

## Sexuality and Disability in an Institution of Care

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A young person is properly reckoned to have an increasing degree of autonomy in his or her sexual life. During the younger years, sexual contact with that person is reckoned to be exploitative unless there is a similar immaturity in the person with whom he or she is experimenting. We could call this a 'similar age proviso' and notice that it aims to recognise the lack of a power differential between the two parties and the fact that children or young people of a similar age are likely to negotiate a solution to an interpersonal situation in their own terms. I shall return to this later.

When an adult is involved in sexual contact with a young person it is usually reckoned to be abuse, no matter what the relationship between the adult and the young person. Until the age of sixteen it is appropriate to speak of abuse, although the similar age proviso might be a reason not to do so.

The responsibilities for supervision and protection of the vulnerable individual would normally be expected to be discharged by the parent of the individual concerned and so the identification of the person or body *in loco parentis* is important in discussing these issues.

We need finally to consider the peer-support-and-guidance that is an im-

portant part of most young people's upbringing. This support is provided either within the family or outside of it. There is no doubt that a confidential and intimate relationship of this kind forms a context in which the details and uncertainties of sexual relationships can be shared. Sexual relationships are often confusing on both sides and a heavy hand in such matters would seem to make many aspects of these relationships strained and stressful in a way that is not conducive to personal growth or the development of responsibility.

I will now attempt to apply these thoughts to the situation of institutional care by a responsible health and disability support provider.

First, we ought to recognise that a young person with an intellectual disability may have relatively few areas of their life in which they achieve genuine satisfactions and pleasing relationships. Sexual activity may be one area in which, for some particular disabled persons, genuine emotional satisfactions and pleasurable relationships can be built. It remains to balance these obvious positive experiential factors with the ethical safeguards that are needed to compensate for the dangers and uncertainties in this area of a young person's life.

### 1. Protection and Autonomy

We would normally expect parents to provide a certain amount of protection for children in sexual matters while those children were going through the extended process of developing their own autonomy. This is a difficult role, because we realise that a young person's autonomous sexual and reproductive choices may not be those of the parents, and yet we also realise that a 'sink or swim' *laissez faire* parental attitude is irresponsible. In the past we have, arguably, overemphasised parental responsibility and the right to control sexual behaviour in young people, but the arguments for this are not totally Victorian and authoritarian in content. There are, it seems, two good arguments for parental supervision and influence in the decisions made.

(i) The argument from *the vulnerability of the immature* depends on the commonsense fact that young people may put themselves in positions that they do not fully understand. This leads to the put-yourself-in-/ find-yourself-in problem, where the young person may have made certain choices but not fully realise the consequences of those choices or the difficult interpersonal situation they may be creating.

One of Donald Evans' first public engagements in Dunedin will be the delivery of his Inaugural Professorial Lecture on Friday 13 February 1998, as part of the Centre's 1998 Summer Seminar. It will be entitled 'Values in Medicine: What are we really doing to Patients?' Registration details for the Summer Seminar are available by contacting the Centre.

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This problem is pronounced when there is incompleteness of knowledge of the matters at stake in a particular choice or course of events. Where interpersonal knowledge is involved and the effects of one person's actions on other people are a crucial aspect of the situation, any young person, and particularly those who are intellectually disabled may find this quite perplexing.

This is aggravated by inexperience in that life-knowledge and life skills are both developed in relevant experiences and used to solve novel life problems. Obviously relatively naive young people lack the requisite skills and are likely to find themselves in situations where they do not feel comfortable but they do not know what to do.

The lack of relevant life skills is probably a more useful idea in relation to this topic than the idea of incompetence as it appears in the informed consent and psychiatric ethics literature. It is clear that if we were to think about competence then the relevant understanding of reproduction and the possible implications of sexual contact may not be understood by an intellectually disabled young person. That lack of knowledge would mean that they were unable to safeguard their own best interests in this area. That in itself means that a certain amount of parentalism is appropriate, but there are other considerations which tend to lead to the same conclusion.

A young person with intellectual disability often shows a degree of impulsivity commensurate with their general level of maturity (or immaturity). That means that they may put themselves in situations where they will later be unable to cope and where their interests will have been seriously compromised.

This can be worsened by an imbalance of power in which an older or more 'savvy' adviser is able to influence the decisions of a young intellectually disabled person. We shall deal with this in more detail under the topic of exploitation.

In any event it emerges that a young intellectually disabled person, while needing every encouragement to develop autonomy and the life skills that go into that, also needs some protection because of their inherent vulnerability in the face of sexual choices. This protection should

approximate that afforded by normal parental care.

(ii) The argument from *responsibility for consequences* is also important.

If an intellectually disabled young person conceives or develops a complication of sexual contact such as an STD then the need for careful interest-based action is enhanced. Challenges such as pregnancy, possible parenthood, and serious disease involve a person in a level of self-care that is not necessarily part of normal sexual encounters. Often the parents or host institution of a young person will have to bear the consequences of such a development. For the parent this may have a profound impact on their lives but an institution also has an interest in avoiding some of the more serious and costly effects of unwise choices. Thus there is a further good reason, based in the responsibility for dealing with the consequences, why certain safety net features should be in place to mitigate the effects of unwise sexual choices if such choices are going to be permitted.

Neither of these forms an argument for complete prohibition of sexual activity among intellectually disabled young people in an institution, but both are ethical considerations which suggest that responsibility does not end with the giving of permission for sexual activity to occur.

## 2. The similar age proviso

If an under-age person is involved sexually with a person who is fully adult we are suspicious that the imbalance in age and experience has disadvantaged the younger of the two. We therefore offer legal protection to those who are under age. We are prepared to countenance sexual activity in those who are under age when we are relatively sure that they are dealing with an equal, as the prospect of sexual contact between equals does not carry the same overtones of power imbalance and possible abuse.

However, if there are two parties who are relatively inexperienced and who lack life skills in dealing with their sexuality then that fact, in itself, compounds the put-yourself-in / find-yourself-in problem. Both parties have relatively little knowledge, relatively few life skills, and have to deal with impulsivity; and therefore both may

find themselves in a position they would not have chosen had they understood the implications of their actions. This argument tends to offset to some extent the liberalism with which we might otherwise regard more or less consenting sexual choices between intellectually handicapped people. However, again, we ought to note that it does not commend a blanket prohibition on sexual activity between them.

## 3. Exploitation

Exploitation trades on the imbalance of power and knowledge between the exploiter and the exploited. These imbalances are obvious in situations where caregivers or relatively empowered individuals misuse their position of trust and their superior knowledge and life skills for sexual advantages. The system of care ought to have the strongest safeguards in place to prevent such abuse.

However, there are less clear situations where an individual with more autonomy or capability is able to take advantage of a less well-equipped 'peer'. This can lead to disappointment and abuse, even though it is much harder to detect and guard against without being totally prohibitive of normal relations between disabled individuals. It calls for a sensitive quasi-parental role to be filled. It is also a good reason for encouraging support and education in sexual matters from one disabled person to another.

## 4. Peer support and guidance

A peer has a certain sensitivity to the knowledge and naivety of their fellows that a person differently placed cannot attain to the same extent. A person more or less at one's own level has an appreciation for the challenges of life that is inherently closer to one's own than a person who has not had that type of challenge to deal with. This is seen in families, for instance, when siblings will often share the details of their psycho-sexual lives at a level and in the kind of detail that they would never share them with their parents. The fact that people are disabled does not mean that this area of mutuality is completely closed to them. It may, in fact, mean that there is even more to be gained from encouraging it. For this reason same-sex companions or sibling-substitutes ought to be encouraged in instit-

utional settings where the subjectivity of sexuality and disability are going to be taken seriously.

The advantage of the same-sex 'buddy' is the relative equality of power and position between the two people in the relationship. It may be that some such relationships, because of the disabilities of those concerned, will just not function this way, but it seems to me that we ought to be alert to such possibilities and encourage them where feasible.

The other positive feature of such relationships would be the expected development of shared skills rather than control of one party by the other.

This approximates the normal adolescent situation in which same-sex friends do get together and discuss their emotional needs and experiences and their sexual needs, desires, and experiences in ways that are both empowering and supportive. The sharing of perspectives and the sharing of information would both seem to be important; neither would seem to be happily substituted for by non-disabled staff workers or counsellors, although a facilitatory role for such players may exist in some relationships or groups.

The crucial thing that this aspect of the topic should make us consider is the

need for all of us to have some context of intersubjectivity in which our own vulnerabilities, positionings, needs, hopes, concerns, and so on can be aired and shared.

To my mind these are the central axes from an ethical point of view, around which a sound policy in this area ought to be developed.

*The Otago Bioethics Report gratefully acknowledges the permission of AON Risk Services Group to reproduce this paper, which was presented at their workshop 'Between a Rock and a Hard Place' held at Wellington in May of this year.*

## Report

### Letter From Britain

Professor Alastair V Campbell

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I am writing this first of my letters from Britain on the morning of the announcement of the Scottish devolution result. Naturally, as a Scotsman, I feel delighted that there was such overwhelming support for a Scottish Parliament with tax varying powers. But beyond that nationalistic feeling, I have a more general reaction, which I know has been felt by many people in Britain since the General Election. The best way I can describe it is to say that there is a renewal of hope for the future of Britain. Since Labour came decisively to power in May, there has been a sense that things are genuinely going to change for the better – and quickly!

The revolutionary events surrounding the death and funeral of the Princess of Wales have served to re-enforce this sense of democracy renewed. The Prime Minister designated her the 'People's Princess' in a moving speech on the day of her death, and in the week that followed we saw the establishment yield dramatically to the ever-rising tide of public opinion about Diana's significance. For all the sentimentality and idealisation of that public mood, it is worth remembering that what she has come to symbolise is the return of a compassionate society, in which there is a reaching out to

the rejected, and honesty about the weakness of those who offer care to others. These are powerful symbols indeed, a renouncing of the idolisation of wealth and competitive success of the Thatcher era.

So what does all this mean for health care and bioethics in Britain? At a personal level, I have already shared in the energy of the new government. We have for the first time a Minister for Public Health, Tessa Jowell, and she moved quickly to deal with an emerging controversy over how surrogacy takes place in Britain. For some time there has been the feeling that the current arrangements, which allow surrogacy but without commercialisation or any payments apart from expenses, needs critical scrutiny. Matters came to a head when a surrogate mother went public with a claim that she had aborted her pregnancy because she was unhappy with the arrangements with the commissioning couple – a claim which she then confessed was untrue! The government response to the public dismay at these events was to set up a three-person review panel, which will report to Tessa Jowell as quickly as possible. The review team is chaired by Margaret Brazier, Professor of Law at Manchester University (many readers will know her valuable

textbook on law and medical ethics); the other members are myself and Susan Golombek, Professor of Psychology at the City University of London (her research includes work on the psychological effects of assisted human reproduction). Our terms of reference are to consider whether any payments to surrogate mothers should be allowed and, if so, how they are to be determined; and to consider whether more formal arrangements for the regulation of surrogacy are required. To carry out its task, the Review Panel has prepared a consultation document which will be sent out very widely and will be available to any person on request. Early next year we will know the outcome of this consultation and will begin to formulate advice for the Minister. Watch this space for the result! But for the present I want to point out the speed and effectiveness of the government response. This has been true across a whole range of issues – the feeling is of a youthful government wholly determined to see change for the better in British society.

Of course, some or most of this may be post-Election glow, soon to fade. Now that I am involved once more with the National Health Service, I am seeing all the problems so depress-

