

Relationships & Sexuality

A Guide to Policy for Individuals with Intellectual Disabilities and their Residential Service Providers

A Project of

Regional Residential Services Society

&

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* * * * *

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Introduction

With the assistance of a grant from the Community Health Promotion Fund, Regional Residential Services Society (RRSS) set out to develop a prototype policy on Relationships and Sexuality. This policy would be shared with residential agencies which serve people with intellectual disabilities¹ in Halifax and the surrounding area.

At the onset, it was agreed that this policy would:

- respect the rights of adults with intellectual disabilities, specifically the right to self-determination concerning relationships, sexual expressions, and family planning.
- acknowledge loving relationships, sexual identity and sexual expressions as essential aspects of happiness and well being.
- recognize that too few adults in residential care have significant unpaid relationships.
- encompass the "Normalization" principle by supporting intimate and non-intimate relationships.

Any policy development also needed to take into account the risks of sexually transmitted diseases (STD's), unintended pregnancies, and abuse. People with intellectual disabilities suffer an extremely high rate of sexual abuse. Consequently, protection from harm was also a primary objective of the policy development.

In the past, human service workers and other caregivers have responded to expressions of sexuality by people with intellectual disabilities in a variety of ways. Responses have ranged from harsh punitive measures or an absence of any response, to providing thoughtful and respectful interventions. We believe that

¹For the purpose of this document, 'intellectual disability' means a medical diagnosis of 'mental retardation'.

residents² deserve protection of their right to life-enhancing sexuality, and service workers require proactive guidance to ensure that they take reasonable measures to provide protection while supporting residents in expressing consenting and enhancing sexuality. Like many clinicians, authors and human service workers (Acton, 1992; Ames, 1991; Hingsburger, 1994; Jackson et al., 1989), we believe that a detailed policy which provides clear guidance to direct care and supervisory staff is crucial to ensuring quality service delivery.

While adequate policies addressing this area of human services are extremely scarce, we were able to draw substantial guidance from the work of others, notably: ARI Inc. (1994); The Massachusetts Association For Community Living (MACL, 1994); Northern Nevada Mental Retardation Services (1989); The Reena Foundation, Toronto (1991); and the Metropolitan Toronto Association for Community Living (1984). The MACL policy³ was particularly helpful and we would suggest that residential agencies also examine this policy and select the sections which best suit their needs and service delivery philosophies.

We did not feel, however, that any one of the above policies could be adopted in whole for use in Nova Scotia. Firstly, we found that none of the policies adequately addressed the crucial issue of consent to mutual sexual activity. Secondly, we believed that the service delivery needs of people with moderate and severe disabilities required specialized attention. Thirdly, the laws in Nova Scotia are different from those in the United States, where most of these policies originated. Lastly, we believed that the process of developing policy would result in a greater commitment to, and understanding of, sexuality in the context of residential service delivery.

No policy can adequately provide answers to all of the individual situations that may be encountered in service delivery. A policy can, however, provide a decision making framework which ensures as much self-determination as possible. Through an inter-disciplinary team, a process can be established which attempts to involve the resident to the full extent of his/her abilities and which, if necessary, reaches a substitute decision (see glossary) based on the benefits and risks of all available options for the individual.

²While the use of labels has often reflected a dehumanizing of people with intellectual disabilities, for clarity we felt it necessary to use a consistent term. As we are focusing solely on people in residential service, we opted for 'residents' as being the least restrictive label.

³This policy can (and should) be purchased from MACL by writing the agency at One Carando Drive, Springfield, MA 01104-3211: Attention: Gail T. Brown.

Format and Development

A few words are in order concerning the format of the policy and the development process.

We followed the lead of the *Human Sexuality Handbook* (MACL, 1994) in providing the responsibilities of both staff and residents. We shared the view that with rights come responsibilities, and with respect comes expectations. In detailing "Resident Responsibilities" our objective is to set goals, not minimum standards. In other words, we realize that not all people with intellectual disabilities will be able to meet all of the "Resident Responsibilities", but they are presented as expectations for those who can and goals for those who cannot. It is also recognized that agencies come in varying sizes with greater or lesser staff and administrative supports. In this document, "Staff Responsibilities" encompass agency responsibilities.

Each policy section is introduced by a narrative titled "Policy Considerations". These briefly discuss some of the issues, information, and goals or assumptions upon which the policies are based. This allows others to evaluate the policies and procedures in the context of their own, potentially different, assumptions.

Like any effective policy document, this is a "work in progress". It will need ongoing revision as information and resources develop and societal norms and laws change. We hope that this format will assist in the growth process.

A **bibliography** of the resources which were found most helpful is included. Other service providers are encouraged to examine these resources when engaging in policy development.

As to the **development process**, a committee was established by RRSS which consisted of all levels of staff, parents, board members, and various health professionals. A need was also identified to involve residents in the policy development process. It was anticipated, however, that hours of tedious literature review and contentious debate would be required. And we wanted to avoid the tokenism that can come from "name-only" involvement. In the end we opted for a productive opportunity wherein residents could relate their needs and desires and provide ideas on how service providers could respect their rights to sexual

expression and to protection. This was accomplished by taking the policy to the draft stage, then making the contents "resident accessible" and establishing a resident feedback forum. Some key policy sections were also distributed to other service providers for feedback. In addition, some of the policy was examined by a representative of the Health Law Institute at Dalhousie University in Halifax. Feedback from residents and other agencies, and the process for obtaining same, is detailed in Appendix 6.

The final step in the process will be the **distribution of a prototype policy** to other residential agencies within our region. It is hoped that this will stimulate a process of policy development within these organizations and some may find the work adaptable to their situations. To facilitate this process, the copying and distribution of this document is encouraged. Those who develop new policies are invited to reference the contribution of this work to their efforts. However, neither the Regional Residential Services Society nor the Nova Scotia Department of Health take any responsibility for the changes or alterations that may result. As a final note, RRSS is most interested in receiving copies of policies developed by other organizations on this subject.

The Sexuality Review Committee

Throughout the policy, reference is made to The Sexuality Review Committee (SRC). Committee membership may vary depending on agency size, location (urban or rural), and the matters being dealt with by the Committee. In medium and large agencies the core membership will be the agency staff who have received training in the areas of human sexuality and intellectual disabilities. Smaller agencies will look more to the community for committee membership. In both cases, for more complex issues, the committee may be expanded to include external parties such as: parents/guardians; health professionals; and resident advocates (self advocates or representatives who will liaise with residents).

It is not intended that the SRC impose itself on the day to day private lives of residents. Rather, the SRC provides in-depth and prompt examination of individual cases concerning relationships and sexuality which exceed the realm of direct care provision. The SRC examines existing information, ascertains whether further information and/or additional expertise is required, examines benefits and risks to the involved residents, explores community resources and arranges necessary interventions.

The committee is responsible for staying abreast of developing knowledge and resources concerning sexuality and people with intellectual disabilities. The SRC also engages in periodic examination of the policy and initiates updates as required.

Guiding Principles

“All individuals with intellectual disabilities have the same inalienable rights to life, liberty, and the pursuit of happiness as all other individuals. This includes the right to responsibly engage in interpersonal relationships, which include sexual expressions, where there is mutual consent”. (Ames and Samowitz, 1995 : 265)

Loving relationships, which include sexual expression, are an integral component of a person’s physical, emotional and mental well-being. Accordingly, service providers need to consider this aspect of life to be a priority in service delivery.

Service providers also need to recognize that:

- some adults with intellectual disabilities may need support in recognizing opportunities and in developing skills and knowledge which enable them to develop loving relationships;
- many adults with intellectual disabilities may require greater protection against victimization than the non-disabled population;
- adults who are engaging in sexual behaviour in a way which is causing self-harm or harm to others should be interrupted immediately;
- interpersonal behaviour which may signal the need for assistance does not warrant a life time prohibition on loving relationships and sexuality.

(Adapted from Ames and Samowitz, 1995)

Safe and healthy sexual behaviour occurs largely as a result of social skill competencies and social inclusion. This policy focuses on building these competencies by providing means of addressing specific skill and environmental deficits of individual residents.

It is the intention of this policy to reflect human relationships and sexuality as a source of human fulfillment and joy. In light of this understanding, loving relationships and sexuality will be reflected in this policy as human rights. These include:

- Freedom from sexual stereotyping
- Freedom from sexual oppression
- Freedom of information
- Freedom to control one's own body
- Freedom to express affection

(Acton, 1992)

Section 1 - Social-Sexual Education

POLICY CONSIDERATIONS

The following history, philosophy, and research guided the development of this section of policy:

Winnifred Kempton, a pioneer in this field, observed: "They (people with intellectual disabilities) are in the triple bind of being the people who need the greatest amount of basic planned sex education, who receive the least, and who are then punished by society for not knowing what others know" (1986, p.229).

One cannot assume that the knowledge and information that are available to the non-disabled are also available to people with intellectual disabilities. Basic information which is accessible to people who are living independently in the community may not be readily available to persons living in residential services.

Even when sex education is provided, it may not adequately address the needs of participants. It may focus almost exclusively on anatomical terms or be primarily problem focused. For example, it may teach the participants to avoid; sexually transmitted diseases (STD's), unwanted sexual activity, and inappropriate sexual behaviour, while neglecting to explore the skills and knowledge required to initiate and develop friendships and loving relationships. In the past, service providers have had to fumble their way through this area with little direction. Now there are increasing numbers of professionals, articles, videos, and curricula to guide in service delivery.

It may not be possible to compensate for all of the years during which residents were deprived; of planned social sexual education, peer learning, and the inter-personal relationships experienced by the majority of the non-disabled. It is important, however, to recognize this deprivation and attempt to understand the present need. It is also important to realize that persons with intellectual disabilities, regardless of degree, are social-sexual beings and have the same needs and desires as the non-disabled.

A commitment to fostering change requires staff training. There are many staff

development issues that need to be pursued. Social-sexual educators (formal and informal) need to explore their own values, beliefs, and knowledge, and consider whether they possess any impediments in assisting a resident in his/her development. To provide a well planned formal social-sexual education program, educators need to know about resources which will assist in assessment, communication, and learning. Staff also need to ensure that they provide an adequate balance between protecting residents from harm and supporting their rights and needs.

Questions frequently arise about the role of families in sexuality education. For most people sexuality is a subject which deserves the greatest privacy. However, when planned sexuality education is provided, parents or other primary guardians frequently like to be informed. This communication affords the service provider an opportunity to learn about residents' past experiences and explore any family concerns. While resistance is sometimes encountered, experience and the literature suggest that parents are frequently more supportive of sexuality education than may be expected (Pendler and Hingsburger, 1990). Residential staff need to listen to the concerns of parents and explore with them the benefits of education in reducing risks and increasing life enjoyment. Parent groups can be a vehicle to explore concerns and obtain advice for improving service. While open communication is optimal, it must also be realized that residents may not want information about sexuality education conveyed to family. Staff need to discuss with residents the benefits of communicating about sexuality education with parents. Service providers also need to be mindful of such sensitive matters as cultural norms within families and the legal responsibilities of agencies. Unless there is some compelling reason to not do so, families should be advised of planned sexuality education.

Staff Education

Policy:

The agency will provide, and staff will participate in, training to ensure that staff are competent in responding to residents' service needs in the areas of relationships and sexuality.

Agency Responsibilities:

- The agency will provide staff training in the areas of relationships and sexuality concerning adults with intellectual disabilities.
- The agency's policies and procedures concerning sexuality will be included in the orientation of all new staff.
- The Sexuality Review Committee will be available to guide staff in their responses to sexuality issues.
- Staff will be made aware of available resources such as printed information, audio-visual resources, trained staff, therapists and community resources.

Staff Responsibilities:

- Staff will ensure that they have the necessary competencies to support residents in establishing and maintaining loving relationships which may include sexual intimacy.
- Staff will ensure that residents receive accurate information in a non-judgmental manner.
- While it is recognized that there will be significant variance among staff in knowledge, values, beliefs and comfort levels concerning human sexuality, staff are required to support residents in establishing and realizing their own choices in accordance with agency policy.

- Staff will request, and/or be receptive to, education and sensitivity training when they are experiencing difficulty in supporting residents in their choices.

Resident Education

Policy:

Formal social-sexual education will be provided for all residents, regardless of degree of disability. Such education will provide accurate information presented in a non-judgmental and sensitive manner.

Resident Responsibilities:

- Residents will be encouraged to actively participate in formal and informal social-sexual education.
- Residents will ask questions and discuss sexual matters in a way which respects the privacy of the subject matter, at a suitable time and place.
- Residents who believe they have received inaccurate or judgmental information are encouraged to report same to the supervisor and/or a trusted person.

Staff Responsibilities:

- Staff will provide social-sexual information and education to all residents.
- Staff will respond to questions in a non-judgmental and accurate manner.
- Staff will present social-sexual information in a manner which is consistent with individuals' communication and learning abilities.
- When issues exceed a staff person's comfort level, or s/he feels unable to respond in a factual and/or enhancing manner, the staff person will discuss the matter with the supervisor. Together they will explore avenues of training and/or alternate staff support.
- Staff will remember that their interpersonal behaviour serves as a role-model of behavior and relationships for residents.

- Staff will respect residents' rights to confidentiality.
- Staff will provide direction to residents who choose to discuss sexual topics at inopportune times.
- Staff will report to the supervisor any incidents during which residents are given inaccurate or inappropriate social-sexual information.

Section 2 - Privacy

POLICY CONSIDERATIONS

The following history, philosophy, and research guided the development of this section of policy:

Privacy is central to; adult relationships, self concept, individual dignity, and self-determination. The right of privacy within this policy entails three components: privacy of information, privacy of one's body (as it pertains to personal care) and privacy of personal space.

Residents often feel that they have little or no control over the aspects of their lives which are discussed and with whom. Living in a residential setting can feel like a "fish bowl" existence where every aspect of one's life is open for examination. In the area of adult relationships, documentation and information sharing can feel especially intrusive. In fostering self-esteem and self-determination, it is important that confidentiality be respected to the fullest possible extent. On the other hand, record keeping is a requirement for accountability and good service delivery. Service providers can balance these seemingly conflicting needs by ensuring that documentation is respectful, enhancing, and available to residents or their next of kin. A beneficial exercise might be to ask residents what they think of their daily log. If the documentation contained therein is perceived as a reprimand or an intrusion, it may be time for the staff and the agency to alter their approach.

*Another key area is that of personal care. Agencies need to find methods of providing intimate care which respect dignity and reinforce the message that a resident's body is private, and within his/her own control. In **Just Say Know!** (1995), David Hingsburger provides some excellent suggestions which should be considered by all staff who provide intimate personal care.*

The final component of privacy addressed by this policy is that of personal space. In group living privacy can be difficult to achieve. Yet, without it, masturbation and other forms of private sexual expression are almost impossible. Agencies should strive to provide private rooms for all adults who do not otherwise express

a preference to share accommodations. In the absence of private accommodations, staff and residents will need to work together to provide opportunities for private time and to be ever mindful of each other's private space.

Privacy is not only a concept which is discussed in sexuality education as a rule of conduct. It is a right which must be respected and reinforced in daily service delivery.

Privacy of Social-Sexual Information and Documentation

Policy:

Any documentation in a resident's file concerning sexual matters will be limited to issues of health, safety, and life quality. All communication and documentation will be; respectful of the resident's dignity and self-determination, treated as confidential in nature, and stored and accessed only on a "Need to Know" basis.

Resident Responsibilities:

- Residents will sometimes learn private information about housemates and significant others. Residents will treat such information as confidential.

Staff Responsibilities:

- Staff will acknowledge the private and intimate nature of sexual matters. Staff will treat all communications about a resident's sexual history, behavior, development, and health as confidential.
- Staff will conduct communications in a manner which is positive and respectful of the dignity, values and self-determination of the resident.
- Staff who become aware of confidential information will determine, with the supervisor, who, if anyone, needs to know that information. "Need to Know" will be established on a case by case basis. Whenever possible, residents will be consulted in the process of determining who needs to know.
- As with any other sensitive information, staff will ensure the careful storage of all documentation.

Privacy of Space

Policy:

All residents will have access to private space within their place of residence.

Resident Responsibilities:

- Residents will respect the privacy of housemates' bedrooms by knocking and awaiting permission before entering.
- Residents who share bedrooms will make arrangements whereby each roommate has some undisturbed time alone in the bedroom or in another private area of the house/apartment. Similar arrangements need to be made when residents wish to share space with another individual.

Staff Responsibilities:

- Staff will treat residents' bedrooms as private. Some residents may require monitors for health reasons. When this happens, staff will find ways to respect privacy to the greatest extent possible.
- Unless the well being of the resident(s) requires rapid access, staff will knock and await permission before entering resident bedrooms.
- Staff will support residents' wishes to have undisturbed time alone, or with another consenting person of their choosing, in their bedrooms.
- Staff will make reasonable efforts to ensure rooms other than the residents' bedrooms are also available for those who choose to have private social time with a chosen significant other.
- Staff will facilitate privacy training with residents including training about privacy of information, privacy of body, and the granting and withholding of permission for access to bedrooms.

Privacy of Personal Care

Policy:

Intimate personal care with residents will be conducted in a manner which is respectful of the dignity and privacy of the individual. For the purpose of this policy, "Intimate Personal Care" means assistance with bathing, toileting, dressing, and like activities.

Resident Responsibilities:

- Residents who are touched or assisted in ways which make them uncomfortable will inform the supervisor and/or a trusted person immediately.

Staff Responsibilities:

- Staff who are conducting intimate personal care with residents, in such areas as toileting and bathing, will take special care to respect the dignity and privacy of residents.
- New staff will not, under normal circumstances, provide intimate personal care to residents until a familiarity and trust has been established. This will be determined in consultation with the resident and with the approval of the supervisor.
- Wherever possible, intimate personal care will be provided by staff of the same gender. Other variables such as length of time working in the house, staff and resident comfortability, stated resident (family) preference, and the general support needs of residents will also influence how personal care is conducted and by whom. Agencies and staff need to evaluate and balance the many factors involved with such care. In addition, agencies need to be alert to these issues in assigning and deploying staff.

- Whether or not personal care is provided by same gender staff, staff teams will plan measures which will promote privacy to the greatest extent possible. Such measures might include; ensuring that bedroom and bathroom doors are closed, suggesting that residents wear dressing gowns while using the toilet, installing half shower curtains to enhance privacy while bathing, and using face cloths/bath mitts and/or latex gloves during personal care to preserve personal dignity.
- Staff will not perform "ultra personal" care . Ultra personal care includes such highly intrusive procedures as the application or insertion of creams, medications, suppositories in the rectal, genital, or vaginal areas and performing breast or testicular exams. These procedures will normally be performed by health care professionals or family members. Any exceptions require the written authorization of administration.

Section 3 - Masturbation

POLICY CONSIDERATIONS

The following history, philosophy, and research guided the development of this section of the policy.

“No other form of sexual activity has been more frequently discussed, no other practice more roundly condemned and more universally practiced than masturbation” (Dearborn, 1979 cited in Kaeser, 1996). This observation sums up the attitudinal environment which has impacted on sexual self-pleasuring by people with intellectual disabilities. Residents have been punished for masturbating, they have been denied the privacy needed for any form of normal sexual expression, and some have engaged in inappropriate masturbation practices (often resulting from a prohibitive environment).

It is becoming more common for service providers to support the rights of individuals with intellectual disabilities to express themselves sexually. More consideration is being given to social-sexual education and to the life enhancing benefits of sexual expression. Masturbation serves to reduce anxiety, to develop the persons erogenous self-awareness, and may provide more intense orgasms than mutual sexual behaviour. It is often the only sexual outlet for many adults with intellectual disabilities.

In the ideal situation, an individual has healthy attitudes about masturbation, can effectively fantasize, can stimulate him/herself to orgasm, has a private residential area some or all of the time, has the physical ability to masturbate, and has access to desired masturbation aids. This ideal often does not exist. Barriers to masturbation are frequently ignored. In some cases this has resulted in self-abusive behaviour such as harmful masturbation, non-sexual self-abuse, or harmful rectal stimulation. The latter may be confused with behavioural issues such as fecal smearing when it is actually sexual in origin. In other cases, this has resulted in sexually intrusive behaviour (such as public masturbation), higher levels of anxiety and tension, or sexual frustration.

Where barriers to masturbation exist, assistance must be available. This may be as simple as validating that masturbation is normal and healthy or arranging a private location. It may require more intensive interventions such as clinical training or the use of masturbation aids. When interventions concerning sexuality are utilized, consent must be established. Where a significant communication barrier exists, it may be necessary to rely on behavioural consent, and/or "substitute decision making" (see glossary). Protections against possible abuse must also be in place. While consent may be difficult to establish with residents with severe intellectual disabilities, they must not be excluded from realizing sexual health and enjoyment.

Masturbation

Policy:

Masturbation as a healthy expression of sexuality and as a right of all people will be supported when expressed in a way which does not intrude on others and is not self-injurious.

Resident Responsibilities:

- Residents will express their sexuality in a way which does not result in self-harm and does not result in indecent exposure.
- Residents will accept assistance when needed from staff to ensure that chosen forms of masturbation do not intrude on the rights of others and are not self-injurious or potentially harmful.

Staff Responsibilities:

- Staff will respect the right of residents to express their sexuality through masturbation. Respecting this right includes respecting privacy and refraining from expressing any views to a resident which may be perceived as a restriction of this choice.
- Staff will ensure that each resident has access to private space and time.
- When residents fail to respect privacy, staff will:
 - Respectfully interrupt and redirect to a private location.
 - When necessary, cover intimate body regions with an item such as a coat, towel or blanket.
 - Assist the client in understanding the private nature of sexual acts.
 - Arrange for formal education where necessary.
 - Support residents who have been affected by the indecent exposure.
 - Report the incident to the supervisor.
 - Report repeated incidents via the supervisor to the Sexuality Review Committee (SRC).

- Staff will determine if a resident's masturbatory habits are self injurious. A resident's sexual health, as it pertains to masturbation, will be assessed in his/her "sexuality profile" (see glossary).
- When a resident engages in potentially harmful masturbation, staff will:
 - Intervene immediately.
 - Assess bodily injury and provide the appropriate level of health care (first aid, contact doctor, hospital).
 - Explain to the resident the health concerns presented and the medical assistance being sought.
 - Assist in arranging appropriate counselling, education, and/or masturbatory training.
 - Report the incident to the SRC.
- Staff will recognize that masturbation is varied and that individual's choices may include the use of masturbatory and fantasy aids.
- Staff will recognize that rectal stimulation is sometimes chosen as a form of sexual expression which may be confused with a behaviour such as fecal smearing. In such cases, staff will not discourage the practice so long as it is hygienic and not causing physical harm.
- Staff who are uncomfortable in providing assistance to residents in this area are encouraged to discuss this with the supervisor. Together they will explore avenues of training and/or alternate staff support.
- Barriers to the right to masturbate could result from gaps in education, intellectual disability and/or physical disability. These barriers will be identified and addressed by the staff team or the SRC as deemed appropriate.
- **Under no circumstances will staff provide "guided masturbation training"** (see glossary).

Section 4 - Intimacy Aids and Materials

POLICY CONSIDERATIONS

The following history, philosophy, and research guided the development of this section of policy:

Sexually explicit materials may be referred to as erotica or pornography, depending on the content and the viewpoint of the person using the term. Some oppose the availability of any materials displaying sexually explicit images. Others oppose the stereotypes which are promoted by these products, primarily the depiction of women as objects for male pleasure. Clearly, these are valid concerns. However, it may be paternalistic to prevent adults with intellectual disabilities from obtaining legally available sexually explicit materials. Furthermore, this population may have a particularly compelling case for the use of erotica.

In one study, 85% of non-disabled males and 57% of non-disabled females reported fantasizing daily or on a regular basis. In fact, it has been argued that a significant deficit in erotic imagination can result in serious negative psychological effects (Gallant and Wormith, 1986). It is also known that many adults with intellectual disabilities have difficulty fantasizing. An inability to fantasize may result in decreased sexual pleasure, or in an inability to masturbate to orgasm. Orgasmic dysfunction can result in serious consequences such as public masturbation (the inability to be aroused when in private may be compensated for when stimulated by images or people in public) and/or self injurious behaviour.

These policies reflect a position that residents should not be discouraged from obtaining legally available sexually explicit materials or stimulation aids. Fantasies and explicit images may be an important component of a social-sexual education program. Where inappropriate sexual behaviour has occurred, erotica has proven useful in teaching appropriate behaviour. Training must incorporate the private nature of such materials and the differences between fantasy and reality.

Sexually Explicit Materials

Policy:

The acquisition of legal sexually explicit materials by adult residents will be supported. Residents will respect the private nature of sexually explicit materials by keeping them in a private place.

Resident Responsibilities:

- Residents will limit the use of sexually explicit materials to the privacy of their own bedrooms. Such materials will be stored in a place in the bedroom where they are out of sight to others. Appropriate storage places include a dresser drawer or closet shelf.
- The legal age for obtaining sexually explicit material in Nova Scotia is 18 years.
- Residents will not show or lend sexually explicit materials to anyone under the age of 18. Residents must be aware that it is a criminal offense to show sexually explicit materials to children under the age of 14 years.
- Residents who wish to obtain material, but are unable to do so independently, will accept assistance as arranged by the staff team.

Staff Responsibilities:

- Staff will accept the right of residents to obtain legally available sexually explicit materials and to keep such materials among their possessions.
- Some residents may require assistance with the purchasing of materials. With the prior approval of the Sexuality Review Committee (SRC), staff will assist with same. Staff who are uncomfortable in providing this assistance are encouraged to discuss this with the supervisor. Together they will explore avenues of training and/or alternate staff support.

- Staff will provide, or arrange for, appropriate education in the private use of sexually explicit materials.
- In the case of sexually explicit materials being stored or viewed in a non-private place, staff will remind the resident of the importance of this matter and will assist the resident in identifying a private location for use and storage. Repeated incidents of this nature will be documented by staff and forwarded to the SRC.

Intimacy Aids

Policy:

Like other sexual expressions, sexual aids are primarily a matter of individual choice. Adult residents who choose to use sexual stimulation aids will do so in a way which does not cause self-harm from inadequate hygiene, improper use, or using unsafe objects.

Resident Responsibilities:

- A resident who chooses to use intimacy aids will ensure that such aids are stored in a private place (such as a bureau drawer).
- Residents will ensure that sexual stimulation aids are adequately cleaned before and after each use.
- For reasons of hygiene, objects used for direct sexual stimulation will not be loaned or given to anyone else.
- Residents who are having difficulty adhering to the above responsibilities will participate in educational assistance and training.

Staff Responsibilities:

- Staff will accept that the use of intimacy aids for sexual stimulation is a matter of personal choice. Providing resident responsibilities are met, staff will not interfere with such choices.
- Staff will be aware that intimacy aids may be of benefit to some individuals. Choices may be made from a variety of aids which may ameliorate physical limitations and other barriers.
- Staff will respond to resident requests for information concerning the use of intimacy aids by either providing accurate, non-judgmental information themselves or by assisting the resident in obtaining such information from other sources.

- Staff will refer any resident requests and/or need for intimacy aids to the Sexuality Review Committee (SRC) for complete assessment.
- When residents fail to maintain privacy, staff will remind the resident of his/her responsibilities and will provide or arrange for educational support as required. Repeated failure to maintain privacy will be documented by staff and forwarded to the SRC.
- Staff who are aware of the unhygienic use of intimacy aids will prevent further unsafe use of the object until the necessary educational and training support has been provided.
- Staff will be aware that residents may, on rare occasions, use unsafe items for sexual self-stimulation. Dangerous masturbation practices could include; the insertion of objects such as bottles, candles, or bananas into the vagina or anus; the insertion of objects in the male urethra; or the use of a vacuum cleaner for self-stimulation. All such incidents will be reported to the SRC which will explore the origins of the behaviour and seek safe alternatives.
- When a resident uses an object for sexual stimulation in a potentially harmful manner, staff will; interrupt immediately, arrange for necessary health care, report the incident, and arrange for educational support.
- Staff will be aware of the following associated problems (**adapted from Masters, Johnson and Kolodney, 1985**):
 1. Vibrators provide intense stimulation which may lead to quick orgasms. However, frequent use of a vibrator could lead to a diminished level of sexual pleasure and a resulting sense of restlessness or frustration.
 2. Vibrators may cause health problems such as uterine spasms, increased menstrual flow, or a temporary deadening of feelings in the stimulated area.
 3. Electronic devices, such as penile suction devices, may be poorly manufactured and may pose a physical risk.

Masters, Johnson and Kolodney (1985) also observe that “the vibrator (*or any sexual stimulation object* *) should be seen objectively for what it is for each individual: a toy, a bridge, a crutch, the means for a desired response or a substitute for an absent partner in a time of need” (pp. 292). (* italics added)

Section 5 - Consent

POLICY CONSIDERATIONS

The following history, philosophy, and research guided the development of this section of policy:

Sexual expression between two consenting adults who are in a loving relationship is a life enhancing experience. Trauma can result from non-consenting sexual experiences. Legal barriers to consent include; a stated denial of consent, behaviour which is consistent with a denial of consent, sexual actions toward a person under 14 years of age, and sexual actions with a person under 18 years of age where a relationship of trust and dependency exists.

It is vital that society in general, and human service workers in particular, provide protection to people from coerced sexual acts. At the same time, it may be harmful to prohibit two adults from enjoying a desired sexual relationship. People with intellectual disabilities have frequently been prevented from engaging in consenting sexual relationships due to a number of factors, not the least of which is a disregard for their basic sexual rights. In some cases, residents have been prevented from enjoying consensual mutual sex because caregivers have either inaccurately evaluated the desires of the residents or have determined that the individual's intellectual disability serves as a barrier to consent. It is essential that service providers make all efforts to balance the protection and safety of those supported with a respect for the rights of individuals to healthy sexual expression.

Attempts at providing an "objective" evaluation of capacity to consent to sexual expressions have frequently resulted in pervasive restrictions. Measures of capacity have included; IQ scores, assessments of life skills such as money management, and evaluation of sexual knowledge. Niederbuhl and Morris (1993) assessed 31 residents of a New York State facility using the Socio-Sexual Knowledge and Attitudes Test. Using this criteria, all residents with moderate and severe intellectual disabilities and seven of the twenty people with mild intellectual disability were found lacking the capacity to provide sexual consent. Such criteria serves to withhold the fundamental right of sexual expression from the majority of the people assessed.

Fortunately, there have been experts in this field (Sgroi, 1988; Kaeser, 1992; Ames and Samowitz, 1995) who have started from the premise that sexual rights should not be denied to anyone regardless of disability. They then sought ways to evaluate consent which would provide protection from exploitation and abuse while not discriminating on the basis of disability. These authors expanded the evaluation of consent to include behavioural indices. This policy supports the more inclusive forms of assessment pioneered by these researchers.

Consent for Mutual Sexual Expression

Policy:

Consent is integral to relationships and sexuality. Agencies will implement a process for determining the presence or absence of consent for sexual expression.

Resident Responsibilities:

- Residents will express their consent through their chosen mode of communication, e.g., verbal, American Sign Language, gestures, behavioral, etc.
- Residents will respect consent which is provided or withheld by others.
- Where indicated, residents will participate in a process designed by the Sexuality Review Committee (SRC) to determine if sexual behaviour is consenting.
- Residents will participate in formal and informal socio-sexual education with the aim of developing the skills and knowledge to provide, withhold, and assess consent.
- When a resident is unable to communicate his/her own consent and is unable to determine the other person's consent:
 - The resident will suspend sexual activity until mutual consent has been determined.
 - The resident will be encouraged to participate in a process to determine if s/he would provide or withhold consent in accordance to his/her own preference.
 - The resident will be encouraged to participate in a program designed to address firstly, providing and withholding consent for oneself, and secondly, recognizing the other person's consent.

Staff Responsibilities:

- As part of formal and informal social-sexual education, staff will support residents in understanding and respecting the role of consent in intimate and non-intimate inter-personal contact. Staff will familiarize residents with the legal barriers to consent.
- Special consideration must be given to residents with minimal language skills and/or individuals with low self-assertion skills. Staff teams, directed by the SRC, will conduct and document assessments of each resident to determine his/her capacity to provide consent. Consent capacity will be reassessed at least annually.
- When a resident demonstrates a difficulty with evaluating consent and/or respecting withheld consent, staff will provide education and training. This training will include an understanding of sexual abuse and its consequences.
- Staff will interrupt sexual behaviour between residents when there are indicators that consent may not have been provided by both partners. Reasons for staff to intervene include, but are not limited to; verbal protestations, signs or sounds of distress, medical concerns, indicators from the consent assessment, indicators from the residents communication dictionary (see glossary). Staff response will be non-punitive and respectful of the dignity and privacy of all participants. Where consent continues to be questioned by staff, the SRC will promptly assess the situation.
- Where there is a substantial power imbalance or a significant discrepancy in functional ability between the participants engaging in sexual behaviour, staff will notify the supervisor who will contact the SRC for a consent assessment.
- Where it is clear that nonconsenting sexual behaviour has occurred, staff will notify the supervisor or on-call support immediately. Staff will then document the incident and follow the procedures outlined in the sexual abuse policy.
- Throughout the consent process staff will support residents in a manner which assists them in understanding their rights as they relate to consenting sexual expressions. In evaluating consent, staff will ensure that residents reflect their own priorities, and are not influenced by real or imagined external pressures.

Section 6 - Peer Relationships

POLICY CONSIDERATIONS

The following history, philosophy, and research guided the development of this section of policy:

Statistics Canada (1986) reported that 9.6 per cent of individuals with intellectual disabilities were socially isolated. Almost one in ten people with intellectual disabilities had no contact with family or friends, in person or by telephone (Roehrer, 1995).

"Essential Connections" (see Appendix 4) is a questionnaire which assists staff in identifying and reflecting on the current levels of social inclusion experienced by residents. This evaluation considers questions like whether a resident has quality peer relationships (non-paid and non-volunteer), whether s/he periodically invites a friend or romantic partner over for dinner, and/or whether s/he engages in recreational activities with peers on the weekend. The answers to such questions are likely to reveal that even among those who are not totally "socially isolated", the majority experience low levels of social inclusion.

Service providers have a responsibility to address relationship deficits. To do so, they must be committed to understanding loving relationships and to supporting them as they develop and flourish. It is common for a man and a woman who are intellectually disabled to refer to each other as boyfriend and girlfriend and yet never date or have any contact outside of a sheltered workshop. Such relationships need to be identified and supported. People with intellectual disabilities may never have been exposed to the choices that relationships offer, choices like; spending quality time together, being affectionate, having a person with whom to share one's innermost feelings, having a person with whom to engage in pleasurable love making, and finally, if desired, having a person to commit to as a life partner. It is only by supporting healthy, loving relationships that service providers will help to make these choices available to the consumers of residential programs.

Relationships

Policy:

Friendships, dating and loving relationships are important components of human happiness. Agencies will support residents in developing and maintaining unpaid peer relationships.

Resident Responsibilities:

- Residents who feel lonely, are encouraged to request staff assistance.
- Residents will request assistance, as needed, in expanding their social networks. Areas in which assistance might be sought include information, opportunity planning, and community access.
- A resident who feels uncertain about exploring relationships, including questions about sexual orientation, is encouraged to seek assistance and support from staff and/or another trusted person.
- Residents who wish to marry are encouraged to participate in pre-marital counselling and/or participate in a process designed to explore the joys and responsibilities of marriage and to help develop the skills which increase marital success.

Staff Responsibilities:

- Friendships and romantic relationships are a matter of personal preference. Staff will respect the personal choices of residents and will only intervene when it is necessary for residents' safety. Heterosexual, bisexual and homosexual relationships will be supported equally.
- Relationships require opportunities to begin and develop. Staff will provide the necessary supports to enhance social inclusion and relationship development.
- Staff will assist residents in developing relationship skills. Relationships can include friends, family, dating and long term commitments. Staff will assess

developing relationships and determine whether the individuals involved would benefit from assistance.

- Residents, regardless of their level of independence, will be supported if they wish to date. The level of staff support which is required will be determined by the staff team. The Sexuality Review Committee (SRC) will be available for assistance if required.
- A staff member who has concerns about a resident's well being in the context of a relationship, will discuss his/her concern with the resident(s) in a way which is respectful and does not jeopardize the resident's right to self-determination. Where deemed necessary the staff will discuss his/her concern with the supervisor.
- Staff will consider the effects that institutionalization, segregation and societal homophobia may have had on many adults and which may result in them being uncertain of their sexual orientation.
- Staff who have reason to suspect that a resident requires assistance in exploring his/her sexual orientation, will contact the SRC so that the necessary support can be arranged.
- Staff and the agency will support residents who wish to make a long term commitment to a loving relationship. Staff will meet with the couple to determine the supports they need. Such supports may include; counselling, information on sexuality and sexual health, financial advice, assistance arranging accommodations, and planning the wedding/union.
- Staff will support residents when they encounter challenges or problems within their relationships.

Section 7 - Mutual Sexual Expression

POLICY CONSIDERATIONS

The following history, philosophy, and research guided the development of this section of policy:

Healthy sexual relationships are valued by most people. The pursuit of such intimate relationships can result in joyful and life enhancing experiences. Unfortunately, fears can sometimes overshadow the pursuit or support of such relationships. Unwanted pregnancy and sexually transmitted diseases (STD's) are just two examples. In addition, some forms of sexual expression are more likely than others to pose physical or emotional risks.

This dichotomy presents real challenges. On the one hand, service providers must assist residents in exploring the opportunities that will lead to relationships. In supporting relationships, service providers help residents to achieve their full human potential. On the other hand, service providers who ignore the risks which can be associated with intimacy, place residents in jeopardy. Service providers need to strive for a balance which supports the joys and fulfillment of relationships while providing information that, to the greatest extent possible, protects residents from harm.

Sex education programs play an important role by placing mutual sexual behavior in the context of a growing, loving relationship, where sexual intimacy is not a beginning or end point, but develops out of mutual respect and love between individuals. Residents also need to feel a freedom to discuss problems being experienced in their sexual life, and to expect that assistance will be provided. In addition to education, assistance may include; couple and/or sexuality counselling, overcoming barriers resulting from physical disabilities, or addressing the impact of psychotropic medication on sexual expression.

Mutual Sexual Expression

Policy:

Mutual sexual expression, which is private and between consenting adults, is a healthy and pleasurable expression of affection, bonding, and sexuality. Heterosexual, bisexual and homosexual expressions are matters of individual choice and will be equally supported.

Resident Responsibilities:

- Residents will respect the feelings and desires of sexual partners and will determine the sexual behaviors that are mutually pleasurable.
- Residents will respect the private nature of sexual acts (appropriate location and time).
- Residents will ensure the safety and well being of themselves and their sexual partners by; using appropriate methods of pregnancy and sexually transmitted disease (STD) prevention, practicing good hygiene, and being gentle and considerate.
- Residents will discuss with staff and/or another trusted person any questions or concerns arising from sexual experiences.

Staff Responsibilities:

- Staff will respect residents' rights concerning consenting life enhancing sexual expressions and will ensure their privacy, dignity and confidentiality.
- Staff will support residents in obtaining assistance if they are experiencing difficulties in their chosen sexual expressions.
- Staff will assist residents in understanding private behaviour and will ensure that all residents have access to at least some time in a private location.

- Staff will support residents in understanding that relationships may be enhanced by exploring a spectrum of expressions of affection and sexuality.
- Staff will provide support to residents in the areas of relationships, sexuality education, feelings, counselling, birth control, STD's and consent. (See specific policy statements for details.)
- If a resident fails to respect the private nature of sexual expression, staff will:
 - Respectfully interrupt and redirect to a private location.
 - When necessary, cover intimate body regions with an item such as a coat, towel or blanket.
 - Assist the resident in understanding the private nature of certain acts.
 - Arrange for formal education where necessary.
 - Support residents who have been affected by any indecent exposure.
 - Report the incident to the Sexuality Review Committee (SRC) as appropriate.
- If a resident engages in potentially harmful sexual behaviour, staff will:
 - Intervene immediately.
 - Assess bodily injury and provide the appropriate level of health care (first aid, contact doctor, hospital).
 - Explain to the resident the health concerns presented and the medical assistance being sought.
 - Support the resident in arranging appropriate counselling and education.
 - Report the incident to the SRC.
- If a resident is engaging in multiple partner sexual activity and appears to be unaware of the possible consequences, staff will discuss the concern with the resident. A report will be made to the SRC so that interventions such as counselling, social-sexuality education and possible behavioural programs (see **Kaeser, 1992**) can be considered.

Section 8 - Birth Control

POLICY CONSIDERATIONS

The following history, philosophy, and research guided the development of this section of policy:

While birth control is widely used, it remains a controversial issue. Some religions are opposed to the use of some forms of birth control. Some methods have serious possible side effects. While in the past birth control methods such as the pill and the IUD were used with little concern for the possible consequences, tragic adverse side effects have forced consumers to be more critical of contraceptives and more careful in selecting birth control methods.

For adults with intellectual disabilities, the issue of consent may be the most controversial element of birth control. This was highlighted by the widespread practice of forced sterilization. In response to this violation of rights, protections were established wherein it is now difficult for an adult in residential service to receive a consenting surgical birth control procedure. Also, where the non-disabled rely on condoms as a contraceptive option and to protect against sexually transmitted diseases (STD's), the cost and difficulty of using condoms may make them largely inaccessible to many adults with intellectual disabilities.

The issue of birth control becomes further complicated when a resident experiences substantial barriers to communication. For example, when a woman has been seen to be in a male co-resident's room and both adults have minimal communication skills, what is the ethical response to ensure the prevention of unwanted pregnancies? Does such behaviour present a sufficient risk to warrant the use of birth control? If, despite training, a man cannot effectively use condoms, what protections need to be put in place? Naturally, the consequences of not acting (an unwanted pregnancy, STD's) must also be weighed.

Birth Control

Policy:

Birth control methods will be considered by, and/or for, all residents who are believed to be engaging in intimate forms of sexual activity.

Resident Responsibilities:

- The resident will participate in a process designed to assist him/her in deciding whether the use of birth control would be suitable. This process will involve evaluating the benefits and risks of the various available contraceptive options, consulting with a physician, and seeking further information from other sources such as birth control clinics.
- The resident will demonstrate an ability to use the selected contraceptive effectively. When problems are experienced in this regard, the resident will participate in assessment and training to ensure effective use of the chosen birth control method. If the resident continues to be unable to use the selected contraceptive adequately, alternative methods will be pursued.
- The resident will participate with professionals in follow-up care and s/he will seek assistance if any problems arise.

Staff Responsibilities:

- Staff will support the resident in making informed decisions about birth control by making relevant information accessible to the resident. Staff will not influence the decision of the resident.
- In cases where a resident experiences a barrier to communication, staff will initiate a process with the resident which is aimed at determining whether s/he is sexually active. Where sexual activity can be reasonably presumed to exist, staff will facilitate a process which ensures that the resident is provided with as much opportunity as possible to express his/her choices concerning birth control.

- When there is any uncertainty regarding a resident's capacity to make an informed choice regarding birth control, staff will discuss the matter with the supervisor and the Sexuality Review Committee (SRC).
- Staff will assist the SRC in evaluating the need for a substitute decision concerning birth control. The resident will be informed of this process and will be encouraged to fully participate. Where the need for a substitute decision has been determined, the family/guardian and health care professional(s) will be immediately involved. Recommendations may be made by the SRC regarding the contraceptive options which will provide the greatest benefits and least risks to the resident while best reflecting his/her priorities and life choices.
- When there is any uncertainty concerning a resident's capacity to effectively use a selected birth control method, staff will monitor the resident's use of the contraceptive. Effective use of the method will be evaluated and documented and training will be provided where necessary. Continued inability to effectively use the contraceptive will be reported to the SRC.
- It is recognized that while the benefits of birth control are great, the potential for harm is also significant. Accordingly, an Information Sheet outlining the potential risks of the selected birth control method will be placed in the resident's health records. All direct care staff will indicate their awareness of potential complications by reading and signing the Information Sheet.

Section 9 - Pregnancy and Parenting

POLICY CONSIDERATIONS

The following history, philosophy, and research guided the development of this section of policy:

Among the non-disabled, pregnancy and childbirth are typically seen as joyful events. When pregnancy involves adults with intellectual disabilities however, the event has often been viewed as catastrophic. This policy begins with the assumption that pregnancy and childbirth are welcome events. Agencies need to work from the premise that adults with intellectual disabilities, like the non-disabled, may consider parenting a desirable social role, especially when they are in long-term, loving relationships.

The history of human services is full of examples where the right to bear children was denied to adults with intellectual disabilities. The recent history of widespread non-consenting sterilization is evidence of this fact. There are now legal protections against coerced sterilization. Nevertheless, societal prejudice and a lack of information on the part of service providers continue to prevent many adults with intellectual disabilities from experiencing the joys and challenges of parenting.

The violation of the right to parent, based solely on disability, cannot be supported. On the other hand, there is an immense emotional cost to be paid when a parent no longer feels capable of parenting or loses custody of a child. In addition, neglect or abuse can result in long-term harm to the child. All of these factors must be considered during any assessment of the parent(s)' capacity to raise a child. Such assessment(s) may serve to prevent future trauma. They must, however, be conducted in a manner which safeguards the resident(s)' rights and dignity.

Pregnancy

Policy:

The agency will support residents by ensuring access to the information and counselling required to make informed decisions regarding pregnancy.

Resident Responsibilities:

- A resident who suspects that she is pregnant will inform a trusted person and seek medical confirmation.
- A resident who is pregnant, or who wishes to become pregnant, will participate in professional pregnancy counselling to facilitate informed decisions regarding firstly, whether to continue the pregnancy to term or to terminate the pregnancy, and secondly, whether to actively parent the child or place the child for adoption. Important information for the prospective parent(s) to consider includes; the benefits and responsibilities of parenting, the impact of the pregnancy on physical and emotional health, relationship(s), career, finances, and independence, and whether genetic counselling is desired.
- When there are reasonable grounds to question the resident(s)' capacity to reach informed decisions concerning pregnancy and parenting, she/they will participate in a process to ascertain whether substitute decision making is required.
- A resident who is determined to be at high risk of losing custody of a child, will attend counselling to explore available options and to consider the emotional impact of bringing a pregnancy to term.
- The woman is encouraged to involve significant others such as the father of the baby, a friend, or a relative, to support her in this process.

Staff Responsibilities:

- Staff will assist resident(s) in a non-judgmental and supportive manner, encouraging self-determination throughout.
- Staff will assist the resident in obtaining medical care to confirm a suspected pregnancy.
- Staff will immediately inform the supervisor of a resident's confirmed pregnancy. The supervisor will, in turn, inform the Sexuality Review Committee (SRC).
- Staff will assist the resident in accessing community services which will be of benefit in making informed decisions concerning the options of pregnancy, abortion, parenting, and adoption.
- Staff will support the mother during the decision making process concerning the involvement of the father of the baby.
- If the father of the baby is served by the same residential agency, staff will arrange counselling to assist him in identifying and communicating his feelings and hopes concerning the pregnancy.
- When there are reasonable grounds to question a resident(s)' capacity to reach informed decisions concerning pregnancy and parenting, staff will refer the matter to the SRC which will ascertain whether substitute decision making is required.

Parenting

Policy:

The agency will support adult residents who make informed decisions to parent and will assist in arranging the supports needed to realize these goals.

Resident Responsibilities:

- The resident(s) who chooses to become a parent(s) will be capable of providing a safe and nurturing environment for the child, either independently or with existing or available supports.
- The resident(s) will accept the assistance of the Sexuality Review Committee (SRC) in identifying and utilizing the supports needed to successfully parent.
- The resident(s) will bear the primary responsibility for meeting the basic needs of the child.
- The resident(s) will inform a staff member when s/he feels that additional assistance in child rearing is required.
- The resident(s) who relinquishes or loses custody of the child, will explore available options with, and seek emotional support from, trusted others and/or a therapist.

Staff Responsibilities:

- Staff will assist the resident(s) in beginning to explore the joys and challenges of parenthood as soon as the decision to parent has been made. This assistance may include the use of community resources and supports, such as; living arrangements which support both parent(s) and child, parenting skills counselling (group and/or one-on-one), community parent resource centers, financial planning, mother and baby wellness and nutrition clinics, baby-sitting (respite) , community health nursing services, and so on.
- It is recognized that the apprehension of a child by Child Protection

Authorities may result in severe emotional trauma for all concerned. In an effort to prevent apprehension, the service provider will offer the resident the option of participating in an evaluation. The evaluation will be aimed at assessing the resident's present ability to parent and identifying the interventions which might prevent future difficulties. The evaluation will be conducted by a multidisciplinary team and overseen by the SRC.

- Staff who identify that a resident is experiencing difficulty parenting, will inform the supervisor immediately. The supervisor will refer persistent or significant problems to the SRC. The committee and staff will identify the training and supports required to assist the resident in improving his/her parenting skills.
- The agency and its staff are responsible under the law to report all suspected child abuse or neglect to the Child Protection Authorities.
- Ultimately, Child Protection Authorities are responsible for determining whether minimum parenting standards are being met. If a child is being apprehended by the authorities, staff will notify the supervisor who, in turn, will notify the SRC.
- In the event of a child being apprehended, the SRC will ensure that the resident is informed of his/her rights and options and will seek advocacy for the resident. The advocate will represent the interests of the resident in ascertaining the requisite skills and services which will facilitate the eventual return of the child. Advocacy may also include legal representation.

Section 10 - Sexually Transmitted Diseases

POLICY CONSIDERATIONS

The following history, philosophy, and research guided the development of this section of policy:

Until recently it appeared that sexually transmitted diseases (STD's) were declining in prevalence, and that the more serious forms were curable. With the emergence of HIV/AIDS, failure to adequately protect oneself became potentially fatal. Society now struggles with the complex issues of protecting people from exposure to this deadly virus while maintaining the rights of individuals to confidentiality, self-determination, and protection from discrimination.

Within this context agencies struggle with other important issues. What protections are reasonable when a resident has not been able to be taught to use a condom? If a resident is engaging in high risk behaviour (sexual relations with prostitutes, multiple sexual partners, expressed rejection of safer sex practices, shared needle use, etc.), what precautions need to be implemented to ensure the person's and partner's safety?

Also, the confidentiality of a person who has tested positive for an STD (including hepatitis and/or HIV/AIDS) is protected under the law and a physician may only release such information to the Public Health Unit. There are also laws which protect people against forced testing.

While agencies cannot force individuals to engage in safer sex practices nor to undergo testing, they may find themselves liable for the behaviour of the people they serve. Difficult ethical and legal questions ensue. These point to the very great need for agencies to implement resident and staff education programs which are aimed at preventing high risk behaviour, minimizing violations of client rights, and protecting the rights of others.

Safer Sex Practices

Policy:

The agency will ensure that residents who engage in mutual sexual contact are provided with information about Sexually Transmitted Diseases (STD's) including; risks, means of transmission, and recommended precautions.

Resident Responsibilities:

- As part of social-sexual education, residents will learn about the risks of STD's and the methods of prevention.
- A resident who is engaging in high risk behaviour (unprotected sex with new or multiple partners, anal intercourse, oral sex, use of non-prescribed intravenous drugs or sexual contact with an intravenous drug user) will receive counselling concerning testing and preventing the transmission of STD's.
- A resident who suspects that s/he has an STD will; inform a trusted person and contact a physician immediately, follow any directions from the physician for treatment, and ensure that his/her future sexual behaviour does not result in transmission of the STD.
- A resident who is at high risk of contracting an STD, and who is unable to provide informed consent, will participate to the best of his/her ability with the Sexuality Review Committee (SRC) in exploring possible protections including; counselling, behavioural and knowledge assessment(s), education, and STD testing. The client's guardian will be invited to participate in the SRC meeting and/or will be contacted for substitute decision making.

Staff Responsibilities:

- Staff will participate in staff training programs concerning the impact and identification of various STD's and safer sex practices. They will also participate in sensitivity and human rights training concerning sexual expressions, safer sex, and supporting adults with an STD.
- Staff will ensure that items for sexual health and STD prevention, such as condoms, are readily and discretely available to residents in the home.
- Staff will ensure that adequate education and training in safer sex practices (such as condom use) is provided to all residents who are willing to participate in such programs.
- Where condom use continues to be a difficulty for a resident, staff will discuss this with the resident and the SRC. Alternate safer sexual expressions will be explored with the resident.
- Staff who have reason to suspect that a resident may have an STD or is engaging in high risk behaviour, will discuss this concern with the resident and the supervisor. If concerns persist, the matter will be referred to the SRC for further guidance.

Section 11 - Sexual Abuse

POLICY CONSIDERATIONS

The following history, philosophy, and research guided the development of this section of policy:

It is widely recognized that long-term and profound harm may result from sexual abuse. Sexual abuse occurs when a barrier to consent exists regarding any sexual activity. Barriers to consent include; a stated denial of consent, behaviour which is consistent with a denial of consent, sexual actions toward a person under 14 years of age, sexual activities with a person under 18 years of age where a relationship of trust and dependency exists. Sexual abuse includes, but is not limited to, criminal offenses such as sexual assault, public nudity, and sexual touch or exploitation. As direct care staff are in a position of trust and power, any sexual activity between staff and resident is sexual abuse (Roehner, 1992).

People with intellectual disabilities have suffered extraordinarily high rates of sexual abuse resulting from; trained compliance, insufficient social-sexuality education (including recognition of safety and abuse), social isolation, reliance on caregivers (especially for intimate care), service providers disregard for resident privacy, communication barriers, and a low risk of criminal charges being laid when the victim has a mental disability (as defined by law). Prejudicial attitudes concerning people with disabilities may result in sexual abuse not being recognized or believed. Also, the persons who were abused may not be regarded as credible witnesses due to their disability. While measures have been taken to make legal retribution more accessible to those with intellectual disabilities who have been sexually abused, substantial barriers in the criminal justice system remain.

Agencies can play significant roles in decreasing vulnerability to sexual abuse by implementing a variety of preventative measures:

- *Train staff in recognizing and responding to sexual abuse.*

- *Ensure that personal care is provided in a way which respects the person's privacy and dignity (see Hingsburger, 1995 for some excellent suggestions on "Ethics of Touch").*
- *Provide social-sexual education to all residents.*
- *Complete sexual abuse risk assessments for all residents for each of their daily routines and determine how the risk can be reduced (Heighway, et. al, 1992).*
- *Plan one-on-one time with residents (even if only ten minutes per person per day) to discuss their day.*
- *Ensure that caregivers respect and support the self-determination of residents.*
- *Inform all staff that suspected sexual abuse must be reported to the Minister of Community Services (Adult Protection Act., 1985 c. 2, s. 1).*
- *Finally, facilitate opportunities for residents to experience social inclusion including peer relationships.*

Sexual Abuse

Policy:

All individuals have the right to live free of sexual abuse and sexual harassment. Neither sexual abuse by one resident to another, nor any sexual act on the part of staff toward a resident, will be tolerated. Any suspicion of or information about sexual abuse will be reported immediately.

Resident Responsibilities:

- Residents are encouraged to participate in social-sexual education programs which include understanding sexual abuse.
- Residents will refrain from behaving in ways that are considered abusive or harassing by others.
- Residents are encouraged to report to the supervisor or another trusted person any acts of a sexual nature made toward them, whether past or present, to which they did not consent.
- Residents who witness abuse of others are encouraged to report same.

Staff Responsibilities:

- Staff teams will conduct assessments of potential risk for abuse on all residents.
- If staff witness or suspect any sexual behaviour for which mutual consent does not exist, they will stop the behaviour in a non-punitive manner, and provide the necessary support to those affected. Staff will examine the victim for any indications of injury. They will ensure that they take sufficient precautions to preserve, and not contaminate, evidence. These precautions may include arranging for a forensic medical examination. Also, staff will not ask leading questions. Some specific conversational responses are provided as ideas for staff in Appendix 2.

- In protecting evidence, staff will adhere to the following guidelines (adapted from Haber and Broadhurst, 1996) :
 - ensure the victim does not brush teeth, shower, or wash.
 - preserve physical evidence such as clothing and sheets.
 - call ahead to the hospital and inform them that a forensic evaluation and treatment for a sexual abuse victim is required.
 - discuss with the physician whether follow-up examination is required for any bruising which may not be visible for up to seventy-two hours.
 - protect residents and report the alleged abuse, but do not attempt to investigate. This will be done by someone with the requisite, specialized training.
- Staff will ensure that necessary assistance and emotional support are provided to residents throughout the above processes and throughout the subsequent stages of coping with the sexual abuse. Staff will note that, depending on what has occurred and the individual's reactions, the abused person may, or may not, wish to be physically comforted.
- Staff will immediately familiarize themselves with, and carefully adhere to, the "Sexual Abuse Team Protocol" (see Appendix 1).
- Staff will offer, or arrange for, counselling for any resident involved in sexual abuse, whether s/he be the abused, the abuser, or a witness.
- Staff who participate in a sexual abuse investigation may find the experience traumatic. They will avail of opportunities to debrief accordingly.
- Staff will minimize the risk of further abuse by providing education and training to the abused and the abuser, by providing extra supervision, and/or by separating the parties, as necessary.
- Staff will report all cases of sexual abuse, or suspected sexual abuse, to the Abuse Assessment Team. This team will follow the "Sexual Abuse Team Protocol" and will; decide on the assessment steps required, give direction on immediate actions that need to be taken to reduce the risk of further abuse, determine who needs to be notified, and consider legal or other official actions. The Abuse Assessment Team will also refer the matter to the

Sexuality Review Committee (SRC) which will advise on support and follow-up with the residents involved. Both the Abuse Assessment Team and the SRC will provide for as much self-determination as possible on the part of the residents affected. They will also be mindful of the communication limitations of residents with minimal language skills and will ensure that they allow for same throughout the process.

- Staff will provide an atmosphere wherein residents are comfortable with disclosing past abuse. As with reports of recent abuse, staff will take care to not ask leading questions nor to draw any immediate conclusions. Instead, they will document and report the disclosure to the supervisor.

Section 12 - Offending Sexual Behaviour

POLICY CONSIDERATIONS

The following history, philosophy, and research guided the development of this section of policy:

It is a hurtful and inaccurate myth that people with intellectual disabilities are less capable than the non-disabled of controlling their sexual impulses. It is equally prejudicial and inaccurate to ignore the reality that sexual offenses which harm others are sometimes committed by people with intellectual disabilities. Sexual offenses committed by both the disabled and the non-disabled are frequently not reported. In residential service, contributing factors to under reporting include; misinterpreting sexual offenses as being non-sexual and/or non-harmful in nature, lack of clear agency procedures concerning the reporting of sexual offenses, insufficient staff training, and the mistaken belief that nothing can be done to assist a person with an intellectual disability who has committed an offense.

There is now a growing body of research, publications, and clinical tools available to clinicians and service providers to assist people who have committed inappropriate or deviant sexual acts. Interventions may range from social-sexual education to intensive treatment. What is clear is that the cost of ignoring offending sexual behaviour and of doing nothing can be detrimental to both the offender and to others who are in contact with him or her.

Service providers have a responsibility to identify knowledge/skill deficits, and/or behaviour which places a resident at risk of hurting others and of coming in conflict with the law. At the same time, service providers must focus on expanding social networks and on educating and supporting residents in a way which facilitates life enhancing relationships.

Offending Sexual Behaviour

Policy:

The agency will support residents who engage in sexual behavior which has the potential of placing them in conflict with the law. Such support will be provided within the framework of the least restrictive model with the goal of minimizing risks and sustaining quality community life.

Resident Responsibilities:

- Residents will refrain from behaving in ways which are in conflict with the law.
- Residents who behave in ways which are in conflict with the law will participate in interventions aimed at preventing the recurrence of such offenses.

Staff Responsibilities:

- Staff will be alert to inappropriate acts which may place residents at risk of being accused of offending behavior.
- Staff will report the above acts/behaviours to the supervisor. Staff will adhere to confidentiality policies throughout this process.
- The supervisor and staff, in consultation with agency program consultants, will develop strategies to reduce the risk of offending behaviour. Strategies to be considered include education, counselling, assistance, increased supervision and other means of support.
- If behaviours and risk of conflict with the law persist, the supervisor will report same to the Sexuality Review Committee (SRC).
- The SRC will oversee further assessment of the inappropriate behaviours and any subsequent interventions.

APPENDIX 1

Sexual Abuse Team Protocol

Team Composition:

Two or more of the following may constitute the team.

1. The Director of the house.
2. The Program Director/Coordinator of the house.
3. An alternate Director.
4. An alternate Program Director/Coordinator.
5. The Executive Director.
6. Other members as required.

Other members might include family, therapists, community services officials, etc. as indicated by the specific incident. The team is composed in this manner to provide optimum handling of the incident. In smaller agencies, the administrative positions outlined in #'s 1 to 5 above may need to be substituted with other agency or community personnel. In either case, the immediate supervisor is deliberately left out of the mix so that s/he can be free to provide on site support.

How the team is activated:

Once a resident has been determined to be at risk, the staff who made this determination will contact the supervisor with the relevant information. The supervisor will then contact the director, who will initiate the formation of a team.

Team Goals:

As directed in specific policies and procedures, actions will be taken to ensure the safety and security of those involved in, or affected by, the incident. In general the team will:

1. Assist in stabilizing the situation, including providing any immediate or emergency interventions for those involved. This may include people who have not been directly involved but have been affected nonetheless.

2. Conduct an initial assessment of the situation.
3. Provide support and direction to those involved in or affected by the incident.
4. Provide access to resources relevant to the incident, including the provision of incident debriefing and long term support for those involved.
5. Provide written and verbal reports as indicated by the incident.

Further information regarding these goals is outlined below.

Team Responsibilities:

The key team responsibility is to begin an assessment of the incident while keeping the supervisor available to ensure all those within the staff and resident group of the house are provided with immediate measures of stability. The supervisor will be called on to provide information/action as determined by the team as the examination continues. Additionally, the team must determine whether an internal or external investigation should be pursued and whether outside authorities should be involved.

Actions to be Taken:

Actions will be taken as applicable to the incident. All steps need to be looked at simultaneously in the review process. These actions may include but are not limited to the following:

- Support and Direction: delegate immediate responsibilities in conjunction with the supervisor.
- Stability: coordinate additional staffing as required; establish processes which will prevent additional abuse/incidents.
- Assessment: Meet with reporting staff, supervisor, residents as required; coordinate family and support persons as needed; cooperate with external investigating team as required.
- Coordination: Coordinate resources such as Community Services, Adult Protection, and relevant generic services.

- Reporting:
 - contact family/support persons initially by phone
 - follow up contact in person with family and support persons
 - notify executive director, who notifies Board of Directors as needed
 - contact police, Adult Protection, and/or other authorities as required
 - submit detailed written report to Central Office upon completion of the process; report to be retained in organization's files
 - include in report any recommendations for protocol revisions as a result of this incident

APPENDIX 2

Non-leading Questions and Statements concerning Sexual Abuse

The following script will assist staff in ensuring that witness statements are not contaminated:

" Please tell me what happened."
"What you are telling me is very important."
"What happened next?"

If clarification is required, ask only the following as appropriate:

"Where did it happen?"
"Who was there?"
"What was said to you?"

Questions must NOT:

1. Contain the answers.

As in: "Did it happen in your room?" or "Did s/he tell you not to tell?"

2. Be choices of answers.

As in: "Did s/he touch you on the thigh or on the penis/vagina?" or "Did this happen on the bed or on the floor?"

3. Name the suspect before the victim identifies him/her.

As in: "Did Zach touch you?" or "I have been told that your uncle/aunt made you feel bad."

4. Describe the alleged offense.

As in: "Did he put his finger inside your vagina?" or "Did he tell you to rub his penis?"

5. Contain your own assumptions.

As in: "We want you to tell us how Stephen hurt you." or "This happened in his bedroom, right?"

(adapted from Frederick cited in Yuille et al, 1993)

APPENDIX 3

Assessing Capacity to Consent

The information required to assess an individual's capacity to consent may be acquired in a number of ways. For those with effective communication abilities, participant interviews may elicit the necessary information. In other cases, information may need to be gathered from past or present caregivers. In any case, family members or guardians should be informed of the evaluation and be given the opportunity to participate. Not only is the relationship between family members/guardians and residents highly valued, but they often possess crucial information and insights which would be highly beneficial to the process (Pendler and Hingsburger, 1990). Once a determination has been made, it should be reassessed at least once a year to allow for changing knowledge and abilities.

Service providers may find it helpful to consider the following questions as they attempt to determine a resident's capacity to consent: (adapted from Fred Kaeser, 1992)

1. When interacting with others:

- Do the residents appear happy and content?
- Does their body language suggest that they enjoy each other's company?
- Does each participant seek the other's company?
- Does each participant actively locate him/herself in proximity to the other participant?
- Does s/he enter the other person's bedroom?
- Has s/he ever indicated a desire to escape from physical contact with the other resident?
- Does s/he appear under duress or show signs of discomfort?
- Is there a substantial power discrepancy (e.g. assertiveness, IQ) between the

participants ?

- Does each participant occasionally initiate contact with the other?

2. Regarding health and safety:

- Does the resident understand the transmission and impact of Sexually Transmitted Diseases (STD's)?
- Does the resident know how to use a condom?
- Has either of the participants engaged in behaviour that poses high risk for STD's ?
- Does each participant know how to use a condom?
- Has each resident been tested for communicable diseases (STD's, Hepatitis)?
- Is there reasonable protection from unwanted pregnancy?
- Does each participant demonstrate a respect for the private nature of sexuality (appropriate time and place)?
- Does either individual use aggression to exert his/her will?
- Are there other safety concerns?

3. In terms of understanding and expressing feelings and choices:

- Does the individual communicate displeasure (e.g. reject disliked food)?
- Has the individual been witnessed to say no to a request?
- Has the individual sought staff or other assistance for interpersonal conflicts?
- Does the individual understand public and private locations?

- Does the individual understand intimate and non-intimate touch?
- Does the individual alert staff when experiencing pain or discomfort?
- Does s/he express feelings to others?
- Does s/he exercise choice between those s/he wants and does not want to interact with?
- If participant could verbalize his/her preference concerning this relationship/sexual expression, what do you think s/he would say?

APPENDIX 4

Essential Connections

Editorial Note:

This was retyped for clarity from original documents prepared by Joan MacDonald, Holland College, P.E.I.

Directions:

In order to feel good about ourselves, to feel productive and in on things, all of us need eight *essential connections* (see accompanying sheet). That is, we all need access to information (for instance, about sexuality and relationships) and a significant person in our lives like a mentor, an intimate relationship, a close friend.

We need to belong to a group, like a church group, a recreational organization, etc. We all need a meaningful role in life. We need support people around us, a source of joy, a system of values, a sense of family history, and a sense of place or a feeling of belonging to a community.

The following questions will help you fill in the *essential connections* sheet for a person you work with. In order to answer them, spend some time with this person.

Ask the questions, observe the person, go places with him/her. Do anything you need to do to get to know what his/her life is like.

IF I WAS _____

1. What would my day be like? my weekend? my week? my year?
2. Who are the people in my life?
3. Who are my friends? How many friends do I have?
4. Who and how many people are paid to be in my life?
5. What is the quality of my relationship with others:

- others do for me

- one-sided
- patronizing
- respectful
- caring
- loving
- instructional only
- mutual friends

6. Who do I give to? - listening ear, - friendship, - help.
7. What possessions do I have? What do I call my own? What is precious to me?
8. What do I like?
9. How often do I go to: movies, skating, shopping, dances, restaurants, church, visit friends, walks, vacations, family events?
10. What choices do I make in the course of the day?
11. Who do I tell my secrets to? Are my secrets kept?
12. Who touches me, hugs me, holds me? How often? How often is the touch or hug *my* choice?
13. When I make decisions to act for myself, what happens?
14. Who loves me? Who do I love?
15. How do I make others understand my needs, desires?
16. What organizations, clubs, groups do I belong to? What role do I play in those organizations? For instance, do I participate or do I feel like an outsider?
17. What do I laugh about? When did I last cry and why?
18. Do I have a family? Do they visit?
19. What kind of work do I do? Is it something I enjoy?

20. What do I have to be proud about?

Using these questions as a guide, answer the following:

1. How are my needs for belonging, love, security, autonomy, personal power, freedom, choices, fun, being met?
2. If you were this person, what would you want in your life? Which *essential connections* are missing?

Building and Maintaining Essential Connections of: _____

Connection	How to Build	Who	How to Maintain	Who
Information				
Significant Person				
Group				
Meaningful Role				
Support				
Source of Joy				
System of Values				
History				
Belonging				

(adapted from Michael Polowdny, New York)

APPENDIX 5

Sexual Abuse Risk Assessment

This is a process (formal or informal) which examines the broad categories which may place an individual at risk of being abused. Such categories include but are not limited to; cognitive functioning, physical disability, entering a relationship for the first time, unusual or new sexual behaviour, visits to environments where known or suspected abuse has occurred or is occurring, and unusual or unexplained physical presentations.

Staff must be aware of changes in relationships, environment, staffing, and family dynamics which may lead to potentially abusive situations. Information from the sexuality profile (see glossary) may provide baseline information by which significant changes may be viewed. Major changes in behaviour, positive or negative, and particularly of a sexual nature, should be documented. Staff must also be alert to, and document; infections around the genital area, bruising on unusual areas of the body, new or unusual sexualized behaviour, or sexualized behaviour which is beyond that which is thought to be within the experience of the resident.

The process for assessing risk of sexual abuse is facilitated by:

- Agencies having sexuality policies.
- Staff and residents having access to and participating in sexuality education.
- Residents having privacy.
- Staff being aware of the status of evolving relationships between residents.
- Changes in the nature of relationships being documented in order that potential signs of abuse may be detected.
- Communication dictionaries (see glossary) being developed for residents who need them.

Thoughtful consideration of the above variables by service providers will go a long way to facilitate the prevention and detection of abuse. Few formal tools exist for evaluating the possibility of sexual abuse. The research conducted by this project did lead to one such assessment, "Sexual Abuse Risks Assessment - S.A.R.A", (STARS, Heighway, Kidd Webster, Shaw, 1992, A Waisman Center Program). *While the sponsors and authors of this project take no responsibility for the validity of the assessment, it is included here for the information of readers.*

SEXUAL ABUSE RISK ASSESSMENT S.A.R.A.

Editorial Note:

This was retyped for clarity of copy from "STARS - Skills Training For Assertiveness, Relationship - Building and Sexual Awareness", by Susan Heighway, Susan Kidd Webster, Marsha Shaw, 3rd edition, July, 1992. S.A.K. means "Sexual Attitudes and Knowledge" and appears in the same document.

This tool is used to identify situations or factors in the participant's life that may be increasing the individual's risks for abuse. The assessment provides a profile that aids the trainer in:

- 1) identifying areas of concern where support, training, or intervention should be focused.
- 2) individualizing training and making the content and activities of the training relevant to the participants life.

Procedure

1. The trainer should identify a person who is most familiar with the participants to be responsible for completing the assessment. This person is often the referral source. If the trainer knows the participant well and is familiar with the individual's activities, relationships, and daily routines, then he/she may complete the assessment.
2. To the extent possible, the individual being assessed should be involved in the completion of the assessments.
3. The assessor may want to consult with significant others involved with the individual.
4. Some questions may seem difficult to answer. It is all right to write "don't know."
5. There is no formal scoring involved. We suggest you *questions and sections that raise issues around safety. If moderate or high risks are checked at the end of a setting section, *this setting.
6. After completing the assessment, the trainer needs to carefully review the information in order to:
 - a) identify concerns that may increase risks for sexual abuse or prevents the development of positive sexuality.
 - b) identify strengths and positive aspects in the participant's life settings and

relationships.

This information, along with the results of the S.A.K. will be used in developing an Individual Training Plan (see form at end of this section).

POINTS TO PONDER

Supervised does not necessarily mean safe.

Unsupervised does not necessarily mean unsafe.

Group living does not necessarily mean safe.

Independent living does not necessarily mean unsafe.

I. LIFE SETTINGS ASSESSMENT

In this section, you will assess the physical safety and security of the individual's environments and identify his/her settings as places that enhance or inhibit healthy expressions of sexuality. These settings include home, school, work, leisure, and recreation, and other settings specific to the individual.

A. Home

1. Describe type of residence (e.g., foster home, group home, adult family home, birth family, supported apartment, unsupported apartment, nursing home, institution):
2. Describe location (e.g., residential neighbourhood, business area, rural, isolated):
3. What is the size of the residence (number of people)?
4. Is the residence in good repair and adequately secured against intruders (e.g., adequate locks on doors and windows, telephone or emergency call system)?
5. Is the residence arranged to respect the person's right to privacy? Are there private spaces?
6. Does the individual have his/her own bedroom?
7. If the person is in a group living situation, does the residence have a policy regarding sexual expression? If so, what is it? Does the individual understand and agree with this policy? Does the staff understand and agree with the policy?
8. Do you think these policies enhance or inhibit expression of healthy sexuality?
9. Do you think the characteristics of the residence (e.g., location, daily schedule, policies) support or inhibit the individual in developing friendships (with non-paid staff) and close relationships? Explain:

10. Has the person or others ever expressed concern about safety in this setting? If yes, what is the nature of the unsafe feeling?

Based on your knowledge about sexual abuse and your understanding of this setting, how do you rate the risk of sexual abuse in this setting?

_____ low _____ moderate _____ high _____ unable to assess

B. Educational or Vocational/Work Setting

(If a person has more than one job, describe each setting)

1. Describe the type of setting (e.g., public school, adult activity centre, community job, sheltered workshop, etc.).
2. Beside staff, are there people who do not have disabilities in this setting?
3. Describe location (e.g., downtown, isolated area, business district):
4. How does the person get there?
5. What are the hours of training or employment?
6. Within the site, does the individual have isolated or private workspace or does he/she work beside others? If isolated, are there other workers in the building or the area?
7. Does the setting have a stated policy regarding sexual expression and is the person aware of the policy?
8. Does the setting have a stated policy regarding sexual harassment? Is the individual aware of the policy and does he/she know how to report incidents?
9. Does the setting foster building of social networks and friendships for the individual?
10. Has the individual ever expressed concern about safety in this setting? If yes, what is the nature of his/her concern?

How do you rate the person's risk of sexual abuse in this setting?

_____ low _____ moderate _____ high _____ unable to assess

C. Leisure/Recreation Settings

1. What does the individual typically do for leisure and recreation? List activities.

2. For each of these activities, describe the settings in which they take place as indicated below:

<p>Activity:</p> <p>Place:</p> <p>Who With:</p> <p>Transportation:</p> <p>Does it provide an opportunity for interaction with persons who do not have disabilities?</p> <p>Does it provide an opportunity for enhancing friendships, social relationships?</p> <p>Do you consider the risks for sexual abuse in these settings to be:</p> <p>_____low _____moderate _____high _____unable to assess</p>
--

Activity:

Place:

Who With:

Transportation:

Does it provide an opportunity for interaction with persons who are not disabled?

Does it provide an opportunity for enhancing friendships, social relationships?

Do you consider the risk for sexual abuse in this setting to be:

_____ low _____ moderate _____ high _____ unable to assess

Activity:

Place:

Who With:

Transportation:

Does it provide an opportunity for interaction with persons who are not disabled?

Does it provide an opportunity for enhancing friendships and social relationships?

Do you consider the risk for sexual abuse in this setting to be:

_____ low _____ moderate _____ high _____ unable to assess

D. Other Settings the Individual Frequent (Respite, Camp, Relatives)

1. Describe the setting:
2. Why does the individual go there?
3. Transportation:
4. Has the individual expressed any concerns about his/her safety in this setting.
5. Do you consider the risk for sexual abuse in this setting to be:
 low moderate high unable to assess

1. Describe the setting.
2. Why does the individual go there?
3. Transportation:
4. Has the individual expressed any concerns about his/her safety in this setting.
5. Do you consider the risks for sexual abuse in this setting to be:
 low moderate high unable to assess

II. RELATIONSHIP ASSESSMENT

A. Family

Does the person have contact with family members?

With whom?

How Often?

Does person express positive regard toward family members?

Any Concerns?

B. Friends (Other than service providers)

Does the person have friends?

A close friend?

A friend who does not have a disability?

How often does he/she see these friends?

Does the person want more friends?

Does the person date?
one person?
more than one person?

Any concerns?

C. Intimate Relationships

(While these questions are very relevant to assessing risks of sexual abuse, they are optional due to personal nature)

Does the person have intimate relationships?

What types of sexual activity does she/he engage in, (e.g., kissing, hugging, petting, intercourse)?

With the opposite or same sex?

With one person?

With more than one person?

Any concerns?

D. Service Providers

Most likely the person you are working with is involved with numerous service providers (e.g., residential counsellors, job coach, social workers, health care providers, case managers, skill trainers).

In general, does the person perceive these people as "Authority Figures"?

Does the person need assistance from staff for basic physical care (e.g., dressing, bathing, toileting)?

Does the person have a staff person who she/he can confide in (e.g., would tell if someone hurt them)?

Are there any service providers of whom the person is afraid of? Do you know why?

E. Other Significant Relationships

Describe any other significant relationships not covered above:

Do you think the person's relationships with any of these people are potentially unsafe. If so, what is the nature of your concern.

APPENDIX 6

Feedback from Residents and Service Providers

Part 1 Residents

October 21, 1997

The Process:

It was important to ensure that the policy sections were a useful resource to consumers of residential services. A detailed, resident-friendly presentation, incorporating core policy information and pictures, was thus prepared. Ten residents were selected on the basis of their abilities to communicate when asked to express specific opinions and to participate in the group process. Eight residents were present for the session. Two were unable to attend.

The room was set up with chairs in a semicircle around the central area. An overhead projector was positioned so that policies could be displayed in a brief table format. Each overhead sheet contained the following sections: Policy Heading with criteria headings of My Choice (O.K.), Doesn't Hurt Me or Others, What Staff Should Do (see table on page 90).

Each policy was illustrated with pictures from a variety of sex education and social skills curriculum sources, chosen for the clarity with which they depicted the words of the policy. The facilitators were two of the committee members who had been involved directly in the writing of the policy.

When direct care workers asked the selected residents to participate in the presentation, some of the residents were told in general terms, that the meeting was about rules that were in a book that was being developed. The concept of rules essentially replaced "policy" throughout the presentation because of this understanding.

The facilitators informed the residents that it was an important session because their

feedback would help to determine if the work accomplished the intended purpose, i.e., if the policies were clearly presented and if the rules were truly useful to consumers. It was estimated that the presentation would take approximately three hours. Participants were asked if they were prepared to work for that long, and there were no reservations.

Green "thumbs up" cards - (good) and red "thumbs down" cards - (not good) were used alternately to solicit feedback on the various policy sections. The thumbs up/down process was introduced and modeled to everyone in attendance.

Participants were asked to rate each policy on the following criteria:

- a. whether the written explanations were clear for each of the three categories?
- b. whether the pictures were consistent with the text?
- c. whether they agreed with the content of each policy?

Participants were told that this policy was developed with two main purposes in mind: firstly, to educate staff so they could do their jobs better, and secondly, to educate residents as part of their contract for services. It was explained that in developing the book, the committee hoped that the following would be accomplished:

- a. that there would be an increase in resident safety as it related to better relationships.
- b. that there would be a decrease in abuse of residents.
- c. that staff would be better able to support loving relationships within the context of their jobs.
- d. that residents would notice a decrease in their feelings of isolation (if they currently felt any).

Participants were asked to comment on their service delivery experiences with regard to relationships and sexuality. This included the availability of information about safer sex practices and relationships, and how staff had responded when approached for information about sexuality and relationships?

As a follow up on the question about past experiences, residents were asked "Would this policy have made a difference in your past relationships?". In other words, if they had had access to similar information as contained in this policy in

years past, did they think things might have been different for them with regard to relationships?

Throughout the session, the "Guiding Principles" (see page 10) were incorporated and clarified in examples and questions.

Findings and Recommendations:

Participants found that some pictures did not match the text they accompanied. They indicated that these pictures conveyed an opposite, or at least confusing, message compared with the text. This feedback was immediately noted by one of the facilitators directly on the overhead.

Participants who were able to read were generally able to get a sense of the purpose of the policy in question based on the Resident Rights statement. Those who were not able to read found that the pictures often provided a sense of the overall purpose of the policy.

Several of the policies were contentious to the participants. The objections were all based on the personal views of the participants. That is, an individual might say "I don't think people should have sex if they are not married" (when discussing having children when the couple are not married). The facilitators then clarified the issue by stating that this policy was not necessarily about them directly. Participants were then asked to consider the situation where someone did wish to have a child but perhaps not get married. In that case, would this policy protect their rights and safety, as well as reduce the likelihood that staff could make arbitrary decisions for them? When framed in this manner all participants agreed that the policy in question would accomplish the desired purpose.

Most residents indicated that this policy would probably have made a difference in their lives if they had access to it in the past. Two residents indicated that they would not have done anything differently even with the information presented in the policy.

From the facilitators' point of view, it was clear that by following the basic table of headings, with some carefully chosen pictures, the policy was adaptable for curriculum purposes to a variety of ability levels. Residents commented on this finding in an indirect manner. When asked if they thought the information with

which they had been presented would be useful to persons living in group homes, several of the residents suggested that it would be. They added that it would probably be used best if staff took the time to present the process in a similar fashion as had been presented to them, perhaps on a one to one basis (i.e. one staff to one resident).

Committee Note:

Up to press time there was no attempt to present this policy to persons who did not communicate verbally. This was not because the authors believed that the policy did not apply to, or would not be understood by, such persons. Rather, time limited the ability to do so. It should be noted, however, that prior experience of the facilitators strongly indicates that, with proper attention to pictorial presentation, clear concise language, and sufficient time for review, persons with limited verbal skills can benefit from such presentations. It is hoped that this policy will be used for all persons with intellectual disabilities who would benefit from assistance with developing relationships or learning more about sexuality education and health.

STDs AND AIDS

<i>MY CHOICE (O.K.)</i>	<i>DOESN'T HURT ME OR OTHERS</i>	<i>WHAT STAFF SHOULD DO</i>
I need to learn about what keeps me and my boyfriend or girlfriend safe when we have sex	I need to be sure that we use things that keep me and my boyfriend or girlfriend safe, like a condom, diaphragm and spermicide. I need to know what keeps us safe from STDs and AIDS.	Help me learn about STDs and AIDS. Help me meet with a health nurse or doctor to learn what I need to know. Help me get things that keep both of us safe during sex.

SEX

<i>MY CHOICE (O.K.)</i>	<i>DOESN'T HURT ME OR OTHERS</i>	<i>WHAT STAFF SHOULD DO</i>
If me and another adult want to touch bodies (sex), that's our choice.	Both people must want to. It must be done in a private place (bedroom). We must be careful about sex diseases and not having a baby before we are ready. We must try not to hurt the other persons's feelings.	Help me understand the pleasures of sex. Help me learn about birth control and sex diseases. Help to ensure I have privacy.

RELATIONSHIPS

<i>MY CHOICE (O.K.)</i>	<i>DOESN'T HURT ME OR OTHERS</i>	<i>WHAT STAFF SHOULD DO</i>
I Choose who I spend time with.	Respect choices of the person you are with. Other people make their own choices about their relationships. People's feelings get hurt sometimes. I'll try not to. It is never o.k. to hit someone.	Help me in meeting people and doing things with them. Talk about my relationships with me, but don't decide who I will or will not be with.

SEX EDUCATION

<i>MY CHOICE (O.K.)</i>	<i>DOESN'T HURT ME OR OTHERS</i>	<i>WHAT STAFF SHOULD DO</i>
It is important to learn what makes me feel good and what are my choices in relationships.	I need to know what will keep me and my girlfriend or boyfriend safe.	Staff will help me learn what I need or want to know.

SEX AND THE LAW

<i>MY CHOICE (O.K.)</i>	<i>DOESN'T HURT ME OR OTHERS</i>	<i>WHAT STAFF SHOULD DO</i>
If I have done something which hurts another person or gets me in trouble, I should be offered help.	I need to know how not to hurt others. I need to know what is against the law. I need to change if what I am doing is hurting someone.	Staff won't judge me. Staff will keep information about me very private. Staff will arrange what help I need.

PRIVACY

<i>MY CHOICE (O.K.)</i>	<i>DOESN'T HURT ME OR OTHERS</i>	<i>WHAT STAFF SHOULD DO</i>
I can be alone in my bedroom with another person. If I share a room I can still have some time alone in my room. If I occasionally want to be private with a person in a sitting room, I want to help arrange this.	Other person in my room decides if they want to be in my room or not. Person I share the room with must also have time alone. I must respect the privacy of the people I live with.	Knock before entering my room. Help me and my roommate to arrange time when I have the room to myself. When it is possible, help me be alone in a room other than the bedroom.

CHOOSING WHO I LIVE WITH

<i>MY CHOICE (O.K.)</i>	<i>DOESN'T HURT ME OR OTHERS</i>	<i>WHAT STAFF SHOULD DO</i>
I can live with a person I love. If I need a live in staff, I still can live with a person I love.	Living with a person is difficult. I can learn ways so that we both enjoy living together.	Listen to me when I tell you that I am in love and want to live with this person. Help me to make arrangements. Help me learn ways to make living together easier.

MARRIAGE

<i>MY CHOICE (O.K.)</i>	<i>DOESN'T HURT ME OR OTHERS</i>	<i>WHAT STAFF SHOULD DO</i>
If me and the person I'm in love with want to get married, that is our choice.	Think about counselling to go over all the good things and difficulties about marriage.	Support my choice to get married. Help me make arrangements.

BIRTH CONTROL

<i>MY CHOICE (O.K.)</i>	<i>DOESN'T HURT ME OR OTHERS</i>	<i>WHAT STAFF SHOULD DO</i>
I can choose which birth control is best for me and the person I am with.	Learn about different birth control. Make sure that you don't have a baby by accident. Find out about possible health problems from the birth control you have chosen.	Staff will help me decide if I need birth control. Staff will help me learn about the good things and possible problems about the different kinds of birth control. A doctor or clinic is where I need to go to make my decision.

HAVING A BABY

<i>MY CHOICE (O.K.)</i>	<i>DOESN'T HURT ME OR OTHERS</i>	<i>WHAT STAFF SHOULD DO</i>
If me and the person I am in love with are ready to have a baby that's our choice.	We must be ready to do all the hard things to take care of a baby.	Staff will help me in deciding if we are ready for a baby. They will help me make the arrangements to be a parent if that is what we decide.

GAY / LESBIAN

<i>RIGHTS (O.K.)</i>	<i>DOESN'T HURT ME OR OTHERS</i>	<i>WHAT STAFF SHOULD DO</i>
If I like touching bodies with someone of the same sex, (man and man or woman and woman), I want to be supported in this.	Both people must want to. It must be done in a private place (bedroom). We must be careful about sex diseases. We must try not to hurt the other person's feelings.	Staff will not tell me what is best for me. Staff will support me in my choice. This can include helping me go to gay and lesbian places.

SEX MAGAZINES AND MOVIES

<i>MY CHOICE (O.K.)</i>	<i>DOESN'T HURT ME OR OTHERS</i>	<i>WHAT STAFF SHOULD DO</i>
I can have magazines or movies that I find sexy.	I can only look at stuff with naked people in my bedroom when I am alone or with another adult who also wants to look at them.	If I want to buy or rent a sexy magazine or video staff will help me if I need help. Staff will help me learn how to keep these private if I need help.

PLAYING WITH MYSELF

MY CHOICE (O.K.)	DOESN'T HURT ME OR OTHERS	WHAT STAFF SHOULD DO
<p>I can touch my body in any way that feels good for me. If I want to use a device for this that is o.k. too.</p>	<p>I only touch my sex parts when I am in a bedroom or my bathroom at home with closed door. I must be careful not to hurt myself.</p>	<p>Staff will respect my choice and my privacy. If what I am doing may hurt me or someone else, staff will help me learn a safe way.</p>

Part 2

Service Providers

November 13 & December 3, 1997

The Process:

These sessions were intended to ascertain whether other services providers found the policies relevant and useful. Feedback was sought from 12 agencies which operate residential services or which have direct and extensive contact with residential service providers. Invitations were sent out and receipt of the information was confirmed by phone by one of the facilitators. Six agencies participated in the feedback sessions.

The purposes of the sessions were four-fold:

1. To provide a research context for the need for such a policy manual, particularly where others already exist.
2. To briefly recreate some of the philosophical and ethical debates that went into the development of the policy (some of which are reflected in the "Policy Considerations" sections).
3. To present the information that had been gathered from the resident session to clearly establish that the policy meets resident, as well as agency, needs.
4. To elicit face to face feedback from persons outside the committee regarding the utility of the proposed policies.

The facilitators were the same committee members who had conducted the session with residents.

Approximately 30 minutes was given to establishing the empirical need for the work. An additional 45 minutes was devoted to philosophical and ethical dilemmas, possible future policy development, outlining on a practical basis what the manual might accomplish, and resident feedback. Finally, 90 minutes was committed to roundtable discussion on those policies distributed prior to the session and those presented during the session itself.

As in the resident session, the "Guiding Principles" (see page 10) were incorporated and clarified through examples and questions.

Empirical need:

The following is a summary of information presented to service providers who attended. The presentation was drawn from research done for the purpose of this project.

Despite the staggering frequency of unwanted pregnancies, high levels of abuse and neglect, and a 50% chance of marital breakdown within the non-disabled population, no one advocates that a ban on sexual behavior would "cure" these problems. Yet, this seems to be the solution when persons with intellectual disabilities are considered. Rather than provide reasonable education in socio-sexual matters, it is often believed that a total ban on relationships or sexual activity will stop any real or perceived problems. This argument flies directly in the face of research from both the disabled and non-disabled literature. Such research indicates that high quality socio-sexual education, delivered at a level appropriate to the audience, will help prevent problem behavior regardless of level of ability.

A factor which may be equally well placed under philosophical issues is that of a person's right to pursue a relationship, versus the need to protect that same person from the harm that a relationship may cause. Too much protection can, in fact, make a person more vulnerable than if s/he were provided with factual knowledge.

Such knowledge may lead to some exploration of healthy relationships. When one tries to consider all the factors affecting the safety and well being of an individual, it becomes difficult to sort out "my values" from what is truly in the "best interest" of the person. These issues, coupled with the traditional problem-focus taken with most life issues of those with intellectual disabilities, place the already value-laden area of sexual behavior very much at risk of causing damage rather than affecting positive life events.

Associated with the overall lack of education in life skills, persons with intellectual disabilities are far more likely to be lonely or isolated than are their non-disabled contemporaries.

The benefits of providing a policy which promotes loving relationships rather than stopping poor ones can be summarized in several points:

1. Rights are more consistently respected and advanced than in the problem

- focused approach.
2. The focus can also be one of anticipating problems and preventing them rather than fixing crises.
 3. The overall quality of life of individuals also seems to increase when the purpose of education is one which enhances rather than stifles experience.
 4. With policy direction which can be proactive in nature, greater consistency across agencies is possible.

Philosophical and Ethical Dilemmas and the Developmental Process:

The policy development process was explained. Committee composition, frequency of meetings, general format of the meetings and editorial process were set out. This explanation was done to clearly establish the long stages of development involved. The bibliographic information was pointed out as a valuable resource to agencies developing their own working versions of relationship and sexuality policies.

The role of the committee and its work was discussed in some detail. In many ways the committee functioned as a microcosm of society. Individual members all agreed on the need to develop policies. At the same time, the individual values and beliefs of committee members acted as filters in arriving at the final draft of each policy. In the end, the committee concluded that an entirely new policy manual should be developed since, as good as the research base was, no single policy satisfied the committee's evolving vision.

One of the key components of the current policy is the Sexuality Review Committee (SRC). The composition and purpose of this group was discussed in detail.

Face to Face Feedback:

Following the presentation, participants broke into small groups and discussed the policies that had been mailed out and those that were provided at the session (all participants received the same mail outs). With the help of the facilitators, they were asked to provide written and verbal feedback on the policies. Participants were encouraged to express their candid opinions, likes, dislikes, and any and all criticisms. Feedback was sought in an open, "round table" fashion with each participant being given the opportunity to express feedback and, if none was forthcoming, being directly asked for feedback .

The "bottom line" question asked was, "Is the body of information both accessible (user-friendly) and useful to the agency you represent?"

Resident Presentation:

Agency representatives were given a brief overview of the earlier resident session. Samples of the tabled information were made available to the participants and a summary of the findings was also shared (see above).

Findings and Recommendations:

Participants suggested that a more detailed description was needed of the Sexuality Review Committee (SRC). More needed to be said about the committee's membership, the balance of skills needing to be available to it, and the fluidity of membership, based on the matters before it. The resources available to such a committee in both rural and urban environments was discussed. It was noted that smaller organizations might need to look more to the community for committee membership as they would have fewer internal resources. It was also noted that the level of involvement of the committee needed to be clarified, in that it was not intended to impose itself on the day to day private lives of residents. Rather, it was to be available to provide general leadership to the organization and to provide problem solving, direction and decision making when needed. This feedback resulted in redrafting that section of the document (see page 9).

The rest of the feedback was more general in nature. A summary follows.

Participants felt that the style of the policy reflected everyday language and, as such, was easily accessible to agency staff. The format was clear in its presentation. The policies themselves seemed to apply to a variety of levels of resident ability. Specifically, it was felt that the approaches suggested did not limit the usefulness to only more capable individuals, but also suited nonverbal people or individuals with significant challenges. It was noted that issues around aging were not specifically mentioned. While participants did not feel that this population was necessarily excluded from the work, the need to not forget this group and their issues was underscored.

Participants also felt that the policy supported, but did not impose sexual behavior in any way. The final choice with regard to the type and quality of a relationship

was left, as much as possible, within the individual resident's discretion.

The distinction between ultra personal care and other more general forms of personal hygiene, such as bathing, etc., was appreciated by the participants. Most felt that the intrusive nature of this type of care required particular caution. This policy seemed to raise the issue to institutional staff that personal care and privacy issues can have very distinct sexual connotations associated with them. It is not just a matter of medical care.

Participants indicated that the Policy Consideration sections provided a helpful springboard into the policy sections that followed. The research, together with the discussion of philosophical, moral and ethical issues, helped to frame out the complex issues being examined.

Several participants felt that the sheer size of the policy is far too bulky to be useful as a part of a regular, agency policy manual. Instead, it was suggested that only the policy statements be included in an agency policy manual with reference to the "Relationships and Sexuality" manual for specific resident and staff responsibilities.

Although the policy was not meant to educate any group, the participants commented that it seemed that it could stand on its own as a teaching tool for parents. It shows clearly the full range of lifestyle choices their sons and daughters can make.

On the "Intimacy Aids" policy, a specific comment was made that although the recommendations are important, intimacy aids should never be pursued as the only option available for an individual to explore their sexuality.

With regard to the policy on masturbation, participants agreed that the first line of the Policy Considerations does indeed sum up the dilemma of masturbation.

Under Consent, participants expressed a need to clarify that residents can only consent to sexual relationships when they have had access to quality sex education which is geared to their need and abilities.

APPENDIX 7

Glossary

1. Communication Dictionary:

A typical dictionary provides an alphabetical list of words and their meanings. When words are not used in the traditional manner or when methods other than speech are used to communicate, a different kind of dictionary may be required.

This is a "communication dictionary". The communication dictionary is unique to the individual and provides detailed descriptions of the sounds, gestures, facial expressions, pictures and so on, that the individual uses to communicate his/her emotions, concepts, wants, needs, and desires. The dictionary is prepared by those closest to the individual and enables those less familiar with the resident to understand his/her unique style of communication.

2. Guided Masturbation:

"Guided masturbation" is a highly intrusive clinical method of teaching masturbation. It should only be used under well defined and controlled circumstances by properly trained clinicians. **Under no circumstances should residential agencies or their staff use this technique.**

3. Sexuality Profile:

A "sexuality profile" is a portion of a larger document known as a "Resident Profile". A resident profile documents an individual's likes and dislikes in a wide variety of lifestyle areas. Within this context, the sexuality profile records a resident's known choices and preferences regarding sexual orientation, history, education, and so on. The profile contains information of an extremely personal nature and must be stored in as confidential a manner as possible. The collection of information for the sexuality profile begins before the resident even enters the agency, with family, past caregivers, and the resident all contributing to a developing body of information that is continually updated throughout the service delivery period.

4. Substitute Decision Making:

A resident is considered capable of making decisions regarding his/her day to day choices unless observation and documentation show an inability to do so. On occasions when it is determined that a resident is not able to make an informed decision, and where the individual's quality of life may be affected, assistance with the decision making process may be required. It is important that this assistance be offered in a manner which leaves the resident with the greatest possible degree of control. The following steps are suggested:

- Initially, information is presented to the resident in a manner which best suits his/her communication needs. This process includes summarizing the most salient points and using various communication aids such as signs, pictures, role playing, and so on. This step by itself may allow the resident to make an informed decision.
- If the resident demonstrates a continued inability to make a decision, staff will document the methods they have employed to communicate the issue and their reasons for suggesting that others may need to decide on the resident's behalf. This is what this policy refers to as "substitute decision making".
- Substitute decisions are best made by those in a resident's immediate support network, such as family or close friends. Failing this, and depending on the type and seriousness of the decision, legal avenues such as guardianship or the Public Trustee may need to be sought. Throughout this process staff and managers act as resources, defining the issues, providing documentation and other information, and ensuring the continuing involvement of the resident to the greatest extent possible. If substitute decisions are contrary to a resident's wishes the reasons for such decisions will be documented and placed in the resident's file.

In no case should "substitute decision making" be taken lightly, as it infringes on the individual's fundamental rights. Each time that a substitute decision is being contemplated the situation requiring the decision must be carefully considered on its own merits and must be based on direct examples from the resident's own decision making history.

APPENDIX 8

Policies Used For Guidance:

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APPENDIX 9

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