REDUCING THE RISK OF SEXUAL ABUSE FOR PEOPLE WHO USE AUGMENTATIVE COMMUNICATION*

A COMMUNITY RESPONSE

THE SPEAK UP PROJECT

Safeguarding People who use Augmentative Communication from
Sexual Abuse / Victimization

Operated by The Anne Johnston Health Station
2398 Yonge St.
Toronto, ON
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Augmentative and alternative communication (AAC) refers to communication systems used by people who have severe speech impairments. These systems include communication displays and / or electronic devices.

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Executive Summary

People with physical disabilities combined with severe speech disorders are 2-6 times more likely to suffer physical, mental and sexual abuse as a result of their inability to communicate effectively (Sobsey, 1994). Victims who cannot communicate are less able to prevent or report abuse. Without access to the words they need to communicate, people who use augmentative and alternative communication (AAC) cannot discuss, learn about, disclose or report issues, let alone take legal action relating to victimization (Farrar, 1996).

The Speak Up Project – Safeguarding People who use Augmentative Communication from Sexual Abuse / Victimization was designed to: 1) explore the experiences and needs of people who use AAC in relation to sexual abuse; 2) provide resources, education, vocabulary and strategies to respond to and / or to reduce the risk of abuse in their lives; and 3) provide support to community agencies that should play a role in responding to, or preventing the sexual abuse of people who use AAC. The project findings suggest that many people who use AAC experience a range of abuses, including sexual abuse. They may lack information about healthy and abusive relationships; have no means of communicating about sexuality and abuse; and lack supports in their personal lives and in their community services to cope with relationship difficulties and, specifically, within abuse and justice services.

This report aims to highlight the challenges faced by people who use AAC relative to issues of sexuality and safeguarding, and to propose community guidelines for future initiatives to reduce their risk of sexual abuse.

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Background

The Speak Up Project – Safeguarding People who use Augmentative

Communication from Sexual Abuse / Victimization (hereafter referred to as Speak Up)

was a 3-year project (2001–2004) funded by the Ontario Trillium Foundation. The

project was operated by The Anne Johnston Health Station in Toronto, and took place in

three metropolitan communities in Ontario.

It is estimated that there are 150,000 people with complex communication

disabilities in Ontario. People have difficulty speaking due to disabilities such as cerebral

palsy, traumatic brain injury, developmental delay, and autism. Having a severe speech

disorder affects many aspects of a person's life including the ability to live in the

community, direct one's care, find employment, discuss sexual matters and report or

prevent abuse. People who use AAC have severe speech impairments and use a variety of

means to communicate such as picture or letter boards, computers, or voice output

devices.

Twenty-six adults (12 females, 14 males) with physical disabilities and who use

AAC systems participated in the Speak Up project. The participants ranged in age from

24 to 62 years. The majority of the participants use attendant services and live within

group home settings with internal attendant services or supported living units (i.e. an

apartment with shared attendant services within the building).

Sexuality is defined as an integral part of the personality of every man, woman,

and child. It is a basic need and an aspect of being human. Sexuality includes physical

contact and sexual intercourse, sexual desire, sexual awareness, sexual identity, and other

nonphysical sexual expressions (Wisconsin Coalition Against Sexual Assault, 2003).

Within this framework, safeguarding refers to tools, skills, and strategies that are used to reduce the risk of sexual abuse. Sexual abuse is when someone forces another person into sexual activity such as vaginal, anal, or oral sex; unwanted touching, unwanted displays of a person's sexual parts, unwanted use of pornography (Farrar, 1996). For the purposes of the Speak Up project, the censoring of information about sexuality and the suppression or denial of sexual expression and lifestyle choices was also considered a form of abuse.

The Speak Up Project established a unique multi-disciplinary team with expertise in the areas of AAC, sexual health, abuse counseling and violence and disability issues to address the broad range of intersecting factors that compound services for this population.

Members of the Speak Up team engaged in the following activities over the duration of the project:

1. explored the experiences and needs of people who use AAC in relation to sexual health and safeguarding;

2. developed and provided vocabulary and strategies to respond to and / or to reduce the risk of abuse in their lives;

3. researched and adapted key resources on sexuality and safeguarding topics;

4. provided educational forums and resources on topics relating to sexuality and sexual abuse to groups of adults who use AAC;

5. provided individual support in accessing community services, such as counseling, addiction and sexual health services;

6. provided workshops for abuse counselors, sexual health educators, health care professionals, police, legal professionals, victim service workers, attendant service providers and disability advocacy organizations;

7. hosted focus groups to share the findings and perspectives of people who use AAC, identify current service gaps, and define effective practices for community sectors such as attendant service providers, abuse counselors, sexual health educators, police, victim assistance services, legal professionals, health care professionals;

8. developed guidelines for parents, educators, service providers and consumer advocacy organizations about their roles in reducing the risk of abuse for youth and adults who use AAC; and

9. documented and shared Speak Up resources on the Speak Up website www.aacsafeguarding.ca.

The sexual health and safeguarding needs of the participants emerged through the full range of Speak Up project activities including participant surveys, educational sessions, and individual consultations. The findings are summarized in the next section of this report, followed by a presentation of the community response guidelines that are framed as lessons learned. For more background information on the Speak Up Project, see www.aacsafeguarding.ca. A list of resources available on the Speak Up Project website appears in Appendix B.

Speak Up Project Findings

The majority of participants expressed that they had experienced and/or continue to experience a range of abuses and infringements on their personal rights. The types of abuse experienced by people who use AAC are similar to those experienced by people with disabilities who do not use AAC. These include physical, verbal, sexual, financial, threat of abuse, neglect, withholding or destruction of equipment, inappropriate administration of medication, providing services when intoxicated and inappropriate exertion of control (Powers, Curry, Oschwald, Maley, Saxton, & Eckels, 2002). The participants cited incidences where they were threatened with the withdrawal of services, subjected to degrading comments, and given the "silent treatment" from their service providers and caregivers (Collier, 2004). They also reported incidences where service providers denied the individual the right to exercise personal autonomy and decision-making, and at times would engage in behavior where they could not and / or would not allow the person who uses AAC to communicate. A recurring theme during the discussions was the lack of privacy for the participants. One female participant expressed feeling degraded and humiliated when her attendant saw her sexuality vocabulary and referred to it as "dirty pictures". The participants frequently communicated about an overall lack of respect from people in their lives, a sense of condescension and being treated less than equal to non-disabled people. One male participant shared his experience:

> *I was living in an institution. I was 26. A man who was mentally*
>
> *handicapped raped me. He came into my room. I was naked. He held my*
>
> *penis and held me down. I couldn't move. When I told the supervisors –*

they laughed. They said, "He couldn't help it." I think he rapes a lot of

people there. The supervisors knew about it before I was raped and they

did nothing. I wanted to call the police – I had nobody to help me.

People who use AAC report that frequently they do not disclose abuses because:

1. They may not know their rights and may not recognize when their rights are violated;

2. They may not have a way to tell someone what happened;

3. If they do tell, they might not be believed;

4. They may not have someone to tell;

5. When requesting assistance with sexual activities, they may be unclear about the attendant service agency's policies and practices related to roles and responsibilities of staff and consumers;

6. They may be intimated and / or may not know how to make a complaint;

7. Community health and social services may not be accessible to them;

8. The justice system may not respond to their disclosure; and

9. They may not be able to navigate the social / justice system without support.

If we are to reduce the victimization of people who use AAC, we must begin by acknowledging, understanding and addressing these issues within the community context. The community response guidelines that follow were based on the expressed needs of people who use AAC and emerged from seven community focus groups. These focus groups included the following sectors: sexual health educators, abuse counselors, consumer advocates, attendant services, police and victim services, legal professionals, families, educators and clinicians. A list of those who contributed to the focus groups

appears in Appendix C. Speak Up did not host a focus group for health care providers and relied solely on input from the participants in the project in documenting guidelines to extend health services for people who use AAC.

Addressing the sexual health and safeguarding needs of people who use AAC is a shared responsibility. While many of the proposed guidelines are universal to a range of community sectors, some are specific to that sector. A summary of the proposed guidelines for each sector appears in Appendix A.

Lesson Learned

Information

People who use AAC want information about healthy sexuality, their rights and abuse. Some of the participants in Speak Up had considerable gaps in their knowledge and experience related to the expression of healthy sexuality. Many of the participants did not see themselves as having a sexual identity, and had few experiences with healthy relationships. There was often a deep sense of sadness and regret and in some cases, anger and resentment about limited life opportunities, reduced access to information about their rights and sexuality, and the curtailment of sexual freedom and expression. Many of the participants reported that they did not receive sex education from their parents, at school as they were growing up, or from their health care professionals (Pyne, Odette, & Collier, 2004).

One male participant explained:

I didn't hear about sex until I moved to a city in 1984 after my mother

died. Then I heard about it on TV and in movies and from just thinking

about it I tried to figure it out. I started to hear about AIDS on TV too. I

didn't understand it. All I knew was that it had something to do with

needles. I heard that people who are gay and people who are drug

addicts got it. I didn't worry about it. A little while after I moved to

Toronto I saw on TV that people can AIDS from a blood transfusion. I

had never heard this before. I had got a blood transfusion in 1978. I

didn't know what to think. I was shocked, scared, and worried. I was

using a picture symbol book to communicate and it had no words about

sex or AIDS in it.

The participants expressed an overwhelming need to learn about and discuss aspects of healthy sexuality. While many people have difficulty discussing topics relating to sexuality and abuse, the participants reported additional barriers in that some people in their lives, including their service providers, did not consider them to have sexual needs or a sexual identity. A number of the participants expressed that people without disabilities and particularly families and service providers should be educated about the sexual identities of people who use AAC.

The lack of information and resulting misconceptions create barriers for people who use AAC to access information and services. If service providers and authors of sexual health information fail to recognize the sexuality of people who use AAC, they remain unaware of the need to extend their services and resources to this population. Moreover, these misconceptions lead to a denial of the rights of people who use AAC to explore personal sexual identity and a tendency to over protect people who use AAC. This situation can, in turn, increase the risks for people who use AAC to enter into relationships that may be abusive or exploitive.

Recommendations to support people who use AAC in learning about sexuality, their rights and abuse:

- o Parents, clinicians, medical professionals, and educators should be aware of the role they play in promoting healthy sexuality and safeguarding in youth and adults who use AAC.

- o Sexual health educators within the school system should play a role in supporting youth who use AAC. They may require support from AAC service providers, teachers and family members in extending their services to youth who use AAC.

- o Sexual health and education services should extend their age and gender mandates to accommodate people who use AAC.

- o Sexual health and safeguarding resources and information services should be available to parents, educators, AAC service providers, and health care professionals via a number of means, including pertinent websites, newsletters, brochures, and conferences.

- o Peers and mentors can play a role in supporting adults and youth who use AAC by discussing issues related to sexuality.

- o Peer support groups, comprised of people who use AAC and facilitated by a leader trained in ways to ensure the participation of people who use AAC, can provide valuable environments for learning and sharing.

- o Resources about sexuality and disability should be available in a range of formats for people who use AAC.

Communication

People who use AAC want vocabulary to communicate about sexuality and abuse. Communication is fundamental to exercising one's right to sexual expression, to protecting oneself from abuse and sexually transmitted diseases, and to accessing relevant health, education, social, and justice services. The majority of Speak Up participants (73 – 88%) had no vocabulary (pictures or symbols) to communicate about healthy sexuality or abuse (Collier, McGhie-Richmond, Odette, & Pyne, 2004).

The participants wanted vocabulary to communicate about privacy, body parts, feelings, sexual activities, as well as vocabulary on all forms of abuse, and communicating about abuse with police, victim services, legal professionals and in court. Speak Up discovered that there was a significant lack of research and resources on these topics and worked with an AAC manufacturer to develop graphics around these needs.

Without access to the words they need to communicate about sexuality and abuse, people who use AAC cannot discuss and learn about sexuality or report abuses when they occur. Speak Up worked with the developers of Boardmaker, a popular graphic library and display making software used by many AAC clinicians when supporting people who use AAC who require pictures to communicate. With input from people who use AAC, sexual health educators, and counselors, a vocabulary of approximately 300 new items was developed. These are available as an addendum to the Boardmaker software at no cost from Mayer-Johnston Inc. and can be viewed and downloaded from the Speak Up website.

Recommendations to support people who use AAC in communicating about sexuality and abuse:

- o AAC service providers, educators, family members, sexual health educators should work together to ensure that adults and youth who use AAC have the vocabulary they need to communicate about sexuality and abuse.

- o AAC clinicians should provide people who use AAC with sexuality and abuse vocabularies using the vocabulary and communication displays suggested on the Speak Up website.

- o AAC clinics should obtain the graphic library for inclusion in their communication board making software in order to customize displays for people who use AAC.

- o AAC clinics should act as a resource to other service providers by facilitating communication with people who use AAC and providing appropriate vocabularies.

- o AAC clinics should make the Speak Up brochure, Promoting Healthy Sexuality and Safeguarding, available to parents and family members in their waiting rooms and by distributing them to their clientele.

- o Sexual health and abuse counselors should have vocabulary resources available to support people who use AAC in communicating with them.

- o Researchers and developers working with children and youth should develop age appropriate vocabularies and resources to address these populations.

Attendant Services

People who use AAC want to reduce their risk of abuse within the context of their attendant / care giving services. Sixty-five percent of the participants had questions about an attendant's role in assisting them with sexual activities such as preparation, positioning, using safer sex supplies, birth control, and masturbation. Sexual assistance in the context of attendant services refers to having an attendant provide assistance to a consumer who wants to engage in consensual sexual activity. It does not refer to or imply that the attendant engage in sexual activities with the consumer. Some attendant services support a consumer in sexual assistance and many more do not. Consumers who can speak may direct an attendant to support them in accessing birth control or safe sex methods. People who use AAC may be severely compromised in these areas if they do not have the communication tools and skills to do this.

The issue of sexual assistance is an emerging issue within the realm of attendant services, and brings with it a number of issues to be considered. The majority of Speak Up participants reported that they did not know their attendant service agency's policies and procedures on requesting assistance with sexual practices. When a person who uses AAC does negotiate assistance, it is usually done with a trusted attendant with whom he/she has a good relationship. The dynamics of negotiating around this issue are complex and can lead to increased vulnerability as well as fear of offending and possibly disrupting a working relationship with an attendant. Some group home residents reported that they do not know if they "are allowed" to have sexual relationships within that setting.

Abuse, when it does occur within the context of attendant services is complex in that it is integrally related to the experiences of dependence and interdependence. It compromises an individual's access to daily life activities, as well personal health and safety (Powers et al., 2002). The reliance on multiple personal attendants is a critical factor in understanding the risks for abuse for people who use AAC.

One male participant explained:

> *I was hit three times on the chest by a nurse and she said bad, angry*
>
> *things. It happened because I accidentally hit her chest with my hands.*
>
> *This was part of my cerebral palsy and she thought it was deliberate. She*
>
> *told me not to tell anyone – she threatened me that she would be more*
>
> *angry if I told. For a full year I was upset and worried about her.*

People who use AAC and who make disclosures about their caregivers or attendants fear reprisal from other staff and in some cases from other residents. One male participant disclosed unwanted sexual touch by a staff member. This resulted in a court conviction two years later. As a result of making this report, the man reported being shunned, degraded and mistreated by other staff during that period. There were and continue to be few accessible shelters or alternate living arrangements for people who use AAC in Ontario.

Recommendations to reduce the risk of abuse within the attendant / caregiver context:

- o Attendant / care giving services should develop policy and practice guidelines around sexuality and sexual assistance for attendant service providers, including provisions for rights and responsibilities of consumers, as well as attendants.

- o Attendant / care giving services should provide information about their policies and procedures in accessible, alternate formats for people who use AAC who have reduced literacy skills or who may be unable to turn pages in a book.

- o AAC clinicians working closely with people who use AAC and a sexual health service provider should support people who use AAC in communicating with their attendants when directing services relating to sexual activities.

- o Attendant / care giving service providers should have training in communicating with people who use AAC and in providing assistance with sexual activities.

- o Residential agencies should review safety procedures such as locking doors and keeping personal property safe. A 'safety plan' should be developed and reviewed with the person at the time of orientation to services.

- o People who use AAC should provide agencies with a list of three or four contact names in the event of an emergency. The procedure must include

asking the person who uses AAC to select the most appropriate contact in a given situation.

o   Agencies should have specific client-centered policies and procedures, separate from a general complaint process, that outline measures for responding to abuse disclosures, including sexual abuse. Abuse disclosures should ensure that appropriate and safe supports are in place, criminal and civil options are provided, as well as guidelines for when to call the police, lawyer and an AAC interpreter / communication facilitator.

o   Independent advocates and consumer advocate agencies could, with training and resources support people who use AAC in making complaints and disclosures within the attendant / caregiver context.

o   Independent advocates and consumer advocate agencies could support people who use AAC in establishing circles of support and in accessing peer groups to reduce social isolation and provide a network for support.

Social / Health Community Services

People who use AAC want equal access to social / health services within their communities. Barriers exist for people who use AAC in accessing community-based health and counseling services (Odette, 2004). These barriers include physical accessibility (i.e. access to buildings, rooms, examination tables, attendant services, etc.), as well as communication accessibility (i.e. service providers who know how to communicate with people who use AAC and who are familiar with issues relating to disability, sexuality and abuse). In addition, people who use AAC report that many service providers do not treat them with the same level of respect as people without disabilities and who speak.

Thirty four percent of the participants (5 males and 4 females) requested support in accessing sexual health education and / or clinics. There are few sexual health services that are accessible for people who use AAC. Many have restricted mandates for age and because of funding mandates, are limited by the services they are able to offer. Typically, sexual health services are geared towards youth and women.

Fifty percent of the participants (5 males and 8 females) expressed a need for counseling services related to past and ongoing abuses. Although some were sexual in nature, the majority of the abuses related to human rights and dignities. The participants identified the need for counseling to support them in dealing with high levels of stress, anxiety, and feelings of disempowerment within their lives.

Most abuse counseling services are funded to provide services to women. To date, there are few services for men who have experienced trauma or abuse. Additionally, many services are not adequately addressing the needs of people living with disabilities.

Within the context of 'domestic violence', the focus is on spousal or intimate partner relationships and does not extend to addressing issues within the context of the attendant / caregiver relationship. Initial access to sexual assault services is typically through telephone hotlines, and referrals must be made in person and not on someone's behalf, making it difficult for a person using AAC to access these services (Odette, 2004).

Many people who use AAC have limited choice with regards to their health care providers. Most people who use AAC do not have attendant services that can escort or accompany them to medical appointments in order to provide them with assistance. People who use AAC frequently report difficulties communicating with health care professionals who may have limited time and experience in communicating with a person using AAC. One male participant waited 11 years for an HIV test because he had nobody to support him in communicating with the nurse. Another participant could not go to an emergency department until he had found a friend to accompany him and assist him in communicating. A woman who was hospitalized reported that the nurses took away her communication device and locked it up for safekeeping. She had no way to communicate with her doctors and nurses.

Recommendations for making community services accessible for people who use AAC:

- o Community agencies and organizations should be accessible to people who use AAC.

- o In addition to physical access, which includes access to buildings, office space, washrooms, elevators, emergency exits, tables and countertops, communication accessibility should be an integral part of accessibility.

- o Communication access includes service provider and point of entry (i.e., receptionist) skill in communicating with people who use AAC; access to and ability to use AAC interpreters; available communication materials and resources; confidentiality / consent forms in alternate formats; alternative signage, telephone and internet access; feasible appointment planning and agency partnering arrangements.

- o Community services should have access to resources for training and support in the area of communication accessibility.

- o People who use AAC should be engaged in consulting around communication accessibility of agencies.

- o Agencies should extend their mandates to include people who use AAC, regardless of age and gender.

- o People who use AAC need to be informed of the service agencies and range of services that are provided. They may need assistance in finding out about accessible services to meet their needs.

Justice System

People who use AAC want equal access to the Justice System. People who use AAC who are victims or witnesses of crime do not currently have equal access to the criminal justice system in Ontario because their physical and communication needs are not recognized or accommodated. One male Speak Up participant in his thirties used his communication display to disclose a sexual abuse incident to the police. The police did not pursue the matter because they did not think he would make a "credible witness" in court. There is currently no training or support for police, lawyers, crown counsels, judges, victim support services or shelters in addressing the needs of people who use AAC.

The Honorable Judge Donna Hackett (1998) identified many barriers that limit access to the justice system for people with disabilities. In addition to physical barriers (i.e., ramps, doors, etc.), she cites difficulties with language and communication, problems with interpretation, use of cross examination techniques which may not be accurate measures of the credibility of people with disabilities who may have limited communication skills. She states, "if vulnerable witnesses with special needs cannot access our courts, then our system will be an obstacle in their quest for justice, which will increase their vulnerability".

Emerging from Speak Up is the need to work with the Justice System to provide access for people who use AAC. To this end, Speak Up has initiated discussions for future initiatives with various justice sectors.

Recommendations for providing equal access to the Justice System for people who use AAC:

- A range of resources and supports should be developed within the context of an equal access framework, to accommodate the physical and communication needs of people who use AAC.

- Effective protocols, along the lines of the Nova Scotia Protocol (1991) need to be developed to guide justice officials in cases involving people with physical and / or communication disabilities.

- Justice officials require training in providing services and accommodations to people with disabilities and specifically to people who use AAC.

- People who use AAC require tools, skills and strategies to facilitate their communication with police and legal professionals.

- Policies and Procedures for using AAC interpreters should be developed for supporting the communication of people who use AAC during disclosures and in the court.

- Guidelines for interviewing people with communication disabilities should be developed and justice officials should be trained or supported in their use.

- Expert Witnesses for people who use AAC should be trained in their role and responsibilities.

Community Access

People who use AAC may need support in navigating, accessing and communicating with community-based social / health / justice services. Many of the Speak Up participants identified their need for a support service, independent from their families, friends and attendants services, to assist them in accessing community events and services. Ninety-two percent of the participants asked for assistance in finding accessible services in their area (e.g. legal services and health and counseling services). Eighty-five percent asked for assistance in setting up appointments and in communicating during appointments – particularly appointments of a private / sensitive nature. Ninety-three percent of the participants requested assistance in managing multiple service providers, in arranging and hosting their case conferences and in coordinating their services.

The majority of participants wanted an independent advocate to support them in issues relating to their attendant services. Seventy percent wanted assistance in communicating with attendants, understanding their rights within the service context, and in negotiating and handling conflicts etc. As one female participant noted:

It is important to have someone who listens when there is a problem.

Seventy percent of the participants also requested assistance with making telephone calls, programming vocabulary into devices or putting new items on communication displays. A male participants reported:

Attendants do not have the time to do these things.

Eighty-five percent of the participants felt that a support service should be available to assist them around safety concerns and in accessing legal counsel in situations of disclosures.

Finally, many participants felt that consumer support agencies could play a significant role in reducing their social isolation, providing them with a network of support and assisting them in accessing and participating in leisure and recreational community activities.

Recommendations to support people who use AAC in navigating and communicating with social / health and justice services:

- Consumer advocate agencies can play a significant role in supporting people who use AAC in navigating and finding accessible community services.

- Consumer advocate agencies should ensure that staff is trained in a range of communication techniques to support and enhance their communication with people who use AAC.

- Consumer advocacy agencies should provide training and resources to staff on the full scope of service needs required by people who use AAC and how to facilitate these for and with people who use AAC. These needs include advocacy techniques, conflict resolution, problem solving, coordination, team management, directing attendant services, legal matters, and responding to disclosures.

- Polices and practices are required for facilitating communication for people who use AAC. The Augmentative Communication Community Partnerships-Canada is exploring this further. For information see www.accpc.ca.

- Agencies should explore ways of informing people who use AAC about whether their service providers have been trained or have experience communicating with people who use AAC.

- Consumer advocacy agencies should be trained in ways to support AAC users in setting up and maintaining their social and support networks.

Conclusion

People who use AAC have the same rights and freedoms as people who do not have disabilities. They have the right to make their own relationship and lifestyle choices. They have the right to be safe and free of abuse.

The Speak Up project revealed that people who use AAC are very often not afforded these same rights. In addition, people who use AAC experience a full range of abuses – many of which are criminal offenses.

Reducing the risk for abuse for people who use AAC needs to be addressed by the full range of existing social, health, education and justice services in Ontario. Currently the majority of these services are not equipped or prepared to provide the types of supports and accommodations required by people who use AAC. The guidelines presented here are intended to provide direction for future initiatives towards the risk of abuse for people who use AAC.

For information about Speak Up – www.aacsafeguarding.ca

For information about trainings / resources to support the recommendations in this report, contact:

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APPENDIX A: Sector Guidelines

Attendant Services:

- Policy and practice guidelines are required around sexuality and sexual assistance for attendant service providers, including provisions for rights and responsibilities of consumers, as well as attendants.

- Management, front line and consumer levels of attendant services require ongoing education on sexuality, sexual assistance and safeguarding as it relates to attendant services.

- Attendant service providers need to be trained in communicating with people who use AAC and be provided with sufficient time and resources to support their needs.

- Agencies need to provide information about their policies and procedures in accessible alternate formats for people who use AAC who have reduced literacy skills or who may be unable to turn pages in a book.

- Agencies need to review safety procedures such as locking doors and keeping personal property safe. This might comprise a 'safety plan' to be reviewed with the person at the time of orientation to services.

- People who use AAC should provide agencies with a list of three or four names to contact in the event of an emergency situation. The service's procedure must include asking the person who uses AAC to select the most appropriate contact in a given situation.

o Agencies should have specific client centered policies and procedures that outline measures for responding to abuse disclosures, including sexual abuse. These policies should be separate from a general complaint process. Abuse disclosures should ensure that appropriate and safe supports are in place, criminal and civil options are provided, as well as guidelines concerning contacting the police and / or an AAC interpreter.

Abuse Counselors / Psychotherapists:

In addition to making services accessible in terms of accommodating physical, communication and attendant needs:

o Counselors should have information / training on issues relating to sexuality and abuse for people who have disabilities and on communicating with people who use AAC.

o In cases where physical accessibility is an issue, agencies should investigate innovative partnerships and outreach services.

o A full range of services, including addiction services, need to be made available to people who use AAC.

o Information concerning the types of counseling services provided and whether counselors have experience and training in disability and AAC need to be made available to people who use AAC.

o Word / picture symbol vocabularies that include items specific to abuse counseling needs (i.e.) feelings, abuse, legal issues, conflict, discrimination, and sexuality should be accessible to people who use AAC and counselors.

- o Counselors should consider and evaluate non-language-based techniques, e.g. focusing, bodywork, expressive arts, meditation, sand trays, painting, clay, art, drama, music, and movement in order to meet the diverse needs of people who use AAC.
- o Counselors could play a significant role in improving the mental health of people who use AAC by providing wellness services in the community.

Sexual Health Services:

In addition to making services accessible in terms of accommodating physical, communication and attendant needs:

- o Sexual health educators within the school system should play a significant role in the supporting youth who use AAC, however they may require support and training from AAC service providers, teachers and family members.
- o Sexual health services should extend their age mandates to provide services to adults who use AAC.
- o Sexual health clinics should be available to both men and women.

Justice System:

- o Resources and supports should be developed within the context of an equal access framework to accommodate the physical and communication access needs of people who use AAC.

- o Effective protocols along the lines of the Nova Scotia Protocol (1991) should be developed to guide justice officials in cases involving people with physical and / or communication disabilities. This should include responding officers, unit investigators, victim services, legal professionals, judges, shelters etc.

- o People who use AAC require tools, skills and strategies to facilitate understanding of and their communication within the justice system.

- o Justice officials require training in providing services and accommodations to people with disabilities and specifically to people who use AAC.

- o Policies and Procedures for using AAC interpreters should be developed for supporting the communication of a person who uses AAC in court.

- o Guidelines for interviewing people with communication disabilities should be developed and justice officials should be trained or supported in their use.

- o Expert Witnesses for people who use AAC should be trained in their role and responsibilities.

Independent Advocacy and Consumer Organizations:

In addition to making services accessible in terms of accommodating physical, communication and attendant needs:

- Consumer advocate agencies should ensure that staff is trained in a range of communication techniques to enhance their communication with people who use AAC.

- Agencies should provide training and resources to staff on the full scope of service needs required by people who use AAC and how to facilitate these for and with people who use AAC. This should include advocacy techniques, conflict resolution, problem solving, coordination, team management, directing attendant services, legal matters and responding to disclosures.

- Agencies should plan social events that include people who use AAC.

- Agencies should support people who use AAC in setting up circles of support and in accessing self-help and peer support groups.

Families and Educators:

- Parents and educators need to be aware of the role they play in promoting healthy sexuality and safeguarding in youth who use AAC.

- Families and educators need to have access to sexual health and safeguarding resources and information services via pertinent websites, newsletters, brochures, and conferences.

- o Families and educators and service providers of youth who use AAC should be aware of the key safeguarding elements and how to foster these in people who use AAC from a young age.

- o Sexual health information that relates to their disability needs to be available to youth who use AAC.

- o Vocabulary, skills and opportunities to communicate about sexuality and safeguarding need to be made available to youth who use AAC.

- o Non-disabled youth require positive information / depictions of disability included in their sexual health education.

- o Child-centered picture and symbol vocabularies and resources are required to address child / pre-adolescent developmental issues.

- o Youth who use AAC and families need opportunities for peer networking and support.

- o Youth who use AAC need to be supported in peer group educational sessions and / or individual consultations from people with expertise in sexuality, disability and AAC communication.

- o Adults with disabilities and people who use AAC can contribute to the education of youth and families about issues relating to sexuality and safeguarding.

AAC Clinics, Clinicians, and Other AAC Service Providers:

- o Clinicians need to be aware of the role they play in promoting healthy sexuality and safeguarding in people who use AAC.

- o AAC clinics and service providers should work with educators, family members, and sexual health educators to ensure that youth who use AAC have the vocabulary they need to communicate about sexuality and abuse as well as resources related to sexuality and safeguarding.

- o Clinicians who provide services to adults who use AAC should play a role in providing vocabulary and communication strategies to communicate about healthy sexuality, safeguarding, and abuse.

- o AAC clinics should obtain the Boardmaker graphic library for inclusion in their board making software in order to customize displays for people who use AAC.

- o AAC clinics should make the Speak Up brochure, Promoting Healthy Sexuality and Safeguarding available to parents and family members in their waiting rooms or by distributing these to their clientele.

- o Service providers in children's treatment centers that focus on child abuse issues require information, resources and skills to extend their services to children with disabilities who use AAC.

Health Care Professionals:

- o Health care professionals may require information and training on sexuality, and abuse issues for youth and adults who have disabilities.

- o Health care professionals may need training and / or support in communicating with people who uses AAC and when and how to use an AAC interpreter;

- o People who use AAC need information about their health and the means to communicate about their health concerns.

- o Health care providers / educators should be informed of community resources for people who use AAC, know when and how to advocate on behalf of a person who uses AAC, and include people who use AAC in decision making.

- o Health care providers / educators should play a significant role in improving the mental health and wellness of people who use AAC.

APPENDIX B: Resources

The following resources are available on the Speak Up Project website at

www.aacsafeguarding.ca

- o Accessibility Needs for People who use AAC

- o Tips for Working with People who use AAC

- o Making Services Accessible for People who use AAC.

- o Educational Topics for Service Providers Working with People who use AAC

- o AAC Services in Ontario

- o Guidelines for Communicating with People who use AAC

- o How to Use an AAC Interpreter

- o Guidelines for AAC Interpreters

- o Communication Facilitation and Person Centered Counseling

- o Communication Displays

- o How to use Speak Up Displays

- o Promoting Healthy Sexuality and Safeguarding in Youth who use AAC – Guidelines for Parents, Teachers and Service Providers

- o Personal Stories of Adults who use AAC

- o Responding to Abuse

- o Sexual Health Issues for People who use AAC

- o Safeguarding Issues for People who use AAC

- o Safety for People who use AAC

APPENDIX C: Contributors to Sector Focus Groups

Speak Up wishes to acknowledge the valuable contributions made by the following people to the guidelines presented in this report.

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