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A Survey of the Perceptions of Twenty-Three Service Providing Agencies on the Sexual Behaviors of Persons with Severe or Profound Mental Retardation

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This study surveys the perceptions of 23 service providing agencies on the sexual behaviors of persons with severe or profound mental retardation. A 17-item questionnaire was mailed to 200 service providing agencies in New York State requesting information about the masturbatory and mutual sex behavior patterns of persons in their care. A total of 34 responses were returned, and of these, there were 23 agencies that completed the survey as requested. Subsequently, data were collected on the masturbatory behaviors and mutual sex behaviors of 1,288 and 1,220 adults respectively. The results indicate that masturbation occurs within all 23 agencies and that orgasm problems can be found in 22 of them. Furthermore, masturbation was reported to occur at a mean range from 31.9% to 40.9%, and of those who do, close to one third experience orgasm difficulty. A total of 20 respondents indicated that voluntary sexual contacts occur between people and 12 of these 20 said that there are persons who engage in sexual intercourse. There were 19 respondents who suggested that between 7% and 12.8% of the individuals whom they supervise participate in some sort of mutual sexual contact. The author discusses these results and their implications in an attempt to better understand the role that sexuality plays in persons' lives.

KEY WORDS: profound and severe mental retardation; sexuality; masturbation; mutual sex.

It is easy to understand why the sexual behaviors of persons with severe or profound mental retardation would be of major concern to those who are responsible for their care and safety. Yet, as incredulous as it may seem, there has been virtually no attempt to investigate or determine the extent and scope of

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these behaviors as they manifest among this group of individuals (1,2). Remarkably, what most every human being chooses to do in life, that is to express oneself sexually, is a need that has been practically ignored by service providers and caregivers when it concerns persons with severe or profound mental retardation. Perhaps more disturbing is the literature that does exist on the subject generally suggests that persons have little interest and involvement in sexual matters (3,4,5). The assumption for many is that the more mentally retarded one is, the less sexual that person is expected to be. Although these assumptions may be widely held, they are nevertheless only assumptions. They are certainly not based on empirical evidence and, as such, represent individual beliefs and opinions only.

In fact, close examination of the two research studies that have been conducted would suggest just the opposite. That perhaps far more persons with severe or profound mental retardation express themselves sexually than is suspected. Gebhard examined the masturbatory behavior of 12 persons with IQ scores under 50 and found that 10 of them masturbate (3). He was also able to determine that 8 of 15 persons with IQ scores between 31 and 50 had participated in genital touching and intercourse with each other. West assigned staff members at an institution in Australia to observe the sexual behavior patterns of 31 people with severe mental retardation for a period of one month (6). Results indicate that 16 were observed to masturbate, 15 engaged in genital touching with each other, and another 7 had sexual intercourse.

Is it possible that persons with severe or profound mental retardation are more sexual than many people are willing to give them credit for? Given the restrictive practices and repressive attitudes of caregivers toward the sexuality of individuals, it seems rather astounding that persons behave sexually at all. Considering that discouragement and even punishment of sexual expression are still very common today, and that the laws that define standards of capacity to consent preclude the right of persons with severe or profound mental retardation to engage in sex, one should expect to see far less sexual expression than would exist among the general population of persons without mental retardation (7,1,8,2,9,10). However, are the rates of sexual expression as low as many people think? And if they are, is it because persons have no interest in sex or because of intolerable restrictions that relegate individuals to live a life of forced abstinence? It would seem reasonable to suggest that far more people would engage in sexual behaviors than are presently accounted for if they were provided with the same or similar opportunities to be sexual that are granted to other persons in society. If this is true, then it may well be incumbent upon the collective family of service providers and caregivers to re-examine the programatic, clinical, and policy related decisions that are currently being rendered specific to the sexual needs and behaviors of persons. Certainly, in view of the fact that these decisions are being made without the benefit of empirical knowledge, let alone

any well-grounded theoretical underpinning, underscores the need to learn more about the sexuality of persons with severe or profound mental retardation. Otherwise, the decisions that are made, may be ones that are not in the best interests of individuals and may conflict with their personal choices and preferences.

METHOD

Two hundred service providing agencies in New York State that provide care for persons with mental retardation were contacted by mail and asked to respond to a brief survey pertaining to the sexual behaviors of persons with severe or profound mental retardation. With the assistance of a large state-wide provider association, the survey was addressed to an administrator at each agency who is the designated staffer that the association usually sends their mailings to. The survey (see Table 1) comprises 17 questions that pertain to masturbation and mutual sex expression (i.e. sexual contact between two people). More specifically, the questions refer to one's perception of the approximate percentage of persons who masturbate, including those who have difficulty masturbating to orgasm and who do so in public places, and the percentage of persons who engage in sexual contact with others and the frequency of those contacts. There was no attempt to learn the age of persons, their race, gender, or place of residence.

It is assumed that the survey was completed by someone at each agency who has some knowledge of the sexual behaviors of the persons provided for. However, there is no definitive way to tell if this was the case. Also, there is no way to determine just how accurate the responses are. A major barrier to studying the sexual behaviors of persons with severe or profound mental retardation is the inability of the researcher to ask the individuals themselves about their own sexual behaviors. As such, it is assumed that any pertinent information that is obtained probably comes from a caregiver who is familiar with the sexual activities of persons. Unless one has the opportunity to directly observe these behaviors as they occur over time, one must rely on the best estimations of a knowledgeable third party to provide information about them. Such is the case in this study. Consequently, the responses to the questions posed in this survey should be viewed with some skepticism.

A total of 34 responses to the survey were returned. Four did not provide for persons with severe or profound mental retardation and another seven were so incomplete that any information that was included was discounted. Of the 23 agencies that completed the survey as requested, the data that were collected represent information about the sexual behaviors of 1,288 adults ($M = 56$) under their care and supervision.

Because of the limited number of responses, it is not possible to make any

Table 1.

1) How many adults with severe or profound mental retardation does your agency provide for? _____

2) Do any of these adults presently masturbate? yes _____; no _____

3) The actual percentage of those who masturbate is _____; don't know _____

4) The approximate percentage of those who masturbate is (check one)

1–10% _____	11–20% _____	21–30% _____
31–40% _____	41–50% _____	51–60% _____
61–70% _____	71–80% _____	81–90% _____
		91–100% _____

5) Of those who masturbate, approximately what percentage masturbate every day? _____
several times each week? _____
at least once every two weeks? _____
at least once each month? _____

6) Do any of these adults masturbate in a problematic or inappropriate faction?
yes _____; no _____

7) Do any of them masturbate in public? yes _____; no _____
Approximately what percentage? _____

8) Are there those who masturbate in a dangerous or harmful fashion? yes _____; no _____
Approximately what percentage? _____

9) Of those who masturbate in a dangerous or harmful fashion, briefly describe up to three different ways in which they do this.

_____

_____

_____

_____

_____

_____

10) Are there those who masturbate without reaching orgasm or in limited fashion only?
yes _____; no _____
Approximately what percentage? _____

11) Of those who have difficulty masturbating to orgasm, approximately what percentage appear frustrated in some way after attempting to masturbate? _____

12) Of those who have difficulty masturbating to orgasm, approximately what percentage become abusive to self or others after attempting to masturbate? _____

13) Do any of these adults with severe or profound mental retardation engage or attempt to engage in voluntary sexual contact with others? yes _____; no _____

14) Are there those who mutually masturbate? yes _____; no _____

15) Are there those who engage or attempt to engage in voluntary sexual intercourse of any sort?
yes _____; no _____

16) The approximate percentage of those who engage or attempt to engage in voluntary sexual contact with another is (check one)

1–10% _____	11–20% _____	21–30% _____
31–40% _____	41–50% _____	51–60% _____
61–70% _____	71–80% _____	81–90% _____
		91–100% _____

17) Approximately what percentage of those who engage or attempt to engage in voluntary sexual contact with another do so
every day _____
several times each week _____
at least once every two weeks _____
at least once each month _____
at least once every two months _____

meaningful interpretation of how the data relate to the whole population of people with severe or profound mental retardation. The sole purpose of this study is to provide some small amount of insight into the patterns of sexual behavior of persons. Consequently, I can only describe the data that have been collected and offer some commentary on what the possible implications would be if one assumes the data to be reasonably accurate. Nevertheless, for the first time, data have been obtained that relate to the type and frequency of sexual expression (i.e. masturbation, sexual contacts, and intercourse) and about certain concerns of masturbatory behavior (i.e. lack of orgasm, public masturbation, and harmful masturbation) of individuals with severe or profound mental retardation.

RESULTS

Each of the 23 respondents indicated that masturbatory behavior occurs among persons in their care. The distribution scores for the perceived masturbatory behavior of persons is indicated in Table 2. The approximate percentage of persons who masturbate within each of the agencies range from a low of 1–10% to a high of 81–90% (M = 31.9–40.9%). Of the 1,288 individuals represented, the approximate number of persons that are thought to engage in masturbation is between 411 and 528 (M = 31.9–40.9). Twenty-two of the 23 respondents said that of those who masturbate there are individuals who either do not reach orgasm or have difficulty doing so. Nineteen of the 22 were able to

Table 2.

Percentage Range of Those who Masturbate	F	CF	RF	RCF	N	NM
91–100%	0	0	.00	.00	0	0
81–90%	2	2	.09	.09	74	59–67
71–80%	1	3	.04	.13	4	3–3
61–70%	1	4	.04	.17	200	120–140
51–60%	3	7	.13	.30	183	94–110
41–50%	3	10	.13	.44	124	52–62
31–40%	1	11	.04	.48	9	3–4
21–30%	4	15	.17	.65	291	60–87
11–20%	4	10	.17	.83	144	17–29
1–10%	4	23	.17	1.00	259	3–26

F - frequency of scores
CF - cumulative frequency of scores
RF - relative cumulative frequency of scores
RCF - relative cumulative frequency of scores
N - approximate number of persons represented within each percentage range
NM - approximate number of persons within each percentage range who masturbate

indicate the approximate percentage of masturbators who had difficulty, while 3 said they did not know. Percentages range from a low of 1% to a high of 52% (M = 23.2%). Of these 19 respondents (N = 1,208) who claim between 404 and 408 masturbators (M = 21.3–25.3), the approximate number of persons who do not reach orgasm or have difficulty doing so is between 128 and 153 (31.7–31.9). Seventeen of the 19 indicate that there are persons who become frustrated after such an episode. The percentage of persons who experience frustration range from a low of 1% to a high of 100% (M = 32.2%). Six of the 19 said that individuals become abusive afterwards, with a range of 1% to 100% (M = 14.3%).

Twenty-two of the 23 respondents claim to have individuals in their care who masturbate in public places. Five of the 22 did not know the approximate percentage of persons who masturbate in public, but of those who did, estimates range from a low of 1% to a high of 100% (M = 20.9%). Twenty respondents said they knew the frequency of persons' masturbation, of which 14 said they have individuals at their agency who masturbate every day. Percentages range from a low of 5% to a high of 100% (M = 32.1%). Ten of the 23 respondents said there are persons who they care for who masturbate in a dangerous or harmful manner, while 12 said they do not, and one was unsure. When asked to describe the different dangerous or harmful ways that persons masturbate, responses include rubbing one's genitals against hard objects, such as sticks, forks, shoes, toilet seats, floors, cars, and washing machines; inserting objects into the vagina; and banging one's penis against walls.

The distribution scores for the perceived incidence of voluntary sexual contacts are listed in Table 3. Twenty of the respondents said there are persons

Table 3.

Percentage Range of Those Engaged in Sexual Contacts	F	CF	RF	RCF	N	NCS
91–100%	0	0	.00	.00	0	0–0
81–90%	0	0	.00	.00	0	0–0
71–80%	0	0	.00	.00	0	0–0
61–70%	1	1	.05	.05	145	88.5–101.5
51–60%	0	0	.00	.00	0	0–0
41–50%	0	0	.00	.00	0	0–0
31–40%	1	2	.05	.11	50	15.5–20
21–30%	2	4	.11	.21	74	15.5–22.2
11–20%	2	6	.11	.34	39	4.3–7.8
1–10%	13	19	.68	1.00	912	9.2–91.3

F - frequency of scores
CF - cumulative frequency of scores
RF - relative frequency of scores
RCF - relative cumulative frequency of scores
N - approximate number of persons within each percentage range
NSG - approximate number of persons within each percentage range engaged in sexual contacts

within their agencies who engage in voluntary sexual contacts and 12 of the 20 said there are individuals who involve themselves in voluntary sexual intercourse. The approximate percentage of persons who engage in voluntary sexual contacts range from a low of 1–10% to a high of 61–70% (M = 8.9–17.9% based on 19 respondents). Of the 19 respondents (N = 1,220; M = 64.2) who indicate that sexual contacts occur, approximately 133 to 243 persons (M = 7–12.8) are accounted for. The most frequently cited rate of occurrence for sexual contacts was one per person, per month. Interestingly, only 5 of the respondents claimed that mutual masturbation occurs.

DISCUSSION

It has been suggested that the freedom to express sexuality can serve to enhance one's overall adjustment and quality of life (4,1,2,8). If the data that are presented here are even somewhat reflective of the larger population of persons with severe or profound mental retardation, perhaps the need to learn as much as is possible about the sexual needs and behaviors of individuals is long past due. Whether one considers the data to be significant or not, the likelihood that there are people who are in need of knowledgeable and reasonable guidance concerning these needs and behaviors seems real. If it is generally accepted that close to 1% of the total population of persons with mental retardation is comprised of individuals with severe and profound mental retardation, then the potential exists that thousands of people are currently presenting particular sexual concerns that are not being addressed or are being addressed inadequately (11).

Consider for example the issue of masturbation. If as many persons masturbate as are suggested by the data here, one question that immediately arises is, "Does the caregiver have an obligation to consider the need to teach, proactively, the concept of masturbatory choice-making to individuals?" If as many persons with a severe or profound cognitive deficit have learned on their own about masturbation as has been proposed by this study, do we not have the obligation to at least explore the potential benefits that may come from offering masturbation as a choice to all persons?

I make the assumption that the overriding majority of persons who presently masturbate do so voluntarily, free of any undo coercion. That is, it is their personal choice or preference whether or not to masturbate. If persons were provided with similar opportunities to masturbate, would not many more engage in this behavior than are presently accounted for? Perhaps caregivers are ignoring the basic guiding principles of normalization and inclusion by not providing the opportunity for masturbatory choice to persons with severe or profound mental retardation.

After all, masturbation has been determined to provide individuals with a considerable number of health and therapeutic benefits. For example, it has been demonstrated that masturbation helps to sharpen the body image and heighten one's sense of reciprocity which should ultimately aid in the socialization of the sex drive (12,13,14). It also appears to help relieve anxiety and assists to reduce levels of tension and has shown to produce more consistent and intense orgasms than do other types of orgasmic behavior (Masters & Johnson, 1966) (15,16,17,18,19). Because of the many positive outcomes associated with masturbation, it certainly seems plausible for it to be recognized as a possible choice-making activity.

Apparently, there are persons who have difficulty reaching orgasm when they attempt to masturbate and who, perhaps, masturbate in a dangerous or harmful fashion. Orgasm problems that affect individuals without mental retardation are well documented, and although the exact incidence is unknown, it is thought to be low (20,21,22). While the percentages noted in this study might seem high, it is important to consider the influence that a cognitive or behavioral deficit could have on one's ability to learn how to masturbate in a relatively efficient manner. Is it not possible that because of these deficits there could exist a considerable number of persons who have difficulty reaching orgasm?

Masturbation is a learned behavior and not something that just occurs (23,24,1). Anyone who masturbates must learn the variations of touch, grip, speed, friction, and pressure that will enable him or her to develop a successful masturbatory style. This includes the ability to anticipate an orgasm or to be able to recognize the different reference points that are inherent throughout the sexual response. Additionally, one must be able to negotiate any contradictory cultural messages (i.e. religious and familial beliefs, gender roles, etc.) that could serve to confuse one's sense about the appropriateness of masturbation. When viewed in this way, severe or profound mental retardation has the potential to negatively impact one's ability to successfully complete these different masturbatory tasks. This could be one explanation why persons may be more at risk for experiencing orgasm related problems than are others.

As reported previously by Cleland and Kaeser, it seems likely that some individuals may experience some level of frustration following unsuccessful attempts to masturbate (26,1). If we know that masturbation to orgasm relieves both psychic and physiologic tension, is it also not possible that unsuccessful attempts to masturbate to orgasm, especially repeated attempts, could cause tension or frustration levels to increase (17,18,26)?

Harmful or dangerous masturbation may be a problem as well. I have personally witnessed people engaged in some very hurtful forms of masturbatory behavior as have Robinson, Conohan, and Brady (27). This survey supports these accounts as all but one responding agency indicated they provide for

persons who have mistakenly channeled their sexual energy in a manner that is both inefficient and destructive.

Because of these potential masturbatory related problems, there may well exist significant numbers of persons with severe or profound mental retardation in need of some clinically designed therapeutic treatment program to address these matters. If it is expected that all people should be afforded the care and treatment that are suited to their needs and should be provided educational techniques which assist them in overcoming their deficiencies while promoting meaningful behavioral growth, then this same premise should apply to orgasmic and other sexually related problems (28). Although specific therapeutic treatments exist, they have been virtually ignored for use with persons with severe or profound mental retardation. For example, masturbation training is recognized as a commonly used intervention for the treatment of orgasm dysfunction for persons without mental retardation (20,29,22). However, very few attempts to utilize a similar treatment for persons with severe or profound mental retardation have been reported (1).

An immensely curious and intriguing phenomenon is when two persons with this degree of disability engage in sexual contact or intercourse with each other (although the term "sexual contact" was not defined for the respondents in this survey, it is assumed that most people would interpret this to mean any physical expression of a sexual nature between two people). Apparently, there are some persons who participate in mutual sex behaviors with each other. How they came to express themselves sexually in this manner is an extremely important topic to explore, but is one that is beyond the scope of this study. Nevertheless, the matter of two persons with severe or profound mental retardation having sex with each other should pose an immediate concern for those who provide them with care and supervision. The moral and legal implications, as one can imagine, are varied and diverse. For example, should persons be forced to stop their sexual contacting, no matter how beneficial the behavior might be, because of a legal standard that says one must possess the capacity to render informed consent before participating in sex? Is it morally right to categorically preclude others' ability to voluntarily engage in a sexual act? If so, what would be the positive and negative consequences of such an arrangement and how would these consequences affect the quality of life and overall adjustment of individuals?

Certainly, most people can attest to the pernicious effects of having to endure sexual abstinence during certain periods of their adult life. I suppose that this comes easier for some than it does for others, but the capability that most persons have to be able to rationalize these lonely moments is something that may be difficult if not impossible for individuals with severe or profound mental retardation to do. As such, if there are two persons who voluntarily engage in mutual sex, and if these behaviors could be reasonably supervised by

trained caregivers, is it really ever in their best interests to be deprived of the right to make these personal sex choices? If the roles were reversed, would the typical man or woman be so willing to abide by any restriction that prohibits them from exercising free choice in their personal sex lives?

If the data in this study are typical of the total population of persons with severe or profound mental retardation, then the proportion of those involved in voluntary sexual relationships range somewhere between 1 out of every 11 to 1 out of every 7 people. To think that all of these individuals have probably had to endure prohibitive restrictions and that many have likely experienced various forms of punishment for their behaviors, it seems rather astonishing that there may be this many who continue to express themselves sexually. Yet, my own personal observations in this matter also tend to support the percentages that are presented here. The apparent desire to act upon one's expressed sexual desires must be of such significance that persons are willing to risk whatever negative consequences that could come as a result.

Admittedly, the questions and concerns that pertain to mutual sex behaviors and activities are many and will require extensive discussion to arrive at reasonable solutions. It appears crucial that caregivers need to develop policy that seeks to establish a balance between the need to protect persons from harm with their right to exercise voluntarily determined sexual choices. As with so many risk-taking activities of life that also have the potential to provide valuable benefits, caregivers must continuously evaluate not just the risk-gain ratio of persons' behavior, but whether the behavior is in their best interests and whether it reflects their personal choices and preferences. They must determine as well what level of supervision, if any, is required of them in the maintenance of these persons' behavior. Perhaps caregivers should be responsible for the supervision of mutual sex behaviors much like they are responsible for supervising any risky but beneficial non-sexual behaviors. The present inability of caregivers to render third party consent decisions in the sexual matters of persons they care for, represents the only activity of one's life that a caregiver doesn't have that legal capability. What with all the third party decisions that are made daily in persons' lives, if people with severe or profound mental retardation were denied the opportunities to have others assist them in their daily decision making activities, there would be very few things in life they would have a chance to participate in. Is the concept of "supervised sex" really any different than the concept of any other supervised activity or behavior?

Accordingly, a thorough analysis of the physical, emotional, and psychological risks and gains that are associated with mutual sex and forced abstinence is an appropriate starting point for determining whether a change in the present standard of capacity for engaging in sexual expression is warranted. Should the data that are presented here be accurate, there is an urgent need to do so. If, for example, 10% or 26 million people of the total population of the

United States were denied outright their basic constitutional right to privacy associated with voluntary sexual decision-making, one would have to believe that a considerable level of protest would ensue. Because we are talking about persons with severe or profound mental retardation should we expect anything less?

CONCLUSION

The sexual needs and behaviors of persons with severe or profound mental retardation are not easily understood. Apparently, there are persons who masturbate and who voluntarily partake in mutual sex interactions. While it would be useful and interesting to know the specific incidence of these behaviors, a far more compelling concern would seem to be the determination of the best interests of persons' sexuality and how these interests should be preserved and maintained. For example, would an analysis of masturbatory behavior indicate that this activity is more beneficial than it is costly? Are the benefits of masturbation training greater than the risks and how does this risk-gain ratio compare to the risks that are associated with a life of orgasmic dysfunction? How do the risks and gains of voluntary sexual behavior fair when matched against the ones for forced abstinence? Also, what are the risks and gains that are involved when caregivers are required to supervise voluntary sexual interactions?

Presently, there are far more questions concerning persons' sexuality than there are answers. Considering how little investigation there has been in such matters this is not surprising. However, if caregivers and advocates are as committed to individuals with severe or profound mental retardation as we purport to be, then it is incumbent upon us to provide some of the answers to these questions and ones like them. The overall quality of life and adjustment of persons may well be at stake.

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