meeting the socio-sexual needs of severely impaired adults

A Scandinavian experience

Why does the sexuality of the retarded and impaired make us uncomfortable?
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A Scandinavian experience

In the spring of 1969, I visited Denmark and Sweden. I had very much looked forward to this visit as an opportunity to become better acquainted with these countries, to study their mental retardation service systems, and to commune with leading thinkers in the field, such as Bank-Mikkelsen, Grunewald, and Nirje, to all of whom we owe so much.

Some of the things I learned on this study tour are documented elsewhere in this book. In this chapter, I want to discuss a topic we often associate with Scandinavia with a good deal of awe, indignation, and/or merriment: sex. To be specific: sex for impaired and retarded individuals, and even those who are severely impaired or severely retarded.

It is generally well-known that in Denmark and Sweden, unmarried couples who are fond of each other readily engage in sexual relations. They will not make a secret of this fact, and everybody takes the practice for granted. While in many cases, these relationships eventuate in marriage, in that culture, sexual relationships between unmarried consenting adults who are attracted to each other is culturally normative behavior. It may come as a surprise to us to learn that sexual permissiveness prior to marriage is accompanied— at least in Sweden— by relatively strict standards in regard to marital conduct, and by a divorce rate that is only about half our own.

However, knowledge of what some have called the ‘dedramatization of sex’ did not prepare me for the Scandinavian attitudes I encountered regarding the sexuality of the retarded. Early during my trip, in Copenhagen, I visited one of the finest hostels for mildly to moderately retarded young adult women that I have ever seen. There I learned that as the 14 residents in this hostel are socialized into the culture and into adulthood, they are also socialized into ‘normal’ i.e. culturally normative, sexual patterns.

For instance, as these young women learn to date and relate to male peers, they may become very attached to a young man; in time, the young couple may decide to have sexual relations, and the girl may ask the housemother for contraceptive guidance. The housemother sees it that the girl will be counselled, and if her intent is confirmed, she may be given a choice such as between the pill, an intrauterine device, or voluntary sterilization. In time, she may go to live with the young man, and the national mental retardation service system may provide the couple with an apartment. Eventually, she may marry. The woman might not have children, but the fact that she is married, or lives with a man, or engages in a socio-sexual relationship, does

For helpful criticisms, I am especially indebted to Gunnar and Rosemary Dybwad, Karl Grunewald, and Robert Perske.

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not faze the retardation service system, which continues to provide services
to her. In other words, where a Canadian or American housemother might
admonish one of her date-bound retarded girls to ‘be good’, the Scandi-
vavian housemother is more apt to remind her to ‘be safe’, to know her own
mind, and to make her decisions strong ones.

In an institution in Sweden, the canteen sold girlie magazines on the
rationale that the magazines were available on every community newsstand,
and if one did not accustom institution residents to this phenomenon, they
would then react maladaptively during later community habilitation. In some
hostels, men residents were not discouraged from posting provocative pin-up
pictures, because it was felt better that this be out in the open, supervised,
and worked through rather than hidden. In some institutions, resident couples
were permitted to live together, and perhaps even furnished with their own
small apartments. In time, such couples might be permitted to marry.

I freely admit that these discoveries (in early 1969), as well as the matter-
of-fact way in which they were viewed and communicated to me, shook me
up. But aside from my personal moralistic attitudes (call them hang-ups if
you wish), I could see a logic and consistency in this approach.

Many people have stereotyped misconceptions about sex in Scandinavia,
and may dismiss Scandinavian management of sexuality of the retarded as
merely reflecting poor moral standards. This would be missing some very
important points. Firstly, Scandinavian sexual practices are perhaps differ-
ent than ours, but there is probably less difference in what is done than in
what is said, claimed, admitted, and pretended. Secondly, the management
of sexuality in the retarded reflects not merely cultural attitudes toward sex,
but is part of a much more comprehensive human management system that
subscribes to the ideology of normalization, and in which normalizing sex
management is only a minor aspect.

Especially this last fact has crucial implications for the management of the
severely impaired, since normalization ideology prescribes that culturally
normative means be employed in order to enable a person to emit culturally
normative behavior. This applies not only to sex, but to innumerable other
aspects of living. Most of these other aspects do not have overtones of moral
controversy to us, although some may stir up controversy on historical and
programmatic grounds, as has the issue of normalized residences versus
traditional institutions. But there may be aspects which are nearly as con-
troversial to us as sex. An example here is alcohol consumption by the
retarded, which the Scandinavians are also handling in a way which, to
them, has become largely noncontroversial because of their acceptance of
the normalization principle.

In most of Europe, drinking, per se, is not attached with the many con-
flictful symbolisms of our Puritan past. Therefore, no one thought much of
it when a mental retardation service system in Uppsala, Sweden, operated a
bar in order to initiate retarded adults to drinking in socially accepted ways

2 Surprisingly, however, drunkenness is much less sanctioned in Scandinavia than in
North America, and a number of indices of alcoholism suggest lower rates for Scandi-
vavian countries than for the United States. A manifestation of this difference in
sanction is found in drunk-driving laws. These laws are extremely strict in Sweden, as
in many European countries, while in North America, they are not only lax, but it is
even difficult to obtain a jury conviction when the evidence is overwhelming.
and manageable quantities. The rationale is nearly unassailable: either you teach the retarded adaptive ways of using alcohol, or many of these men and women who will live partially or fully on their own in society will come in contact with alcohol in maladaptive and potentially disastrous ways.3

To return now to sex, it is clear that to the Scandinavians, the normalization principle very logically dictates that steps should be taken to make available to the handicapped – as much as possible – those sexual and socio-sexual privileges and benefits which are considered normative in the general culture. Since regular Danes and Swedes are relatively free in regard to sex, and since the principle of normalization is universally accepted, their attitude to normative sex practices by the handicapped is: ‘So what is the problem?’

**Why does the sexuality of the retarded and impaired make us uncomfortable?**

Why did this shock me? Why would so many of my fellow North Americans have been shocked – at least in 1969? I suspect that aside from a general cultural Puritanism, there are many and varied reasons, but that among these, five are prominent.

The first two reasons imply a historical but now invalid perception of the equivalence of sex and procreation. Thus, reason No. 1 is that many of the impaired should not engage in sex because this might result in impaired offspring. Reason No. 2 concerns the more severely impaired specifically, and implies that they would be inadequate parents.

Reasons three to five concern primarily severely and multiply handicapped persons, and/or severely retarded ones. Thus, reason No. 3 is that such individuals are not fully human, and though perhaps capable of mating like animals, they cannot ‘marry’. The fourth reason is similar, in rejecting any socio-sexual or marriage relationship other than one we can imagine for ourselves. The fifth reason is largely religious, in questioning whether severely retarded and other severely impaired individuals can meet certain marriage criteria which have their origins largely in theological considerations. These five reasons will be elaborated below.

**EUGENIC TRADITIONS**

Ever since the ‘alarmist period’ and the ‘genetic scare’ (*circa* 1890-1920), there has prevailed a general attitude in this country that it would be better if retarded (and certain other deviant) persons did not procreate. During the eugenic alarm period itself, the major rationale for this view was that the deviant would beget the deviant – and perhaps do so in large numbers, out-breeding the rest of the population. Today, a major rationale is that the retarded and other limited persons could adjust better if they do not have to raise children; that they would make inadequate parents; and/or that their children – though perhaps endowed with good developmental potential – would be socialized into mental retardation, poverty, *etc.*

During the alarmist period, wholesale and involuntary sterilization of deviant groups (especially the retarded, epileptic, and legal offenders) was widely advocated, but was only selectively implemented because broad strata of the population had social, political, moral, and religious objections to this measure. However, the idea that many such persons should live a life

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3 I am told that the training bar has been discontinued, and that training now takes place in regular, integrated bars.
of celibacy and chastity was readily accepted. As has been documented else-
where (Wolfensberger, 1969b), most of our residential institutions for the
retarded owe their location, isolation, size, and design to attempts to impose
celibacy upon the residents by segregating them from the community and
from members of the opposite sex.

We now need to reflect upon the fact that while segregation was accepted,
and sterilization rejected, the alternative of contraception was for a long time
not available or feasible, and after it became available and feasible, it was
long impractical for the retarded. Also, until very recently, it was morally
unacceptable to almost as many persons as once was sterilization.

Today, however, we are undergoing three revolutions: one has to do with
the methods of contraception; the second with attitudes toward it and toward
sexuality generally; and the third involves a reassessment of the institution
of marriage itself. The time has come to examine the relevance of these
revolutions, taking place in the mainstream of our culture, as they relate to
the sexual needs of deviant subgroups within this culture, such as the
mentally retarded.

FEAR OF INADEQUATE PARENTHOOD
In regard to the mildly retarded, it is known and generally accepted that
many or most of them will marry; that they will have children; and that they
will be much less successful parents than most citizens, but also much better
parents than had once been thought. To a degree, their adjustment will de-
pend on the services they receive, and on the number of children they have.
In regard to the latter, it appears that many of the married mildly retarded
increasingly follow the pattern of the general population in adopting con-
traceptive methods, and in using them effectively.

It is also widely accepted that in regard to socio-sexual practice, such as
premarital and extramarital sexual relationships, divorce, and remarriage,
the mildly retarded can be expected to do approximately the same things
which are typical and/or legal in the mainstream culture – even if these
typical and legal practices may not always be considered moral or desirable.

Thus, while there is appreciable cultural acceptance of normative socio-
sexual behavior in the mildly retarded person, most of us still experience
unease or outright disapproval at the thought of more severely impaired
persons becoming married, or worse, engaging in extramarital sexual
activity. These feelings of ours are probably derived from a chain of con-
scious or unconscious thinking that goes somewhat like this: the more
severely impaired will not be suitable parents; if they cannot be suitable
parents, they should not get married; if they are not married, they should
not engage in sexual relations; ergo, the severely impaired should lead lives
of chastity and celibacy. Yet, we must now ask the question: if the more
severely impaired are willing to practise contraception, and if this contra-
ception can be made effective, can we continue to deny them the privilege
and benefits of those socio-sexual relationships and arrangements available
to other citizens?

Obviously, a heterosexual relationship unencumbered by childbearing and
child rearing is apt to bestow many advantages upon an impaired person.
Not only are urgent and near-universal bio-sexual needs fulfilled, but very
important affectional, social, and socio-sexual needs as well. This point is so
self-evident that it scarcely requires discussion. But what does require discussion is our reluctance to enable the more severely impaired to enjoy these benefits.

In this context, one thing in particular disturbs me about our attitude toward sexuality in severely impaired persons. In effect, what we have been saying is: 'You are not capable of rearing children, and therefore you should control your sex impulses.' As long as our society offered considerable cultural support for celibacy, this may have been a tenable view. Today, when it is almost impossible to escape the cultural demands for and encouragements of sexuality, this view has lost its validity. If even priests and bishops, nuns and monks can no longer bear celibacy for the sake of God and Church, can we ask the weaker members of our society to remain celibate?

PERCEPTIONS OF THE RETARDED AS NONHUMAN

Earlier, I referred to the history of mental retardation, and how it predisposed toward an attitude of rejection of marriage for the retarded via an attitude of rejection of reproduction by the retarded. Closely related and very relevant is another historical view, namely, that of the retarded as nonhuman. In two other chapters in this book, I have attempted to document that this view is widely prevalent (although it is often held without explicit awareness), and that it may find expression in subtle and indirect ways. One such subtle expression may involve opposition to marriage for the retarded. After all, while animals mate to reproduce, they do not marry in the human sense; therefore, the (nonhuman) retarded should not or cannot marry, either.

EGOCENTRIC CONCEPTS OF SOCIO-SEXUAL RELATIONSHIPS AND MARRIAGE

Aside from the historical reasons mentioned, the idea of socio-sexual and marriage relationships for the more severely impaired may be rejected by the nonimpaired because such relationships might be different from the type that they can picture for themselves. True, love and sex involving severely and/or multiply handicapped persons may be quite different than it would be for the nonimpaired; but then, this does not mean that important and very human functions would not be served.

I am here reminded of the now almost classical description by Mac-Andew and Edgerton (1966) of the symbiotic friendship between two men, one of whom was moderately retarded and blind, and the other one severely retarded, epileptic, partially paralyzed, and nearly speechless. Here, between these two very impaired and grossly deviant persons, a touching long-term and very symbiotic and functional relationship developed which, if it had involved a man and a woman instead of two men, would have had many of the features of a marriage.

Thus, we must strive to become aware of our prejudices and our "normatimorphic" interpretations of the world. Perhaps there can be socio-sexual

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4 A neologism, analogous to 'anthropomorphic', and referring to a tendency to perceive only that as correct, proper, and true which is statistically normative in a society at a given time. Here, we must be careful in our interpretation of the principle of normalization. This principle encourages normative behavior and argues that what is normatively accessible to members of a culture should be accessible to a culture's deviant members. However, the principle of normalization does not imply a judgment that those things which are culturally normative are also moral, true, correct, etc.
relationships and marriages quite different from the ones most persons would choose to engage in, and we must extend tolerance to relationships that we cannot even imagine for ourselves.

RELIGIOUS-THEOLOGICAL OBJECTIONS

Obviously, a fifth major reason for reluctance to support the idea of marriage for many of the severely impaired has its origins in religious-theological grounds. Here, it is even possible that by habit, some people will hold on to religiously-founded objections while no longer identifying themselves with the religion that once inspired these objections.

The issue of contraception is likely to disappear very soon as a major stumbling block here, but the one regarding a person’s physical capacity for sexual relations, or of his intellectual understanding of marriage or of a marriage-type relationship remains. Thus, it may be argued that a severely retarded person cannot give an intelligent, meaningful consent to a marriage-type contract, and therefore a union between two such persons would be ‘mere’ (and normally illicit) cohabitation.

However, moral-religious-ethical views such as these are undergoing change. A very relevant parallel is the Catholic attitude toward the sacrament of communion. This sacrament is supposed to be administered only to those capable of appropriate understanding, and at one time, it was denied to young children and even to the retarded. Today, it is administered to very young children, and even to severely retarded youngsters. In other words, there has been a change in the interpretation of what appropriate understanding is, and/or who is capable of such understanding. We are all familiar with other recent changes in religious views, in theological interpretations, and in traditional practices in our major faiths. Further changes are almost certainly in the offing.

In regard to the specific charge that unions between severely retarded persons would be mere cohabitation, it may be sobering to recall that we legally sanction many unions which are no more than serial cohabitations – as long as the partners are not retarded!

Also, we must distinguish between religious objections on the one hand, and socio-legal issues on the other. There are many things a religious system may command from or deny to its adherents, and there may not always be a state of harmony between what religion commands or proscribes, and what secular law sanctions or forbids. A religious command may call for behavior forbidden by secular law which, in turn, may demand behavior forbidden by religion. Thus, certain culturally normative and legally sanctioned sexual behaviors may well be contrary to the moral-religious precepts of private individuals; but in a secular and pluralistic democracy such as ours, we must practise our moral-religious beliefs in such a fashion as to let others act in accordance with their own precepts – as long as these are harmonious with secular law.

In consequence, from a socio-political viewpoint, it would be wrong to let private moral-religious views about the legitimacy of marital unions of the severely impaired stand in the way of providing a retarded adult with access to socio-sexual privileges that are accessible by law and custom to other citizens. Article 1 of the recently promulgated Declaration of General and Special Rights of the Mentally Retarded (International League of Societies
for the Mentally Handicapped, 1969) states: 'The mentally retarded person has the same basic rights as other citizens of the same country and same age.' The Declaration is reprinted in the 1969 President’s Committee Report, which adds: ‘The retarded are due the same inalienable rights to life, protection of the laws, dignity of person and opportunity as all other Americans’ (p. 27). One would think that these rights would include the opportunity for socio-sexual fulfillment.

A new orientation, and its implications

What does all this mean in terms of specific management implications in mental retardation, cerebral palsy, etc., and in regard to the implementation of the normalization principle in our culture today?

First, we need to recall that normalization is culture-specific. Both the human management tools employed, as well as the behavior outcome desired, should be normative to the specific culture involved. Nonmarital sex may be no more common in Sweden than in North America, but what does differ is the overtness of these practices, and public expression of approval thereof. Thus, in our society, it is doubtful whether at present, we can gain widespread public approval for the advocacy and support of nonmarital heterosexual activity on the part of the retarded (and probably other handicapped groups as well), no matter how rightful we may judge such support to be.

However, what this society does approve is the marital state of adults. In fact, our society values the marital state so much that it is almost impossible to resist social pressures to enter matrimony. Unlike in many other societies, in ours, unmarried older adults are viewed almost as deviant and freaks. Thus, it would appear that advocacy of a childless married state for more of the retarded, and some of the severely retarded and impaired, can be successful at this time. I stipulate ‘childless’, because the North American public will not now approve, and probably never will, childbearing by those unlikely to be capable of child rearing. The same stipulation would probably apply to most other societies.

Perhaps our ideologizing will be facilitated if we distinguish between three types of socio-sexual unions: those perceived in a traditional religious – one could say sacramental – fashion; those more along recent lines of thought about close relationships, which may not necessarily be legitimized by either law or organized religion; and those which are legal in nature, but do not necessarily involve either a close relationship or a religious element.

Many mildly retarded persons, and some who are more severely impaired, could probably meet the requirements of what would be perceived by many in our society as sacramental marriage. Additional impaired persons could form close relationships. Yet others are capable of benefitting from sexual relationships in which the interpersonal element is of an immature nature. However, some observers would accord a more severely impaired person the right to a legal marriage only if he were perceived able to make a meaningful choice, to love, to be faithful, to be considerate, and perhaps to assume community responsibilities. As noble as these things are, I am compelled to view such a stance as discriminatory. While we idealize these qualities, we do not make their absence impediments to legal marriage in the nonimpaired.

There are many nonretarded, physically healthy people who are sex-
driven, shallow, incompetent, unstable, and incapable of deep and perhaps
even of sustained relationships; yet our political system accords them the
constitutional right to enter a legal marriage. In our society, a citizen has the
right to treat sex on the ‘itch-and-scratch’ level, and to enter a legal marriage
that does not rise above this level. Therefore, we should either apply more
stringent criteria to all citizens, or cease applying them to the handicapped.
Actually, we should look upon legal marriage as a political, rather than
sacramental or emotionally meaningful act; if it is an act available to citizens
who are not impaired, it should also be available to those who are impaired.
One might say that just as in a spiritual sense, human dignity implies the
freedom to sin, so does dignity in the socio-political-constitutional sense
imply the freedom to perform those unwise, immoral, and even destructive
things which the law does not define as illegal.

One could even argue that whether a couple is likely to have offspring
which it cannot or will not raise is irrelevant. There are nonretarded persons
whom the law permits to marry even though their chances for begetting
normal children, or for raising or supporting them, are quite low. For in-
stance, we permit couples to reproduce even though genetic examinations
may reveal that the probability of their having a normal child is nil; even
though one or both partners may be so grossly unstable as to make it ex-
ceedingly unlikely that they will rear the child, or rear it to be normal; or
even though both parents may already have been living on public support. In
other words, our society has not as yet established as an impediment to
marriage or reproduction either the likelihood of having an impaired child,
or of rearing him competently, or of supporting him adequately. Yet strange-
ly, when a person is retarded or physically impaired, these factors suddenly
become impediments. This underlines that the above factors are not the real
criteria, but that attitudes toward the impairment — usually mental retarda-
tion — are. This, clearly, is bound to be unconstitutional, in being discrimina-
tory. If unfitness for parenthood becomes a criterion, then it should be ap-
plied both to the retarded and nonretarded alike — and many bright, well-
educated persons are unfit parents!

However, in our service development, we must deal not only with consti-
tutional issues, but also with socio-political realities, and one such reality is
— and may remain — that when a person is impaired and unlikely to be able
to rear his own offspring, his fellow citizens will not accord him the right to
reproduce. Therefore, in order to assure such persons access to socio-sexual
benefits, we must also assure that they remain childless. Furthermore, as
long as society will not permit socio-sexual unions of impaired persons
without legal marriage, then we must use legal marriage as the vehicle for en-
abling and supporting such socio-sexual unions.

Thus, it appears that if a potential union is very unlikely to result in off-
spring, we should accept the concept of marriage for those adults, regardless
of their intellectual or physical impairment, who: can derive emotional,
social, and/or sexual benefits from a heterosexual relationship; can relate to
a potential mate in a constructive manner; and who, when in public, can
relate in a relatively normative decorous fashion to a potential mate.

Sterility of such a union can be assured either by sterilization or contra-
ception. Sterilization, unlike in the past, should be voluntary, and it should be
assumed that any adult who can act decorously in public and relate construc-
tively to a person of the opposite sex will be capable of giving a meaningful consent to such voluntary sterilization. Other means of contraception should also be feasible with many couples, even if one or both partners are severely retarded. Of greatest relevance here will be the almost certain advent of long-acting contraceptive drugs, the development of subcutaneously implanted continuous-action capsules, and similar means that do not require frequent and conscious attention. Finally, impotence and sterility are more common among severely impaired persons, and in the future, more effective and less expensive techniques may be developed which will reveal whether a person is sterile, thus obviating the need for contraceptive measures for them.

It is often argued that sexual impulses in the severely impaired are neither as strong nor as common as among other persons, and that therefore the issues I raise are irrelevant or premature. I submit that we must confront the issue regardless of the number of the severely impaired to whom it applies. Within a given service system, there may be 10 such persons, 100, or 1000; whatever their number, they have, in my opinion, a constitutional right to the sexual and socio-sexual privileges available to their fellow citizens.

While there is reason to be concerned with the stability of marriages of the severely impaired, the same is true for the marriages of the presumably unimpaired. Even among those opposed to serial marriages, few would advocate that civil law prohibit divorce and remarriage. Should such serial marriages then be the civil right of only the unimpaired, or of those who can pay the costs of divorce proceedings?

If we are to accept marriage of even severely retarded persons, then we must reorient ourselves to providing services which not only take into account but also support such marriages. Some such needed services (e.g. citizen advocacy, described in a later chapter, and intensive and sustained contraceptive guidance or supervision) are self-evident; others we will not fully conceptualize until we have had more experience working with couples in which one or both partners are rather retarded.

Obviously, one service implication is that in the development of the future residential service system, which at least in mental retardation will consist primarily of dispersed, small, specialized, community-integrated residences (Dunn, 1969; Dybwad, 1969; Wolfensberger, 1969c), we should begin to think about residences for impaired married couples. One possibility here would be hostels with live-in houseparents, and several kitchen-less small suites for married couples; meals might be cooked for such a hostel as a whole, and taken in a joint dining room. Another alternative is apartment houses for impaired couples, with separate kitchen facilities and some supervision, perhaps by houseparents living in the same building. A third alternative is the placement of one or more impaired couples into larger apartment houses for the general public, with itinerant staff personnel dropping in for a minimal type of supervision every few days. Each of these alternatives could be modified so as to apply to both married couples and unmarried persons. For instance, once could think of an apartment house in which ten retarded adults live, of which some may be married to each other, while others are single. Regardless of the alternative, for maximal normalization, all of the adults will be expected to work during week days, either in community workshops or in competitive employment.
Conclusion

Earlier, I stated that our culture today will probably not sanction nonmarital heterosexual relationships for the more severely retarded and perhaps otherwise severely impaired. This may change as cultural views toward sexuality generally undergo further changes, and in consequence, some years hence we may have to reassess what sexual normalization for the severely impaired means.

Also, throughout this article, I have referred to the sexual needs of impaired adults as if these needs exclusively involved 'typical' forms of heterosexual activity. There are, of course, those (e.g. Albert Ellis) who interpret this view as being very old-fashioned. Yes – we are our own prisoners; I feel accomplished to be able to accept a new view of an adult sexuality for the impaired that would have been totally unacceptable to me a few years ago, and others undoubtedly share my own change experience. Maybe tomorrow, I can write of not only another but even a different sexual frontier for the impaired, but today I can see it no more than I could see the present one some years back.