Part 4

Learning and disability
This has not been an easy chapter to write, because we cannot generalise about disabilities, nor about their effects on people, and we certainly cannot generalise about the way that people who have disabilities learn.

In fact, as Lynne emphasises later in this chapter, uniqueness is a central feature of having a disability. It may also be why people who do not have a disability frequently have problems responding to disability appropriately; we are scared of difference. We often just do not know how to relate to people with disabilities, and that includes those responsible for providing them with what they need in order to be able to learn to the best of their ability.

We need to let go of our assumptions about the cohesion of the grouping of disabled people and open out a much richer range of explanatory possibilities. This means looking seriously at the diverse, discrete and interconnected worlds of unique individuals (Corker, 2000).

**Types of impairment**

People may be impaired in a number of areas. They may have one or more senses working in a way that is limited, or not at all. They may have been impaired since birth, or have acquired impairment later. They may have part of their physical body that is different, and that may work poorly, or not at all.

**Sensory impairments.**

People may have been born without sight, hearing, a sense of touch or sensation, taste or smell, or their sensory impairment may be partial. Others will start off with their senses working, but lose sensory ability later. I lost two of my senses 20 years ago, in an accident. One problem for people with sensory impairments is that they are not usually obvious at first, and the process of revealing their disability can cause, at least, embarrassment and, at best, some hilarious situations; ask any group of blind and partially sighted people (Shepherd, 2001). Robert describes below his experience of learning as a deaf person.

Robert: I am a 50-year-old male and was born with a moderate–severe bilateral sensorineural hearing loss. I was lucky in being born to a mother who had two previous babies with normal hearing. She knew what was usual in terms of babies’ responses to noises around them and additionally was not the sort of person to allow her concerns to be ‘fobbed off’.
The effect of these two factors was that my hearing loss was picked up and diagnosed very early [3 months] and I was later referred to the Royal National Throat, Nose and Ear Hospital in London and was fitted with hearing aids at the age of 3 years. I have been a patient of this hospital ever since. My good fortune extended to being a member of a family that spoke audibly and clearly and my parents ensured that they spoke to me and read to me a lot. I benefitted by developing tone-normal speech and good communication abilities, and this includes some skill in lip reading. I feel lucky when I meet others with similar degrees and types of loss who have developed ‘flat’ sounding speech.

My hearing loss means that, without aids, I can only communicate with people I know well and whom I can trust to make allowances to accommodate my disability.

Engaging with others in a hearing world often means my having to make repeated requests to remove hands from mouths; to face me when speaking; to not whisper in my ear in noisy places – I then lose the ability even to lip read and to repeat things.

Dealing with all of the above requires a degree of ego strength and confidence, something I have only developed and learnt in my later life. As a child, struggling with these difficulties in school was at best tolerable.

With the benefit of experience I believe that I would have benefitted had the normal class teachers had greater awareness of the issues. Class teacher support in ensuring that I could hear what they were saying, had understood what I’d been asked to do and was not being expected to be able to cope unaided with exercises that required the ability to hear well would have been helpful.

In later years my hearing has proved less of an issue: I have learned ways of managing the responses of people towards me; generally others have a greater awareness and tolerance of disability.

I have worked in several blue-chip organisations, including at senior level.

**Physical disabilities**

People may be born with some parts of their body underdeveloped, or partially developed. Or, they may have some part or parts that have developed differently to other people, or indeed different to another part of themselves, as in people with one leg that is like other people’s and one that is not. Or, they may start off life with their bodies like those of others, but have a disease or an accident that changes their body. Or, they may have part removed in an accident or surgery.

Parents may have to make early, agonising decisions about the removal of a malformed limb, in order to maximise their child’s future learning and success. My friend has no leg below one knee. Her parents agreed to its removal, because it would have been impossible to fit a prosthetic lower leg to the distorted one. She is grateful; she was able to learn to run and be physically skilful, and was sports captain at her school. She knows people who have a grossly malformed limb still in place, which impairs their mobility and is always visible.

People may have different neurocognitive development, which may impair learning (Dennis *et al*., 2006), or may develop different learning strategies (Duff and Gordon, 2003; Edelstein, 2004).

We see from Lynne’s account, below, how having a serious physical impairment affects most aspects of learning.

Lynne: I am 62 years old and work as a counsellor, psychotherapist, trainer and supervisor. Before that, I taught English for a number of years in the secondary and FE sectors. I have also worked as a professional actress.

I was born without legs, with a dislocated right hip, a finger missing on each hand and with malformation of both elbows, so that the left elbow does not flex at all, and the right only partially. I walk with prosthetic legs, which, as I often say as an ice-breaker, when meeting people for the first time, belong, officially, to the government. I have walked thus all my life: it is probably rather like walking on stilts. I have to pay attention all the time to keeping my balance, and I tend to keep my eyes on the
ground as I walk, in order to be aware of any obstacles, unevenness, etc., that could make me fall. This makes me seem unobservant to some people, since I can’t always pay attention to everything else that is going on around me. I would guess that, early on, this may have impacted on my ability to take in information, and my natural curiosity, but to what extent, I cannot say. Prosthetic limbs are heavy and I use a lot of energy up walking, therefore get tired quickly. Again, the extent to which running out of stamina has impacted upon my learning can only be guessed at. I have never used a wheelchair.

When people ask, as they do more often than might be considered polite, ‘What happened to you?’ I have no easy answer. I have no peer group. I am, as a specialist once told me, attempting to make it sound like a really good thing, entirely unique. There is no one else exactly like me in the world. I have never met or seen anyone else whose disabilities are exactly the same as my own. When, many years later, in therapy I was introduced to the idea that ‘we are all unique’, my struggle, and my learning, was to take on board that this can be a positive thing. In childhood I experienced it only as a negative. As the only one of my kind, I experienced a unique kind of loneliness. I had no one to learn from, or measure myself against, except the ‘normal’ children I mixed with. I learned that I needed to be strong, and use my brains, and that to get by I should look and act as ‘normal’ as possible.

At primary school and later at grammar school, I had to get on with it. No special adaptations or concessions were made for me. I climbed stairs to classrooms, joined in the class gym sessions as best I could, which I loved (health and safety probably wouldn’t allow it now!) and, where I couldn’t do things, such as netball, the schools attempted to find me worthy alternatives, such as being the umpire. I had no interest in games whatsoever and would sneak off with my cronies as soon as I could, to play the piano in the music room, or smoke a cigarette in the toilets.

Educationally, my parents made the right decision. I did well academically and passed the 11-plus, winning a scholarship to the local girls’ High School, a Girls’ Public Day School Trust school. I was able to go on to higher education, which made it possible for me eventually to take control of my working life and to work when, where, and at a pace that suited me.

In terms of my psychological and emotional development I had to learn how to protect myself against teasing and being stared at (my approach was to stare back hard, till they looked away) and, as the only one of my kind, to find ways of belonging. In class I ‘belonged’ with the ‘bright’ children, but in the playground I was often isolated and paralysingly shy. My schools were not equipped to help me with this. My solution at primary school was to be in control: I collected the little boys in my class together and told them I was their teacher and they had to do what I said. Curiously, some of them went along with this! Only as I grew older did I understand that there are other ways of belonging. Perhaps I only really got it about 16 years ago, when, as a trainee therapist arriving slightly late at a workshop to meet a new group of people, and experiencing that familiar lurch of anxiety in the stomach, I suddenly realised that I could just go in, include myself and nothing more. I was OK. A member of the human race. Unique. Like everyone else.

Learning and disability

People with impairments from birth have to learn what other people do and how they do it, and then endeavour to fit in to a world which was designed by people who do not have disabilities, do not know what it is like to have one and, in many cases, have to design things for the majority of people, who of course are not disabled.

People with sensory and physical impairments are on a continuum of cognitive ability from those with multiple disabilities, both physical and intellectual, to those who have a physical disability, but are geniuses, like Stephen Hawking. Some may have particular learning differences because they have an inherited syndrome that affects physical and intellectual development.
People with disabilities that develop later in life, or are acquired suddenly, as in an accident, do already know how to do things as a non-disabled person, but now have to learn how to do them as a person with a disability. Robert lip reads because he always had to. My grandmother, who became deafened in later life, had to learn it from scratch. I lost two senses when I was 42, and have had to learn how to do things using the other three.

I am constantly struck by the degree of motivation of people with disabilities to find creative solutions so that they can do things, and their tenacity in doing it. When I worked for SKILL, I worked with a man with no arms or legs who drove himself to work, got out of the car and went into the office, with no help from anyone.

What people with disabilities need, as unique individuals with unique challenges, is a physical and social environment that enables them to maximise their potential in their own way. People want to fulfil their potential; they just need a chance to do so.

Interactions

So, for people with disabilities, who are unique individuals, there are a number of factors that will work together to influence their learning:

- their sensory or physical impairment
- its severity
- the age of onset of the disability
- the person’s personality
- their intelligence
- how other people view their disability and relate to them about it
- the physical environment in which they live, learn, work and relate to others
- the culture in which they live
- the physical and practical aids and other assistance available to them
- whether or not they experience neglect, abuse or trauma.

Andrew’s story, below, illustrates this clearly.

Andrew: At the time of writing this, I am in my late forties, and my mobility and coordination are compromised by cerebral palsy. I work in the NHS as a counsellor in a Community Mental Health Team, which are now referred to as Recovery Teams. I am going to reflect on some aspects of my education, connecting them experientially with my physical disability.

Prior to going to school, I suppose my disability was not too apparent to me. I played alone, or with friends from my close neighbourhood. When I started school, things changed. In the light of teasing, name calling and other comments, my difference from the other children became apparent.

To begin with, I had to learn to hold two opposing messages alongside each other: the first being ‘You are different’, and the other, ‘You are the same as everyone else.’ My parents fought and succeeded for me to go to mainstream school; it was their belief this would give me the best life chances. Although, in that there was a denying of the true extent to which I was different. This was also played out at home, where my difficulties were rarely referred to and I was treated very much like my elder brother. Of course, I became drawn into this complicity, and things were rarely discussed, and to my recollection never on an emotional level. Also, I think my schools joined in the complicity. So, two parts of my personality started to pull against one another: one side being, ‘I am and want to be like everyone else’, and the other, ‘I want people to see how difficult this is.’

In secondary school, these aspects of my personality pulling against each other manifested in my venting my frustrations by a type of bullying, where I could be spiteful and hurtful towards my classmates, leaving
them in a position from which they felt unable to retaliate. I did not do badly academically. Again, as time went on difference became more apparent, not being able to take part in games, and feeling unattractive and awkward around girls.

As academic pressures became more intense in upper school, my slow and not-so-neat handwriting became an issue. The physical act of writing brought new frustrations. My concentration became poor, and any motivation I had to learn was greatly diminished. I would talk in classes and get in trouble. My teachers, I guess, were frustrated by me, and I experienced myself as misunderstood, and my underlying anger becoming more apparent. Consequently, the outcomes of my first set of exams were poor.

On leaving school, I went to Technical College for a year to study computer programming. In this focused, more mature environment I flourished and sailed through my City and Guilds, and earned a place at Polytechnic, where I gained a Higher National Diploma in Computer Studies. I went on to enjoy a fulfilling 17-year career in IT, which I left 10 years ago to develop a new career.

Influences on how people with disabilities learn

a) What we know from evolutionary biology

We can learn much from evolutionary biology when we look at how we have come to our current situation, where people with disabilities are internationally disadvantaged in terms of opportunities to learn. Evolutionary biology shows us that the development of our neocortex, our social brain, which we need for most of our learning, developed alongside the growth of our social groups.

It has also shown that, what humans perceive as attractive is pretty standard over the millennia and across cultures. What we like is symmetry, with a touch of asymmetry (Cyril Hoschl (2010) calls it a pinch of asymmetry). This also applies to music, where we like rhythm with a pinch of irregularity (Bidelman and Krishnan, 2009). Perfect symmetry is considered boring, and extreme distortion is a threat; it represents illness and disease and, at a biological level, species shun and avoid it. People with disabilities are frequently deprived of the socialisation they need, usually just because they are different. Social groups often exclude people who they see as different, which means that many people with disabilities don’t receive the social grooming and resulting sense of inclusion that is a fundamental need for all human beings, indeed all primates.

b) What we know from attachment theory

People with disabilities from birth are disadvantaged from the start. For normal brain development, they need physical and emotional responsiveness so that they can form secure attachments (Bowlby 1997: 1998), or they will just not develop a functional neocortex, and will lack a sense of self, sense of other people and an ability to relate fully. They will not, without a good attachment base, have the internal working model that will enable them to develop a theory of mind, reflective functioning and the sort of problem-solving ability that they will need to learn what they need.

We know that babies with sensory and physical impairments are likely to lack the attuned, rhythmic responsiveness required for a secure attachment. This may not only be from their primary caregivers, but if they have special help in special facilities, or operations, they may be retarded in their neurological development. Trauma as well as a lack of attuned responsiveness or actual neglect will all impede good neurological development (Schore, 2003).

Children who lack a secure attachment relationship are at greater risk for extreme dysregulation of affect in the face of trauma and the development of enduring symptoms (Sroufe, 2005). Conversely, the presence of a secure attachment relationship can buffer the adverse effects of disability related trauma and provide the safety and nurturing that allows the child to process any disturbing events and return to a sense of safety.
Secure attachment bonds serve as primary defences against disability-related psychopathology in both children and adults (Finkelhor and Browne, 1984). In children who have disabilities, the quality of the parental bond is probably the single most important determinant of ability to learn well (McFarlane, 1988).

Children form an internal working model of themselves and of the world around them through their experiences in primary attachment relationships. Self and world views are undermined by negative responses to their disability, for example, teasing and shaming, hostility and fear. Insecurely attached children lack protection in their most important relationships and, if exposed to trauma, their limited coping abilities are more likely to be completely overwhelmed by stress, and their learning capacity diminished. Coping alone, with few options or resources, disabled children may respond with hyperarousal or dissociation.

Since reciprocal, supportive interactions within secure attachment relationships appear to be the primary vehicle through which children learn to regulate internal state changes (Putnam, 2003), the negotiation of interpersonal safety needs to be the first focus of learning and teaching (van der Kolk, et al., 1996).

c) What we know from neuroscience

We now know that brain development continues after a child is born and that early experiences shape the development of the central nervous system and the child’s sense of self. This can be seriously impaired if the child experiences trauma, such as an operation, or the abuse and neglect that so many children with disabilities suffer on an international scale.

People who acquire their disabilities later may also have neurological disadvantages if their impairments are associated with emotional or physical trauma, such as an accident. Trauma means that the vagus nerve, or cranial nerve X contracts, which shuts down the neocortex. People may be thought to be intellectually impaired when this happens; what they need is attuned, respectful, person-centred help.

Children with disabilities are very vulnerable to abuse (Westcott and Jones, 1999), a fact known to many children’s charities (Horwath, 2001). Recent research has shown that as many as 80% of abused infants and children have disorganised/disoriented attachment patterns, including unpredictable alterations of approach and avoidance toward their mothers, as well as other conflict behaviours (Lyons-Ruth, 1991).

Early childhood trauma also contributes to adverse adult outcomes, including depression, post-traumatic stress disorder, substance abuse, health problems (probably related to increased stress and wear and tear on the immune system) and decreased occupational attainment (Harris, Putnam and Fairbank, 2004).

People with a disability are at increased risk of trauma (Westcott and Jones, 1999). As stated above, growing up with a disability can be related to psychological trauma. This in turn affects the ability to learn.

Disabled children and adults are often subject to bullying, mockery, and social isolation, as well as having frequent exposure to potentially traumatising physical examinations, medical procedures and operations (Kennedy and Kelly, 1992). Early trauma, particularly trauma at the hands of a caregiver, can markedly alter a child’s perception of self, trust in others and perception of the world (Terr, 1992). This can undermine learning thereafter.

Disabled children who are abused often come to believe that there is something inherently wrong with them, that they are at fault, unlovable, hateful, helpless and unworthy of protection and love. These feelings may create a victim state of body, mind and spirit that leaves the person vulnerable to subsequent trauma and revictimisation, and disadvantaged in terms of healthy learning (Westcott and Cross, 1996; Westcott and Jones, 1999).

The role of motivation

Motivation is the engine that drives learning, and support and encouragement is the lubricant. Robert said of his learning that discouragement is like adding sand. I am constantly in awe of people, often with quite
severe disabilities, who seem to steam on into learning situations, apparently flattening each obstacle to achievement as it arises. The Paralympics are a case in point. Judi describes her progress to competing for Great Britain despite her progressive disability.

Judi: One day, in 1957, a small 10-year-old girl sat reading her Pony Magazine, in the waiting room in the Department of Rheumatology, at The Hammersmith Postgraduate Hospital in London. Professor Bywaters, the expert in juvenile arthritis, approached her and her mother; peering over his spectacles, he shook his head and said gently that she would have to give up riding. I was that small girl and, from that moment, I learnt that you did not have to believe everything that a doctor told you.

On that day the diagnosis of acute juvenile ankylosing spondylitis (AS) was confirmed, which was to change my life.

At the age of 15, I was allowed to have a pony of my own, Kerry, whom I saved up for. My father was a Bank of England official and taught me so much and encouraged me all the way. So I embarked on my O-level year with a new pony, and my very competitive character emerged. I became a West Kent Pony Club member and, for the first year, all went well, but due to loss of hip movement, riding became more difficult. Peter Felgate, my Pony Club instructor, suggested that I tried a side saddle, at a time when most of them were relegated to the loft! I arrived at Pony Club camp having taken delivery of a side saddle, which arrived at the Bank and was brought down on the commuter train from the City by my father earlier in the week. By the end of the week my pony Kerry and I were invincible, and we won the end of camp event, storming around the cross country course. I had learnt to be a serious lateral thinker, aided by my father. If something stops you from doing something you want to do, never give up: there is always another way.

During my second A-level year I had another serious flare up of the AS and spent 12 months in hospital in Taplow.

During that year in hospital I became almost obsessional in exercising, walking further up the corridors on my crutches each day and taking myself out of the hospital in my wheelchair, so I could see normal people. Occasionally, I was allowed home for a weekend and, after the first, on my return, I was asked how the riding went. No-one had dared say I couldn’t, and I didn’t ask! My reply was, ‘Wonderful thanks!’ My parents had helped me up from my wheelchair onto the saddle.

In spite of my AS and the multiple hip surgery which ensued, I have had two wonderful sons, and when they became of an age to learn to ride, I was able to provide them with ponies, and to begin with I did ride out with them. When this became impossible, I remembered a comment of Peter Felgate’s that there was always driving. … Since having Shandy, the boys’ pony, broken to drive, my driving career took off. I have competed both at club level, National Horse Driving Trials, in Germany where we were posted with the Army, and many times for the British Para-Equestrian Driving team. As a result of my driving exploits and my attitude to my disease, I counsel patients from the rheumatology unit, now at Wexham Park Hospital, particularly those who are to have a Girdlestone procedure and who feel rather low at the prospect. I have learnt that, if you really want to do something, never give up, there is always a way.

I hope that I have been able to give something back to the community, and another way I do this is to run a driving group (Stella Hancock Driving Group) within the Riding for the Disabled Association as Chairman and an RDA whip, and hope I am able to show some of my disabled drivers that there is a sport in which I see only Ability, and not disability.

After 25 years walking on crutches, a wonderful surgeon has rebuilt my pelvis, reversed the Girdlestone, and reinstated a total hip replacement. The result is just one stick, and often without – truly a modern medical miracle.
Optimising learning for people with disabilities

Our understanding of human learning is enhanced by the studies of learning by people with disabilities. From the literature, we learn that certain aspects of teaching and learning assist people with disabilities to learn, although there will be enormous individual differences. I summarise these below:

- For people with a disability to achieve optimal learning, it is helpful if anything offered is intensive, individualised, and highly concrete.
- Periodic and ongoing long-term support will be helpful to maintain skills, and both the maintenance and generalisation of new learning will be helped by teaching in real-life settings, for example someone’s own home.
- All learners will need an environment in which distraction (physical and emotional) is kept to a minimum. Learning when there is no distraction results in better retention.
- The goals of any teaching need to be clearly specified and individualised. Information should be presented in small, discrete and concrete steps.
- People with previous negative learning experiences may have problems with sequencing, which affects their ability to organise themselves and to set up time and task sequences.
- Consistent routines need to be established and tasks need to be broken down into smaller subtasks. Visual material helps learning when used either as a way of presenting information or as prompts or cues, particularly where a person’s reading skills are limited.
- Learning will be hampered if different professionals say, do and teach different things or in different ways, particularly in the early stages of learning.
- Once information or new skills have been learned, they need to be maintained over time. This is particularly important in relation to practical skills.
- Professionals should provide a résumé of any new learning in a simply written document containing visual prompts.

In summary, information should be imparted simply (verbally and in writing) and in an individually paced manner. It is important to check that people have fully understood what is taught and that it is repeated and reinforced over time. When training in practical skills, it is helpful to model new skills to promote learning, as well as providing verbal instruction, and to ensure that there are opportunities to practise new skills in a variety of settings to promote generalisation.

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An apology

I have endeavoured to use as up-to-date language as possible, and to phrase things respectfully. I am aware, however, that people with disabilities have often experienced others as phrasing things insensitively, or in a way that shows disrespect. I may have made mistakes in this chapter, and in the way I put things. If I have, I did not mean to, and would be happy to hear from you about how I could have put things in a way you would find more acceptable.

Joanna Beazley Richards
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Learning, sensory impairment, physical disability