoted. In the meantime the behavioural work originating in the 1920s and 1930s retained a firm grip on the field of learning disabilities for a number of reasons. The use of behavioural work has arguably been popular because behavioural methods have been perceived as more testable and therefore 'scientific'; they enabled efficacy to be researched and produced results that gave numerical outcome data. Behavioural methods also allowed for a distancing from the person; professionals were not required to get to know clients or to interact with them, and this provided a solution for avoiding the fear of and guilt associated with disability.

The development in 'talking treatments' with people with learning disabilities, or perhaps the reduction in 'therapeutic disdain' (Bender, 1993) probably came about for a number of reasons, including the climate change towards people with learning disabilities described above. There was also a considerable shift in policy development in the late seventies and early eighties towards people with learning disabilities. For example, the 1971 Education Act stated very clearly that no child is 'ineducable' and that services to children need to adapt in order to provide the most constructive learning environment. Other important developments include Wolfensberger's (1972) work on Normalisation, and the development of important advocacy groups such as People First. These groups, some of which were staffed entirely by people with learning disabilities, pushed the way forward for equality and supported their members in accessing mainstream mental health services.

Who might benefit from a counselling approach? Settings and presenting problems

'Talking' treatments are now being considered viable in a large range of settings. The range of settings where people with learning disabilities live, work or spend their time is now wide.

Case examples will illustrate some possibilities of where people might be living or spending their time; through these, common presenting problems will also be illustrated, although these examples are by no means exhaustive of either problems or settings.

CASE EXAMPLE: Group Homes

Lorraine is a twenty-two year old woman who has mild learning disabilities. She lives in a group home, which is managed by the health service and has seven residents. The home had been created by knocking together two terraced houses in a residential street. From the outside it would not be possible to tell that this is a facility for people with learning disabilities; there are no obvious signs. The home is staffed by a core group of ten care staff, who work on a rota basis, two or three are on duty during the day, and one staff member sleeps in overnight. On the whole, the residents are quite cognitively able though all have a learning disability. Each resident is assigned a keyworker, and Lorraine's keyworker, Debbie, is becoming concerned that Lorraine has been going out without saying where she is going, and coming back quite late at night. Also, a small sum of money has gone missing from one of the residents rooms, and when the staff team asked the group about this, Lorraine became very angry, saying that she was being accused. She then ran out of the house, not returning until late, again refusing to tell anyone where she had been. Debbie found a time when Lorraine was a little calmer, and instead of asking her questions about where she had been and what she had been doing, Debbie talked to Lorraine about how she thought Lorraine might be feeling: perhaps lonely and cross that staff were not very good at taking notice of her unless she behaved in a way they found difficult. Lorraine burst into tears and said she did want to talk to someone, but not Debbie, not someone from the home. Debbie suggested a referral for counselling, which Lorraine agreed to.

CASE EXAMPLE: Hostels

Ms McDougall is a twenty-nine-year-old woman who is living in a temporary hostel for women with learning disabilities. She has moderate learning disabilities, and a slight weakness on her left side, which makes her uneven on her feet.

The hostel has five rooms and is run by social services. Residents are moved in as an emergency measure, because it has been judged that their safety cannot be guaranteed in their current placement. It is, however, considered to be a temporary placement and there is the expectation that residents will not stay much longer than two years at the most. For this reason, the rooms are rather stark and impersonal though there is a welcoming communal area. There is a twelve person staff team who work on a rota basis where there are always at least two staff on duty at any time, nights included. Ms McDougall was given a place at the hostel when she disclosed that her stepfather had been sexually abusing her. She disclosed the abuse to her social worker, who had been concerned about Ms McDougall's behaviour when taken swimming as a supported day activity; she had refused to get undressed and had been very tearful. Her mother refused to believe that she was being abused, and is still very angry about her accusations. Criminal prosecution procedures were taken against her stepfather, but the CPS felt that because of Ms McDougall's learning disability the case would not be successful so it was not taken to court.

Ms McDougall had been living in the hostel for eighteen months and staff were preparing her for a move into the community; recently, however, a number of concerns about Ms McDougall's behaviour have developed. She has been smearing her faeces and masturbating openly in the communal areas. The staff team agreed that one of the hostel staff, Naomi, would make time to talk to Ms McDougall to try and understand her behaviour.

Ms McDougall was initially very angry towards Naomi, shouting and swearing, saying 'what do you care, you just want to get rid of me'. Naomi was able to make helpful links to Ms McDougall about how she was feeling 'got rid of' by the

hostel now, and how she felt 'got rid of' by her mother and stepfather, when she told what had been happening. It was then possible for Naomi to reflect with Ms McDougall about how she had found it difficult to talk about her feelings, linking this with the response on disclosure of the abuse: rejection and disbelief.

CASE EXAMPLE: Supported Living

Mr Michaels is in his forties and is wheelchair-bound. He has cerebral palsy and mild learning disabilities. He lived with his parents until their deaths when he was in his late thirties. Throughout his life he has had carers come into his family home to help with washing and dressing, increasingly so as his parents became less able. Following their deaths within two years of each other, Mr Michaels developed severe depression. He was unable to stay living in the family home for financial reasons, and he was offered the possibility of moving in to a group home for adults with learning disabilities. He declined this offer saying that they were all 'mentally disabled' not like himself. He was then offered a supported living situation, where he was given a ground floor flat to live in on his own with support staff organised to visit on a daily basis to help him with daily living tasks. Mr Michaels appreciates his independence, though he is lonely, and this seems to be contributing towards his depression. His social worker, Miles, has noticed how withdrawn he has become, and how he shows reluctance to go to the local adult training centre drop-in, where he was a keen attendee. Miles suggested that they took some time to talk about his feelings and Mr Michaels agreed.

CASE EXAMPLE: Independent Living

Mr and Mrs Hart both have mild learning disabilities, and are in their twenties, having been married for two years. Their marriage was arranged by their very supportive families, who have provided them with a home to live in. Neither Mr or Mrs Hart are employed, they each get disability living allowances. They have a mutually supportive relationship, Mr Hart does most of the cooking and shopping, as Mrs Hart has a slight physical disability that makes walking long distances difficult for her, and she does the cleaning and washing, which she undertakes with great pride. The couple have a social worker, Eleanor, who visits them every three or four months. On her most recent visit, she found the couple had been arguing, and the state of the house was deteriorating. Both Mr and Mrs Hart seemed quite angry with each other, but seemed unable to listen to each other's point of view. They objected to Eleanor trying to help, saying it was none of her business, and so she suggested that they see someone independently to talk through their worries. They refused this, but two weeks after this visit Mr Hart telephoned Eleanor to say that things had got worse, Mrs Hart had gone back to live with her parents, but she was agreeing to talk with him if someone else was there. Eleanor referred the couple for counselling.

There are a range of other possible settings in which people with learning disabilities can live. These include residential or village type communities, which consist of groups of homes which tend to be run by social or voluntary organisations and often have a strong philosophical or religious orientation. Since the 1990 Community Care Act, people with learning disabilities are more likely to be living as adults in their families of origin, as there are fewer community placements available.

There are a wide range of day services that people with learning disabilities can have access to, in common with the non-disabled population, such as employment, work clubs, social clubs, health-based centres, cinemas and other entertainment centres. Staff in day centres may often be called upon to provide

a supportive, counselling or psychotherapeutic relationship. The range of day activities is explored through the use of case examples.

CASE EXAMPLE: Day Centres

Elizabeth is a twenty-one year old woman with Down's syndrome who lives at home with her parents, her younger brother and her older sister. Four days a week she attends the local day centre for people with learning disabilities, where she has a timetable of arranged activities. The centre is a modern purpose-built building, which is cheerfully decorated and is set on a landscaped plot of land, hidden behind a row of trees. Elizabeth is learning catering skills and computer skills and she attends a social skills group. Elizabeth is collected by local authority transport to attend the centre, and she often goes out on supervised weekend or evening trips with the centre staff and attendees. Over the last few months, staff have noticed that Elizabeth has become more withdrawn. She did not attend out of hours activities for several weeks and even more recently has not turned up to the centre. She also got into an argument with another client, which seemed most out of character.

One of the staff members, Mrs Sharp, has always been quite fond of Elizabeth, and decided to try and talk to Elizabeth about her concerns. Elizabeth was sullen and said that nothing was wrong. Mrs Sharp asked Elizabeth's parents to come in for a review, which Elizabeth attended. Her parents said that they had not noticed any change in Elizabeth recently, but thought that she was probably caught up in the excitement of her sister's forthcoming wedding, on which the whole family were very focused. As Elizabeth's mother talked about this, Elizabeth looked very distressed, and Mrs Sharp had the feeling that Elizabeth was holding back tears. Later, after this meeting, when Mrs Sharp spoke gently to Elizabeth about how she might be feeling that her sister was getting married and leaving home, Elizabeth sobbed, and Mrs Sharp was then able to talk to her about a referral for counselling which Elizabeth welcomed.

CASE EXAMPLE: Flexible day support

Mr Hastings is a thirty-year old man, who lives in a group home with three other men. He has a learning disability, and is the most able of the residents of his group home. There is no suitable adult training centre in his locality, so a day programme has been created to best suit his needs. He attends a work experience centre one day a week, he has a part-time job in a factory two days a week and he goes out on regular day trips with a group of people with mild learning disabilities one day every other week.

Recently he was arrested for exposing himself in the local park to a group of children, and it transpired that he had kept a collection of child pornography at home. The police decided not to prosecute him as it was a first offence and he has a disability. Instead, they recommended a referral for counselling for Mr Hastings. Mr Hastings' GP has referred him to his local adult learning disability team, which consists of a psychiatrist, psychologists, nurses and counsellors.

CASE EXAMPLE: Work experience centres

Carlos is a nineteen-year old man with a mild learning disability. He lives at home with his elderly parents. His four brothers and sisters have all moved out over the last fifteen years, and he has been on his own at home for the last three years. He finished school for people with mild to moderate disabilities in August and for the last four months he has been attending a work experience centre on a daily basis. The centre is primarily set up to teach carpentry and gardening skills to people with mild learning disabilities. They have several contracts with local garden centres to provide garden woodwork such as furniture and fences. The attendees get paid a wage for attending the centre, out of the profits. Staff have noticed that Carlos refuses to work alongside employees who have an obvious physical disability, and that he uses racist language. He has been appointed a key worker, Mick, who has

the task of trying to talk to Carlos about this behaviour. His task is twofold and thus complicated: he has to let Carlos know that this behaviour will not be tolerated, as well as trying to understand Carlos' difficult behaviour.

CASE EXAMPLE: Further education

Ms Caine is a thirty-two year old woman with a moderate learning disability. Since leaving school ten years ago she has attended an adult day centre, but at a review two years ago, she said that she would like to develop her literacy skills. The following academic year she was offered a place at the local FE college on a course designed for people with learning disabilities. This college is a large purpose built building which caters for people with and without disabilities, from eighteen upwards. It runs a range of academic and skills-based courses, many of which lead to a qualification such as the NVQ.

Ms Caine attends the college one day a week, and over the last week there have been growing concerns about her aggressive behaviour. She has hit out at other students, once stabbing a student in the hand with her pen. She can be verbally aggressive and rude to staff at the college. She lives at home with her mother (her father died recently) and her mother has been called in to a review with the course tutor and head in the next month.

There are many relationships that people with learning disabilities may develop that provide settings for counselling. These include advocacy services, befriending services, social services, religious based services and consumer led services such as People First. People with learning disabilities may be more likely to talk to, or express their feelings to, the people they feel closest to; sometimes, however, it can be easier to talk when the recipient will not be seen on a regular basis. Sometimes it can be very difficult to provide regular private time, but this does not mean that boundaries such as privacy should be ignored, as can frequently happen for people with learning disabilities. This issue needs to be worked out on an individual basis. However, it is our respon-

sibility to think about, and recognise, when the people we work with, perhaps on a daily basis, become distressed or disturbed.

SUMMARY

- Historically people with learning disabilities have been devalued and misunderstood. This historical legacy can have an ongoing impact with every new encounter a person with learning disabilities makes.
- On a societal level, devalued groups tend to attract further devaluation, as it can be easier to create a sense of a 'them and us' distinction or split, the devalued group then attracting all the negative attributes and shortcomings felt by others. One such example is the once pervasive idea that people with learning disabilities 'do not have the same kind of feelings' as 'normal' people so there is no point in talking with them.
- On a personal or one-to-one level, the process of internally splitting between attributes that are valued and those which are not, then pushing out the aspects of ourselves which are less valued on to those who are more obviously damaged is a subtle and normally unrecognised process that can hinder development both in individuals and within families.
- People with learning disabilities have been much overlooked for counselling treatments, though gradually and surely there has been a shift. There is a growing awareness of the mental health needs of people with learning disabilities, and of the utility of counselling approaches.
- People with learning disabilities live and spend their time in a wide range of different settings, and they are likely to come into contact with a range of many different professionals throughout their lifetime. It is all of our responsibilities to ensure that when needed they have access to equitable mental health services, and to provide a thoughtful approach that facilitates access to such services.
- When a counselling approach is used with a person with learning disabilities, it should be afforded with respect. This means providing private space to talk, as well as consistent and predictable boundaries around what is said.

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