

family

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Abstract

This article describes how parents frequently experience discussions with professionals about the sexuality of their adult children as a battle over control that they will eventually lose. Parents often feel that if they disagree with the practices of adult service systems, their son or daughter may well be excluded. The authors suggest that parents have a legitimate perspective which needs to be appreciated within the context of an inevitable power struggle with the service sector, and is a perspective which needs to be considered more seriously.

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Asking the right questions:

**PARENT AND PROFESSIONAL PERSPECTIVES
ON SEXUALITY**

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This is the second of a three-part article on "Sexuality and Culture in the Lives of People with Severe Disabilities". A bibliography will be included at the end of Part 111, which will appear in the May Newsletter.

This section will elaborate on the implications of the new cultural context for sexuality of people with developmental disabilities from the distinct perspectives of parents and professionals. To do that we will break away from our collective voice as joint authors, and speak from our separate perspectives directly. We intend to frame our discussion not in terms of a debate, but more as a dual focus that can illuminate different features of common themes. The professional perspective will respond to, and build upon, the comments made from the parent perspective.

Obviously, a complete treatment of any of the separate issues raised here would greatly exceed the scope of this article. However, the point of this section is to illustrate the importance that different perspectives must play in any complete discussion of the topic. It is our belief that in many cases the relationships between parents and professionals are damaged more from misunderstanding of each other's interpretation of what the issues are, than from disagreement about the actual resolution of the issue.

Issues From the Parent Perspective

We (Dianne and Phil) are parents of a 21 year old young man with multiple disabilities. Our son has always lived with us and, to the best of our knowledge, his sexual experiences have been extremely limited. We also suspect that his limited experiences have been unfulfilling, although it is difficult for us to say just how important expressions of sexuality are to him. As parents we would like to broaden this aspect of his life so that it is as fulfilling as possible given the physical and cognitive limitations with which he must struggle. To

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accomplish this, however, we too must struggle with a variety of issues not usually faced by parents of young adults. Parents of youth without disabilities have available to them a variety of strategies for influencing their children's sexual information and practices without challenging larger social taboos and mores.

When we were first invited to prepare this article, we were asked to focus our discussion on the perspective of parents on issues related to marriage, parenting and sterilisation. As we explored our own point of view on these and other issues of sexuality, we discovered that a parental perspective seemed difficult to express through these topics. Marriage, parenting and sterilisation are outcomes available to adults who enjoy the capacity and freedom to develop their own fulfilling sexual life. Instead, we find the issues more central to the concerns of parents of adults with the most severe disabilities to be those which deal with sexual stereotypes, power relationships within formal service systems, what counts as adult status in our society, and the implications of very real limitations in individual capacity.

Over the past 21 years whenever we have been faced with new and troubling experiences, we have sought information and advice from other parents, either directly or through the medium of parents' published narrative accounts. Our efforts in this instance have led us to identify two fundamental sets of issues which seem to capture the focus of concern for many parents.

What Gets Taught? By Whom?

Sometimes it seems to us that discussions about the sexuality of young adults with severe disabilities get hopelessly oblique. We give teachers permission to use a sexuality curriculum with our sons and daughters only to discover that most of the content focuses on identifying strangers, learning when to shake hands and when to hug, or how to talk about being angry with your friends. It is not that such social skills are irrelevant, or unimportant, but they also do not represent the content that we most need others to teach to our son. With a little guidance, we could probably teach him many of these things ourselves. However, we are still waiting to learn when and how someone will teach him to masturbate safely.

While others might have different specific issues, we believe many parents of individuals with the most severe disabilities struggle more with how to help them learn the mechanics of sexual expression than with some of the social rules which govern the use of those mechanics. Mechanics are not part of the curriculum most parents feel able to teach directly, but they are rarely addressed by the professionals to whom we have always turned for such assistance. The skills most critical to appropriate sexual expression for many young people with severe disabilities seem hidden behind a curriculum of social graces. While important, social grace is not sexual competence.

We realise that schools may not be the best context, or educators the best teachers of such mechanics. What concerns us more is how little any of us discuss it. When such instruction does occur, it seems to happen within a

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climate of illicitness rather than discretion. Perhaps the best illustration of the reluctance to deal directly with issues of mechanical competence is the imbalance in sexuality curricula between teaching when to say "no" as compared to "yes". The message seems to be that "sex ed" for students with severe disabilities primarily involves learning not to do it. While effective in minimising possible sexual exploitation, such an approach seems unlikely to us to be sexually fulfilling to many young people.

A second area of content that we find increasingly problematic involves the uncritical acceptance of dominant social/sexual norms, including a variety of gender stereotypes, in most attempts to teach sexuality. In our pursuit of normalisation, including access to images of sexuality on TV, music videos, advertising and movies, we must not forsake the obligation to also deal with issues of social judgement that go beyond deciding when to shake hands or when and where to practise good touching. Certainly parents provide an important source of instruction, in both their words and deeds. However, as our children move out and about in their communities, shifting away from an exclusive reliance on our support, that larger cultural judgement must be addressed in those contexts as well. All too often it seems to us that the efforts of the professionals, upon whom our young adults must also rely for support, fail to address these much more influential judgements about what remains a largely sexist society. Even parents who make a substantial effort to instil a different set of social standards in their children can watch their sons and daughters metamorphose into Macho Man and June Cleaver under the tutelage of professionally managed sexuality instruction.

Some professionals approach the need to teach young people with disabilities about sexuality with great reluctance. Some of this emerges, we expect, from their quite understandable discomfort with such a sensitive and personal topic. Few of us are free of such discomfort in at least some social arenas, and even fewer of us ever find ourselves attempting formally to teach others about sex and sexual expression. However, parents often hear professionals explain their involvement in sexuality instruction as necessitated by parents' unwillingness to teach. While such an accusation may be generally true, we are suggesting that in the case of young people with the most severe disabilities, *what* students need to learn cannot be taught by parents, or at least cannot be taught by them alone. At the same time, those areas of content professionals seem to find most comfortable to teach are the very topics families might appropriately be able to manage. If we are ever going to be able to effectively share responsibility with professionals, we must more directly discuss such issues of curricular content.

Control Versus Choice

If discussions about sexuality and young people with severe disabilities are sometimes hopelessly oblique, the rest of the time they seem adversarial. On the one hand parents feel criticised for not taking more responsibility for teaching their young adult about sexuality. On the other, they hear objections to their involvement: "Why should you have any say at all about whether or not this adult, who happens to be your son or daughter, participates in some

sexual activity?" Such an objection probably calls to the minds of both professionals and parents struggles with their own parents over emerging sexual identity. As a consequence, parents may too often be encouraged to repeat the limited parental involvement that they experienced as children. Our cultural norms tend to favour not just the professional's right to raise the objection, but the parents' "duty" to respond compliantly.

We think it is equally valid to ask of professionals, "What makes you think *you* have the right to be involved in my adult child's sexual choices and experiences?" The response for both parents and professionals is "Only that necessitated by the limits of this adult's ability and opportunity." Both parents and professionals, by virtue of the fact that the relationships we have with this adult are necessarily more substantive in their support, have more involvement in the details of the sexual life of adults with severe disabilities than is typical even for friends and family of persons without disabilities. Choices for many persons with the most severe disabilities must often be made by someone else. The challenge for those who support such choices, to be honest, must as much as possible reflect what we believe the choice of the person might be even when - perhaps especially when - our own choice might be different. Parents have a history of providing this and other types of intimate support that have few analogies in the lives of non-disabled persons. It makes the sharing of that role with professionals without such a history of experience much more difficult.

It would be easy for us to say that the issue of parent involvement in the sexual lives of their adult children is not so much about sexuality as it is about issues of control, independence, and supported choice. But of course it is also about sexuality. Sexuality is such a powerful part of human experience that it provides its own unique urgency of feeling. All of the cultural taboos, religious and moral customs, and social norms so deeply embedded in our culture mean that any topic related to sexuality will gain its own special complexity in a society that cannot make up its mind whether sex is good or bad.

Nevertheless, parents frequently experience discussions with professionals about the sexuality of their adult children as a battle over control that they will eventually lose. The reality of a future when we will not be available to participate in our child's life encourages us to insist on involvement while it is still possible. Of course we are not suggesting that parents do not make bad choices or have unfortunate opinions about the sexuality of their sons and daughters. Still, two additional points can also be made.

First, it is just as true that some professionals can make bad choices, have unfortunate opinions, or support restrictive practices. Parents who wish to support their disabled adult to develop a capacity for fulfilling sexual expression can sometimes face a service system that groups according to gender, regiments activity schedules, and actively discourages any sexual expression, even to the point of using chemical and hormonal restraints. In some situations, for example, the use of birth control pills might be advocated as much to reduce sexual behaviours, or minimise the inconvenience of menses, as to protect young women against pregnancy, when their living

situations and activity patterns only rarely place them in situations where they might develop a sexual relationship with a man.

Second, regardless of which "side" might be viewed as more progressive in any particular situation, the balance of power resides with the service system. Whether progressive or restrictive, professionals often seem to want parent participation as long as the parent agrees with them. This seems to be true of both schools and adult services, despite the fact that educational entitlements invest the parent/school relationship with at least an equality of access to the conversation. No matter how much we disagree with them, the schools cannot tell us simply to go elsewhere. In the face of the adult service system's scarce resources, however, parents more often feel compelled into either silent acquiescence or mumbled opposition. The penalty of participation is the risk of exclusion. For example, we have met and talked with parents who have been willing to make enormous sacrifices in the quality of their family life to keep their adult son or daughter at home. Professionals sometimes view such situations as unfortunate examples of overprotectiveness. Parents view the same set of choices as unavoidably necessary to maintaining their family values - as a forced sacrifice because they refuse to pay the penalty of participation in a system that will not acknowledge their perspective.

As we have pointed out, we are not saying that there aren't parents who are unduly restrictive or who want to pass on their own unfortunate biases and prejudices about sexuality to their children. We also realise that adults with severe disabilities possess many fewer alternatives for resisting their parents' bad ideas. We are simply arguing that parents have a legitimate perspective that needs to be appreciated as occurring within the context of an inevitable power struggle with the service sector.

In this section we have shared our own point of view about issues that are raised for us about our son's sexuality. However, our purpose has not been to describe a "typical" parent perspective on the issues related to the sexuality of their children. We are not attempting to represent our particular point of view as that of most parents. We are, however, suggesting that most parents do have a valuable point of view. Indeed, perhaps the most critical issue from the parent perspective is that such a perspective does exist and needs to be considered more seriously.