

Assessing Risks in the Lives of People with Intellectual Impairment

A Life Any Like Other?

Over the last 20 years there has been increasing attention given to the rights and needs of those people whose intellectual abilities are less than those of the average person. As noted in the introduction to this second edition, changes in government policies and new legislation have both tried to ensure that those who are less able than average, or otherwise impaired, have the same human rights and opportunities as the rest of society. In 2001, the UK government's 'Valuing People' White Paper looked at what needed to change in the way that services were provided in order to improve choice and freedom in the lives of the less able, while the *Human Rights Act* (1998) and the more recent *Mental Capacity Act* (2005) have both led to explicit statements about the legal and moral rights of those who are less able to have a life like everyone else.

The label given to these people varies across history, and throughout the world. In the United States, the term used most often in academic writing is 'intellectual impairment'. In the United Kingdom, they are usually called 'people with learning disabilities', or sometimes 'the learning disabled'. The terms used to describe this group of people are confusing, and often come to be used in ways that can sound insulting or belittling. Thus, the terms are changed from time to time, to try and overcome this problem, and to get away from the negative stereotypes that inevitably become associated with them. Those who were once called 'idiots', 'Mongols' and 'imbeciles' have

been transformed into ‘the mentally handicapped’ and later ‘people with learning disabilities’. These changes of name confuse not only the rest of society, but the people themselves. One person asked me, ‘How come I used to be mentally handicapped, and now I have a learning disability?’

To try and avoid these problems, I shall use the term ‘intellectual impairment’, or ‘intellectually impaired’, to describe the difficulties experienced by the group of people in whom I am interested. This is a term more favoured in the United States than in the United Kingdom, but it is perhaps the most accurate way of defining this group of people. Their difficulties mean that they are less able to deal with complex problems, and as a result, frequently need help to cope with everyday life. It also overcomes the problem that arises when the terms ‘learning disabilities’ and ‘learning difficulties’ are used interchangeably. ‘Learning difficulties’ should really be used only to describe specific learning problems, such as dyslexia, rather than a generalized impairment, but once again there is often confusion between these two.

Whatever we call them, there is no doubt that this group of people, who come into life less well equipped than most people, have been abused and ignored by the rest of society for many, many years. Even when not actively abused, they have often been locked up, prevented from living normal lives, prevented from having sexual partners or children, and been excluded from the job market.

However, over the last couple of decades, these people with intellectual impairments have begun to reclaim the lives they lost in the institutions, having choices, jobs, sex lives and even becoming parents – unthinkable until even quite recently. Slowly, perhaps far too slowly, the rest of the community is beginning to realize that the majority of people with intellectual impairment are not so different from everyone else, and need the same things in their lives that all of us do: work, leisure, partners, and a sense of being part of a social group. They want to feel useful and valued, as we all do.

Sadly, this new freedom is not yet available to everyone with intellectual impairment. Because of their very real difficulties in coping with everyday life, some of them still have to rely heavily on others to help them live what we would call a normal life. For some, this reliance is almost complete. This means that their choices often remain limited because they not only need help with everyday activities but also to make the choices and decisions that we all make as part of a normal life. Nevertheless, we should still be trying to ensure that all those with intellectual impairment are able to have as much of

a normal life as possible. But what is a 'normal' life? In the words of the Report by the Joint Committee on Human Rights, it is 'a life like any other?'

Most of us live in a place we choose, with people with whom we choose to share our lives. We have a job, and we spend our leisure as we please. Of course, very few of us have the amount of choice in these matters that we would ideally like to have. Jobs may be hard to come by. The standard of housing and money available may be less than we want, and relationships do not always work out as we would like. However, few of us would let someone else choose our housemates, or our job, even if these are less than ideal.

At a simpler level, we can usually have some choice over what we eat, or what we wear. We can eat what we want, usually when we want. We choose our clothes and when to get dressed, even if others do not always approve of what we wear. We may have to get up at a time that is determined by the needs of a job, at least in the week, but at weekends we can usually get up when we like, and most of us can go to bed when we like. In our free time we can usually go out when we want, and with whom we want. If we want to go out and get drunk, we can do so, cash permitting. If we stay at home, we usually have some say in what we watch on TV, or indeed whether we watch it at all. If we feel like spending the evening in bed, or reading quietly alone, then most of us can do that, at least sometimes. We go shopping, and choose the things we want, again cash permitting! So an ordinary life, while it has some restrictions, generally includes a fair amount of choice.

Services for those with intellectual impairment have increasingly accepted that people in their care have a right to make choices and decisions, and structure their organization and the care it provides accordingly. Unfortunately, much of this choice depends on the availability of social service funding, and the type and quality of care staff available, so that many people with intellectual impairment still have considerably less choice than they should have.

In spite of these difficulties, there is an increasing awareness that those with intellectual impairment can make choices, and moreover, they want to do so. However, what we often fail to consider is the amount of risk that these choices carry. Most of us have grown up accustomed to risk-taking. Going to bed very late carries the risk that we are too tired to get up for work the next day. If we do that too often, we may lose our jobs. Going out drinking carries the risk that we may make ourselves ill by over-indulgence, or crash the car on the way home because our drunkenness makes it impossible to control it properly. Even crossing the road carries a significant risk.

Most of the time, we do not think about these risks. We calculate risk on our own behalf all the time, but because we do it so frequently it is rarely consciously considered. Generally, we tend to underestimate the level of risk, especially when activities are familiar. It is only when a risk is brought to our attention that we give it serious conscious thought. Research indicates that education about a particular risk often increases people's estimation of the likelihood of an undesirable consequence occurring, at least in the short term. Over the past 20 years or so, the risk of salmonella poisoning from eggs, the risk of contracting HIV from unprotected sex, and the risk of eating beef that may give us CJD, have all been drawn to our attention. Many of us are now aware of these particular risks, and because the media have emphasized them, we may therefore give these risks greater weight than they deserve. It has been said, for example, that the risk of developing CJD is several times less than the risk of being struck by lightning, but many people stopped eating beef, at least for a while, because of their fear of taking this risk.

We probably take the greatest risk in our lives every day that we step into a car, but few of us really consider that risk seriously. This is the other side of the coin; we tend to underestimate the risks involved in familiar activities. Life is full of risks. We all take risks all the time, and the more familiar they are, the less we tend to recognize the real level of risk involved. We are inclined to believe that 'it won't happen to me', even when the objective statistics suggest otherwise.

Moving into Community Settings – Benefits and Risks

As discussed above, the benefits of moving into community settings are many. For those who grew up in the old 'mental' hospitals, community living suddenly offered a whole new range of choices and benefits: new activities, new friends, the chance to work, and most importantly, the opportunity to make choices about these things. Even choice about the more mundane things, such as what to wear, what time to go to bed, and what to eat, can seem exciting, if the opportunity to make these choices is a new experience.

However, along with this freedom to make choices, have come the risks that we all share. If people choose to eat chocolate all the time, they will get fat, and become unhealthy because of the lack of a good diet. This may lead to serious illness in time. How far should choice go? When do we have a

duty of care to intervene because of the risks involved? Would we feel this responsibility to intervene if the person did not have a learning disability?

For those who have the responsibility of caring for people with intellectual impairment, there is a difficult tightrope to walk between allowing choice and associated risk-taking, and yet not forgetting the duty of care that such a role imposes. In law, those who take on a duty of care have a responsibility to protect those that they care for from harm, and they run the risk of being accused of negligence if they do not do so. Because of this, most carers tend to err on the side of caution.

Usually we assess our own personal risks in terms of gains. We tend to balance the short-term gains against the long-term gains, and then make a decision about whether the risk is worth it. Most of us do this automatically, and without much effort. We may not always make the 'best' decisions in terms of our long-term good, because for most of us, short-term gains are more powerful motivators than long-term ones: The pleasures of smoking may outweigh the long-term health risks of doing so. We may know that there are risks, but deny them by being selective about the information we read, or dismissing the research that identified these risks as faulty. We weigh our own experiences more heavily against such 'official' risks: 'My grandfather smoked all his life and he lived to be 95.' Or we may accept the risk as real but simply say to ourselves that the short-term pleasures are worth it. After all, it is not certain that we will get lung cancer if we smoke. It might happen, but it might not. Generally we like to believe it will not.

Where the long-term risk is greater or the consequences are more undesirable, then we may forego the short-term gain. Unprotected sex may not only lead to HIV infection (low risk) but also to pregnancy (high risk). Thus, most of us take some kind of contraceptive measures, but may not practice 'safe sex' in the recommended manner, even while recognizing that sex with a new partner might result in HIV infection. Some people, including those of normal ability, will happily take both risks, blithely assuming that they are somehow immune to the risks involved.

Those with intellectual impairment are subject to the same risks as all of us, but unfortunately they may also be subject to additional risks. They may be bullied or abused by those who have control over them, or by those who realize that they are vulnerable, and because of their disabilities they often find it very much more difficult to assess risk in the way that most of us do. While most of us do not assess risk very efficiently, we generally make some attempt to do so. It is a complex task, and most of the time we do it adequately but not very thoroughly. Those with intellectual impairment

also find this difficult, but may also fail to recognize any risk at all. Therefore, they have particular problems in coping with risky situations and decisions, either because they have not had the same learning opportunities as the rest of us, or because the task of assessing risk in relation to their own activities is too difficult for them, or both.

Choices and Responsibilities – Legal, Moral and Social

Every choice we make carries implications. Sometimes these implications involve a high risk, sometimes a negligible one. We learn these implications in a variety of ways. Often this is from our own experience. Sometimes it is from others, and sometimes from the media or from books. Many people with intellectual impairment have been denied the opportunities to learn from their own experiences. Either the experiences themselves have been unavailable or denied them, or they have been so over-protected that the chances to learn by experience have not been there. This makes it impossible for the person to make a real choice, because they do not know what the alternatives are, or the risks that each alternative carries.

It is important that when making choices about their lives, people with intellectual impairment have the opportunity to learn about the implications of their decisions. Legally, some choices carry a penalty. For example, if a person chooses to seek sexual satisfaction from children, they will come into conflict with the law. Some people with intellectual impairment lack information and understanding about how the law works, and may not appreciate that some behaviours can result in their being locked up.

In making decisions about life choices such as marriage, they need to understand, like the rest of us, that getting married carries legal as well as social responsibilities. It is important that someone with intellectual impairment, who is about to make a decision which carries a legal implication, is made aware of this, and understands exactly what that can mean for them.

A further legal complication is the responsibility that the law places on carers who have accepted a duty of care by accepting their job. This implies certain standards of care which can be seen as essential by a court, in cases where negligence is alleged. It is important that when choices are being made, that everyone – both the person themselves, and those involved in his/her care – have actively considered the likely gains and losses. There is a tendency to assume ‘risk’ always implies something negative. However,

sometimes taking a risk can have a positive result; gambling on the Lottery may mean you lose your money, but it may also mean that you win a fortune. This example also emphasizes the need to take into account the likelihood of any given outcome; losing is a great deal more likely than winning, in this particular case!

Where a decision results in significant losses for the person with intellectual impairment, carers may find themselves held responsible in law for these losses, especially if it is judged that the carers could readily have foreseen that such losses were likely. Although playing the Lottery may not arouse legal concerns unless a very large amount of money is involved, this issue can be particularly important, for example, in cases of those with intellectual impairment who may offend sexually. The consequent loss of freedom, which could result if the person is then legally detained, could be considered to be the fault of the carers who did not take appropriate steps to contain the offending behaviour. In such cases, it is clear that a decision by carers to allow as much freedom and choice as possible for their client may need tempering with caution, and often requires a careful balancing act between containing and enabling. It is worth bearing in mind that risk assessment needs to be a two-way process, including an assessment not only of risks to the person with intellectual impairment, but also any risks they may pose to others. Some people with intellectual impairment will have a very vague sense of what is socially acceptable, or considered to be morally wrong.

Moral aspects of decisions and choices may be more difficult to convey to some of those with intellectual impairment. However, when choices are made about both general social and sexual behaviour, it may be particularly important to ensure that the person concerned has some appreciation of what the moral, as well as the legal, implications of their choice are likely to be. Choosing to have sex with one's best friend's girlfriend may result in a number of unpleasant social repercussions, which are not directly to do with the nature of the sexual behaviour as such.

Similarly, the wider social implications of choices may not be apparent to the person with intellectual impairment, and it should be part of the responsibilities of care staff to make sure that those they care for have some awareness of these implications. For example, choosing to wear unusual clothing, or to have an unusual hairstyle, while not necessarily a problem in themselves, may make the person more vulnerable to teasing, rejection, bullying or other forms of abuse. Limited experiences can mean that many of those with intellectual impairment do not

understand these kinds of social rules, and the risks that making such choices may present.

Problems often arise because the choices that people with intellectual impairment make can embarrass others. Similarly, as above, the consequences of their choices may mean they embarrass themselves. Often they may not fully understand why their actions produced the result that they did, and as a consequence they become fearful of making further mistakes, and reluctant to take any chances. In these kinds of situation, care staff can help greatly by explaining afterwards, in simple terms, what went wrong and why. While this may not always solve the problem, sometimes it may help the person to make better choices next time.

Protection versus Choice

For most growing children, parents make decisions about risks that affect their child in the same way as they make decisions for themselves. Having considered the risks involved in an activity, they put limits around the freedom their children have accordingly. As normal children grow, parents are constantly assessing the abilities of their children to cope with increasing levels of freedom and independence. Most parents, therefore, would allow a child of 13 to have greater freedom and take greater risks that they would a child of 5. Throughout their children's lives, they take risks, and allow their children to take some limited risks. This is essential if the children are to gain the experiences which allow them to develop into normal adults.

As children develop, most parents relax rules, and allow the children more unsupervised activities and time away from them. This enables children to experiment, and learn from their own mistakes, which is an essential part of becoming an adult. Most normal children take greater risks when they are away from their parents, and usually conceal this from them. What did you do as a child, which you would never have dreamt of telling your parents about?

Most parents are aware that their children take risks, and generally they do not allow this to colour their decisions about what their children do to an unreasonable extent. We all know that the rate of teenage pregnancy is unacceptably high. However, the vast majority of us do not try to avoid that risk by locking up our teenage daughters. Instead we attempt to teach them about the risks they may run, and ensure they can deal with them appropriately, as far as possible.

People with intellectual impairment, even when they have grown up at home, are often over-protected because of their difficulties and consequently do not have these opportunities for experimentation and learning. Their development tends not to follow the usual pattern, for both biological and social reasons, and this may result in them being treated as overgrown children for an extended period of their lives, and being given little opportunity to act independently or learn from their own mistakes, even as adults. For those who grew up in institutions, their experiences and opportunities were even more limited, adding to their lack of ability to assess risk for themselves.

Sometimes choices are so complex, that people with intellectual impairment find it very difficult to understand what is involved, and this makes it impossible for them to make an informed choice. By 'informed choice' we mean that the person has assessed the likely implications and risks associated with the choice, and still decided to make that choice. This is where the whole issue of 'consent' for people with learning disabilities becomes so complicated.

For example, consider the difficulty of a woman with intellectual impairment making the decision to have a sexual relationship. Firstly, she has to understand what sex is, and what having sex with someone else involves at a physical level. She has to have some understanding of how sexual activity can lead to pregnancy, and she has therefore to understand what pregnancy is and how likely it is that she may become pregnant. Given this knowledge, she has to know whether she wishes to become pregnant or not, and to do this she has to have some idea of what being pregnant will mean to her, and what it will mean to actually have a child. This may relate to her ability to physically give birth, or to how well she can care for the child, as well as the emotional implications of being a parent. There is also the risk that if she proves to be unable to care for the child, it may be taken into care. In addition, having a child carries a number of legal and moral implications, as well as social and emotional ones.

If she is not to have the child, there are all the problems associated with making a decision about termination, including the likely physical, social and psychological repercussions of such a decision. Alternatively, she may decide to use contraception, and to do so she needs to know what is available, how it works, how to use it and what the medical risks associated with each kind may be. She may need to know that if she takes the 'morning after' pill this carries one set of risks, while the usual daily contraceptive pill carries other risks. If a physical barrier method is to be used for

contraception, she or her partner must be able to learn how to use it effectively, to remember to use it each time they have sex, and have the physical dexterity to do so.

If a decision to use contraception is made, then there are the moral considerations about sexual activity. Should people have sex outside marriage? What are the rules of her religion, if she has one? Is her partner's religion the same? What if one partner is already married, or already has a partner? How does the sexual relationship fit with other relationships? Where does 'love' come in the discussion? Is there any discussion, or has she simply been 'steam-rolled' into a sexual relationship by a demanding partner? Is this the beginning of a long-term partnership, or a one-off, purely sexual encounter?

Then come all the health risks. Being pregnant and giving birth carry risks to health, as do certain contraceptive methods. The risk of contracting some kind of sexually transmitted disease is moderately high, even though the more serious risks such as HIV infection may be still relatively low. It is still possible to die in childbirth, although thankfully it is now rare in the United Kingdom.

Ultimately, assuming that she has all this information available to her, and she can understand it, the woman then has to decide if all these risks are worth any pleasure she may gain from a sexual encounter. It is clear from all the above that making such a decision is a highly complex process, assuming that all of these things are adequately considered.

In fact, of course, what actually happens is probably that, given the chance, she has sex with the man to whom she is attracted without much consideration of all the above. She takes a risk. How many women of normal ability take such a risk in exactly the same way, often many times in their lives? How many of them assess carefully all the risks described above? Is it fair that we should expect a higher standard of decision making from those with intellectual impairment than we demand from the majority of other people?

Because these kinds of decisions are impossible to make for someone else, carers often take the simple way out, and avoid letting situations arise where those in their care have the opportunity to develop sexual relationships. If a person cannot make an 'informed choice', then perhaps it is easier not to offer them that choice. However, recent changes in legislation, namely the *Mental Capacity Act* (2005), have changed the law relating to such situations. The five principles which underpin the act are that:

1. Every adult has the right to make his or her own decisions, and must be assumed to have capacity to do so, unless it is proved otherwise.
2. People must be supported as much as possible to make a decision before anyone concludes that they cannot make their own decision.
3. People have the right to make what others might regard as unwise or eccentric decisions. Everyone has their own values, beliefs and preferences, which may not be the same as those of other people, but they cannot be assumed to lack capacity for that reason alone.
4. Anything that is done for, or on behalf of, a person who lacks mental capacity, must be done in their best interests.
5. Anything that is done for, or on behalf of, people without capacity, should be the least restrictive of their basic rights and freedoms.

This legislation has significant implications for those who work in community care situations. It is no longer acceptable or legal to prevent someone from making choices simply because it is easier to do so. If people are prevented from making choices there must be good reasons for this, and it must be clear that whatever actions are taken are in the best interests of the person concerned, and not just because it is easier for care staff or the organization.

The issue of sexual relationships is perhaps the most difficult and complex, but the problem of balancing risk and choice is a constant one for carers and professionals, in relation to many aspects of everyday life. In the background is the ogre of the law (and/or local management), ready to jump on the unwary, should they get it wrong! No wonder, perhaps, that many have been cautious about enabling such choices to be made. However, now the law is also likely to jump on those who *prevent* others from making choices. The nettle has got to be grasped.

Summary

There are many risks to be considered in everyday life which, as described earlier, we all take all the time. Because we have grown up with opportunities to make choices, take risks and weigh up the consequences, most of us give little thought to the process. A normal life is risky. Unfortunately, for many people with intellectual impairment, there have been many fewer opportunities to learn how to make choices, and in consequence many fewer opportunities to take risks and learn from their own mistakes. Parents and

carers see the vulnerability of someone with intellectual impairment and tend to consider the risks of everyday life as much higher than for someone without such a disability. In their fear of doing the wrong thing they deny the person the right to a truly 'normal life', which is, as for all of us, a risky one.

This book endeavours to look at the areas of life where risks are apparent, and to discuss to what extent these risks are real and significant. It aims to help you look at the lives of those in your care, whether personal or professional, and consider how you can use the process of risk assessment to enhance their lives, not restrict them. It will also look at the implications of the *Mental Capacity Act* (2005) and consider how mental capacity can be assessed.

'Drawing the line' between choice and risk is not easy, but this book endeavours to help you make a decision based on a real assessment of the likely costs and benefits of each choice taken. It will suggest ways in which you can involve all interested parties in a decision-making system, which can be clearly documented. If it is clear that a real attempt has been made to consider and document all possible outcomes, both negative and positive, and that a real consensus has been achieved about what is in the best interests of the person concerned, it is much less likely that carers or professionals will find themselves on the wrong side of the law. People with intellectual impairment have been denied a normal life for far too long. It is hoped that this book will enable those who care for them to move further towards redressing the balance, without putting those they care for in danger, or themselves at risk of prosecution.