



## Speaking Out Against Abuse

by Sarah E. Lever, Leigh Lightholder, Diane Nelson Bryen & Allison C. Carey

**T**his spotlight brings light to some very dark corners of the disabled experience. *End the Silence*, a project of the Institute on Disabilities at Temple University, is the first research project to look specifically at the experiences of people who use AAC as victims of crime and abuse.<sup>1</sup>

*End the Silence* used an anonymous survey to find out about the experiences of AAC users. For the purposes of this survey, the authors defined crime and abuse together as “acts that cause significant harm which may or may not be against the law. Such acts may include withholding property such as a wheelchair or communication device, threatening someone with harm, forgery, robbery, physical or sexual assault, rape and murder.” The survey asked people about their experiences with crime and abuse. For those who had been a victim of crime/abuse, the survey then asked about their experience (for example, what kind of setting did it take place in, how many times did it happen) and the effect the abuse or crime had on the person’s life.

The Institute on Disabilities advertised the survey on ACOLUG and through its mailing list. Forty people completed the survey. Of those who took the survey, all had a communication

disability. Eighty-three percent also had a physical disability and 60% had a mobility disability. Twenty-two women and 18 men took the survey, and most were between the ages of 18 and 39 years old.

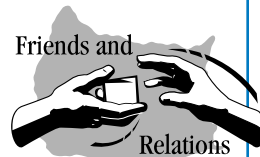
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### Survey Results

Eighteen (45%) of those who took the survey experienced some crime or abuse. Surprisingly, factors that often make a difference in likelihood of victimization did not make a big difference in this study. For example, neither education nor income made a difference. Men and women had similar rates of victimization (50% of women and 44% of men). Older people were more likely to report victimization, but that may simply be because they have had more years in which to be abused.

The survey results show that people who use AAC are very likely to experience crime and abuse. Of the 18 people who had experienced crime/abuse, most people (66%) reported multiple episodes. Nearly half (47%) said they experienced abuse or crime

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# Message from the editor

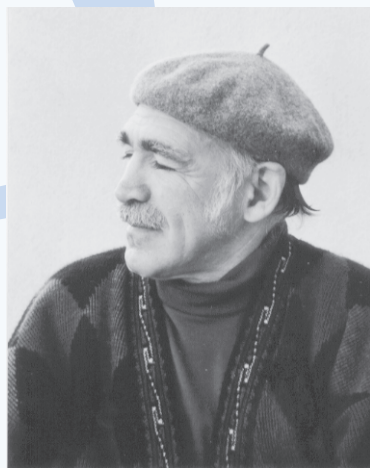
**N**obody likes discussing abuse, including me. As I am writing this I am struggling to find just the right words to fit the topic. I don't want to sound too dispassionate about it; that would be cold. If I become too emotional, I may fan the flames of irrationality.

Augmented communicators often don't have the vocabulary to express what they are feeling when in a situation of potential or imminent abuse. Of equal importance is that a person who grows up with a speech disability often heavily relies on the help of others to survive. This ingraining of dependence may hamper the disabled person's ability to read the danger signals around him; indeed many disabled people may live in such a "protected" environment they may not have the ability to sense danger at all.

When I first moved out on my own, the first thing I discovered is I didn't know how to "read" people and their motives. I hired my first attendant because he looked cool. He liked the same music and shared the same politics I did. I needed help with my daily activities, he needed a place to stay and some walkin' around money. It was a match made in heaven.

Not quite. The guy was more interested in sleeping and partying than helping me with my daily activities and sustaining a minimum level of cleanliness around the house. I lacked the guts to confront the guy about the situation and things just got worse. Fortunately, my upstairs neighbor walked in my place one day, took one look around, threw the guy out and got things straightened up and out while I found somebody competent to help me.

In my more than thirty years of living on my own, I've learned that sizing up people is one of the most important skills you can have. If you can develop the skills of sizing up people and speaking up when things seem not quite right, you will be a long way on the path to an independent life.



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several times and 24% said they had been a victim of crime or abuse 6 or more times! According to the *End the Silence* survey results, people who use AAC are likely to have multiple experiences as victims of crime or abuse.

The most common kinds of crime and abuse were having something stolen (56%), being threatened (44%), being attacked (39%), and being touched in a sexual way when they did not want to be (39%).

The survey found that abuse and crimes against people who use AAC were most likely to be committed by professionals. For the purposes of this survey, the authors defined professionals as paid service providers such as staff, personal assistants, teachers and doctors. Thirty-six percent said that professionals committed crimes against them, 25% said friends and acquaintances, 14% said family, 3% stranger, 18% "other" and 5% "don't know". One-third of people listed more than one type of person who committed crimes against them; on average, people listed 1.7 types of people.

People were most likely to experience abuse in their own home (55%). Crime/abuse also occurred in their work/school/day settings (12%), car/van/other transportation (5%), and in "other" settings (21%). Seven percent did not know. Half of the people reported crime/abuse happening in more than one setting, with the average being 1.8 types of settings. The survey shows that the people who like us, love us or are paid to care for us are most likely

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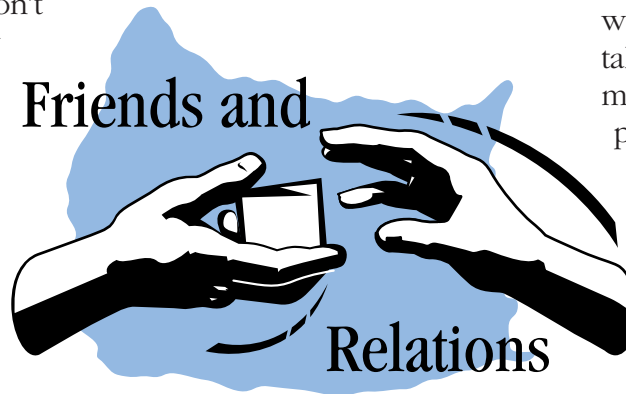
# Recognizing Danger

by Leigh Lightholder

**P**eople who have difficulty communicating are one of the most vulnerable populations for crime and abuse. Perpetrators of crimes may believe that a person with a speech disability won't be able to communicate with others about any abuse or crime. Many augmented communicators don't have access to the vocabulary needed to prevent, stop or report crime and abuse. Even when an augmented communicator speaks up, he or she may not be believed. Therefore, it is very important for people with communication disabilities, and those who care about them, to be aware of the possibility of abuse and know how to avoid and report crime and abuse.

Augmented communicators need to know it is okay to act and/or speak out when they are in danger. It is okay to say "No" to people in charge. It's okay to change one's mind. It is important for people to trust their instincts.

It's especially hard to recognize danger when it comes from people who are paid to provide care. Since people with significant disabilities often depend on care attendants to help with almost all activities of daily living, recognizing danger can be a big problem



for many people who use AAC. Some attendants may get the wrong idea and think they can hurt a person who has communication disabilities without anyone finding out.

Here is an example of how I responded when I sensed danger. One summer I went for a vocational evaluation, and there was

an older couple who overlooked all of the students and lived in the dorms with us. At first the gentleman was so nice and caring; all of us treated him like our grandfather.

One evening I came out of our community room and "grandpa" was sitting there. We were just talking normally and then he moved closer into my space and put his arm around me. At first I thought nothing about it, but I realized it wasn't the normal hug like I would get from my grandpa. I just felt uncomfortable so I got out of that situation. I am not sure what would have happened if I had stayed. Not everyone can leave when they sense danger, so I was lucky.

I was lucky enough to have a chance to get out and did so. If you are afraid or just feel uncomfortable and you can leave, leave. If you can't leave, tell someone. Trust your instincts!

**A**

## Further Reading

Gavin de Becker, head of a security firm that protects high-profile individuals, has written two very approachable books about recognizing danger. *The Gift of Fear: Survival Signals That Protect Us from Violence* (Dell, 1998) does an excellent

job of explaining how you can alert yourself to the signals that warn you about risk from strangers, and how to separate real from imagined danger. De Becker's follow up book, *Protecting The Gift: Keeping Children And Teenagers Safe (And Parents Sane)* (Dell, 2000) is designed to keep parents calm while teaching them to recognize and respond to

potential dangerous situations against children. It also does a good job of outlining how parents can talk about danger to their children without scaring them.

Don't be put off by the rather sensationalistic titles, these are solid works full of useful information.

Michael

# Speaking Out: Access to Vocabulary

by Sarah Lever

**S**peaking out about abuse can be very hard to do. When you have been in an abusive or dangerous situation, it's easy to believe you are the only one this has happened to or that somehow it's your fault. People who depend on AAC may be afraid to speak out, or may not know how to express themselves. Sometimes those who are abused have trouble expressing what truly happened so they keep silent. Sometimes people with communication disabilities are ignored when they report what happened, are not listened to, are told not to tell the police, or are not believed. In effect, others silence them.

## Silence

Many people who use AAC have experienced abuse, but we don't usually talk about it. I had an extremely bad experience with physical abuse. My family had just moved to a new town. We didn't know anyone, and we had to hire someone to help with my needs. My new caseworker brought someone out to meet us. Something didn't feel right to me, but I figured the caseworker had checked her background. I hired her.

On Sunday she had to assist me all day. I woke up at eight, but

she was asleep and didn't wake to help me. I had a bowel movement on the bed. I tried to wake her up for three hours and I was extremely frustrated about staying in bed. I needed a shower.

Finally, she woke up and took me by the arm into the bathroom, dragging my body along the floor.

She didn't have my wheelchair ready when we were finished, and when she left me to get it I fell into the bathtub. She got me by the arm and tried to pull me out. After awhile, she stopped trying. I had to pull myself out of the bathtub and start dressing myself. When I got into my wheelchair, I said something I don't want to say in this article.

As soon as my grandmother got there, she knew something was not right. The next day my mother took me to the doctor; my body was black and blue. I tried to report what happened to the police, but I got upset because I didn't have an adequate vocabulary and couldn't communicate what happened to me. The police couldn't charge her.

## Vocabulary

Sometimes even when we want to speak out, we don't have the right words to do so. Most com-

munication aids don't come with vocabulary necessary to end the silence about crime and abuse. Many of us don't have easy access to the right vocabulary in our communication devices. Not having adequate vocabulary raises the risk of people who rely on AAC being victimized because we are identified as unable to tell anyone when crime or abuse occurs. It allows those who would commit crimes against us to continue undeterred. We need adequate vocabulary to talk about crime and abuse, and we need to know how to use that vocabulary.

Most of the speech-language pathologists I have worked with wanted to stay with basic core vocabulary. That was okay until I was 18 years old, which was when I wanted to have some adult words so I could express myself with vocabulary appropriate for my age.

A part of growing up and being an adult is saying what you want and expecting others to respect your decisions about yourself. It is very frustrating for the non-verbal person and the personal assistant when the AAC device doesn't have enough adult words to discuss some of the more personal aspects of personal care.



I needed adequate vocabulary to talk about feelings, body parts, sexually transmitted diseases and sexual activity. I wanted to have sexual health words like sexually transmitted disease, HIV, AIDS and other words related to sex and my private parts. Later I realized that I also wanted to be able to tell someone if I was a victim of a crime.

### **Social access**

People with speech disabilities can't easily take part in society unless they have access to the right vocabulary. AAC users have the same dreams and needs as other human beings. They want to have relationships, including sexual relationships. Many communication devices are not set up in ways that make it easy to talk about relationships. Words like birth, boyfriend, girlfriend and words referring to sexual activity and sexual health must be added to communication devices so we can step into adulthood and take part in the great things about being an adult in the world while protecting ourselves from crime and abuse.



## **Communication for Justice**

Abuse and crime against people who use AAC remains in the background, ignored by police, prosecutors, counselors and policy makers. As Lesley Chenoweth Griffith said, "There remains a deeply held belief that people with disabilities are somehow less equal than others and that they do not have the same degree of human rights."<sup>4</sup>

In order for people with communication disabilities to receive equal justice, they must first be able to get into the buildings and offices where court procedures and victim services are provided. But this is not enough. Access to the justice system also means that the court system and victim services must be programmatically accessible. This means providing alternative means for communication, whether it is communication with the purpose of testifying or communication for the purpose of receiving counseling.

Justice systems can not remain inaccessible to people with communication disabilities. Each country has a legal system and laws that address crime and abuse, but few provide the supports that would ensure people with communication disabilities have equal access to the protection of the law.

Police, lawyers, judges and victim counselors must listen to people who rely on AAC and provide appropriate communication tools and strategies.

Tools to enhance communication need to be available throughout the criminal justice process. Simple strategies, like taping the testimony of people with communication disabilities and replaying it, can increase the ability of people with communication problems in testifying. Even the simplest AAC strategies are rarely used in legal proceedings, but should be.

Criminal justice professionals, victim's assistants, health professionals and people who use AAC all must learn how to talk about crime and abuse using AAC. Equal access to justice requires that attorneys, judges, and victims service personnel must be trained to provide effective, responsive and respectful advocacy for all victims of crimes. For people who rely on AAC to achieve equal protection under the law, the criminal justice system must learn how to work with us. These changes will make it possible for people who use AAC to benefit fully and equally in the protections of the law.



## The *Speak Up* Project

**S***peak Up* is a project out of Ontario, Canada that is working from several directions to reduce the rate of abuse and crime in the AAC community.<sup>5</sup> Barbara Collier, a longtime AAC practitioner and researcher is the *Speak Up* project coordinator. According to the *Speak Up* website, “Communication is Power: The power to learn about and to express your sexuality, The power to report sexual abuse, The power to reduce your risk from sexual abuse.”

Reporting crime or abuse often requires personal, private or embarrassing words that we don’t usually say or hear. While it may be uncomfortable, trying out the words that might be needed in an emergency is a good way to be prepared. Accepting the potential for crime or abuse is the first step in preventing or stopping any future abuse.

The *Speak Up* project, with the assistance of twelve people who use AAC, has developed specific vocabulary to talk about abuse. The vocabulary is divided into several focused topics: emotional abuse, physical abuse, financial abuse, sexual abuse, discrimination and crimes, as well as broader groups of vocabulary useful for talking about abuse, feelings, conflicts and making decisions.

The project has also developed sample vocabulary displays about sex, sexual health, reproduction and sexual activity. The *Speak Up*

project directly addresses the reluctance many families and AAC professionals experience when faced with the prospect of augmented communicators talking about sex. According to the website, “The expression of sexuality has been widely acknowledged by disability advocates as a basic human right, with the censoring of sexual information and expression recognized as a form of abuse. However, for many people with disabilities, this problem of censorship persists. *Speak Up* believes that people who use AAC should have the same rights and freedoms as people who do not have disabilities. They have the right to make their own lifestyle and relationship choices. In order to do this, they need access to information and communication about sexuality and safety.”

All of the *Speak Up* sample vocabulary displays are available on their website [www.aacsafeguarding.ca](http://www.aacsafeguarding.ca) and from Mayer-Johnson (Betacom in Canada) as text or Mayer-Johnson pictures.

Some of the *Speak Up* project activities aim to make changes in the local Ontario area. One activity focuses on educating police, legal professionals, health care providers and sex educators to make their services accessible to people who use AAC. The *Speak Up* project supports people who use AAC to access existing



community services to get information and communicate about sexuality, sexual abuse and safeguarding.

Another local component provides accessible information about healthy sexuality, abuse and about how people who use AAC can protect themselves from abuse. Kits containing this information are available in formats that can be used and understood by people who cannot physically turn pages or read independently. The kits are available for loan in the Ontario area.

*Speak Up* also is setting up “support circles.” Support circles are small groups of people who trust each other and communicate regularly. This ensures that each person who uses AAC has regular contact with people who will listen if anyone needs to report any abuse.

*Speak Up* has conducted several 10 week series of community workshops for people who use AAC on strategies to reduce their risk for sexual assault/victimization.

The *Speak Up* project runs through December 2004. It is an excellent example of a local community working together to reduce a global problem.

**S**



## SOSC Papers

**E**xploring the compelling questions, “Where are we?” and “Where do we need to be going?”, AAC-RERC project directors met in August 2001 at the State of the Science Conference (SOSC) with members of the AAC community.

The AAC-RERC partners collaborated with 53 SOSC participants and 250 USSAAC conference attendees in order to develop a report of the current “state of the science” in AAC and to recommend priority areas for the future development of AAC technologies. This collaborative process resulted in seven papers, with each one focusing on a different aspect of AAC. The Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) recently published these seven papers in its journal *Assistive Technology*.<sup>6</sup>

### Seven papers

1. “Future Technology Needs: Consumer Perspectives” (Sarah Blackstone, Michael B. Williams and Mick Joyce). Addresses the lack of input from users in the design of AAC equipment. The authors describe three strategies to correct this problem. Ergonomics deals with making devices user friendly and useful. Participatory action research invites users of AAC to help the scientists design and conduct research.

Technology transfer processes adapt existing technology from other fields for use in communication devices.

2. “Improving the Design of Augmentative and Alternative Technologies for Young Children” (Janice C. Light and Kathryn D. R. Drager). Examines the needs of some of the youngest users of AAC. The authors recommend that technology for children should resemble toys: appealing, user friendly, easy to learn and use. These products should grow with the child as well as promote language acquisition and literacy. Current technology falls far short of meeting these criteria.

3. “Improving AAC Use for Persons with Acquired Neurogenic Disorders: Understanding Human and Engineering Factors” (David R. Beukelman and Laura Ball). Focuses on the needs of adults with certain acquired disabilities. Equipment design for recently disabled users must take into account the degenerative nature of their conditions, alternative means of communication, as well as the changing roles of these adults in society and their attitudes toward their new situation.

4. “AAC Performance and Usability Issues: The Effect of AAC Technology on the Communication Process” (D. Jeffrey Higginbotham and Kevin Caves). Examines how operating communication technology affects the conversations that take place between users of AAC and their speaking partners. The authors discuss how to measure important features of communication, such as rate, then consider how to develop devices that are more effective during conversations.

5. “Enhancing Participation in Employment through AAC Technologies” (David McNaughton and Diane Bryen). Considers the state of employment for users of AAC. After assessing the situation, the authors call for major improvements for users and potential employers. They suggest that features of new AAC technology be designed that specifically support the needs of users at work.

6. “Enhancing Literacy Development through AAC Technologies” (Janet M. Sturm, Karen Erickson and David E. Yoder). Considers how well grade school students using AAC can read and how these students, their teachers and support staff use AAC technology to encourage literacy. The authors call for more instructional guidelines and support on how to use AAC to teach reading from kindergarten onward.

7. “Connecting AAC Devices to the World of Information Technology” (Kevin Caves, Howard C. Shane and Frank DeRuyter). Outlines the growth of wireless access to Information Technology in our society. The authors explain how this technology can benefit users of AAC. AAC equipment must be made compatible with all the evolving wireless technology so that users can access it.

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*Johana Schwartz assisted in the preparation of this article.*

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## Sources & Resources

1. For more information about the *End the Silence* project, contact Diane Nelson Bryen, Professor & Executive Director, Institute on Disabilities, Temple University, 423 Ritter Hall Annex, Philadelphia PA 19122, Phone 215-204-1356 (Voice/TTY), Email: [diane@temple.edu](mailto:diane@temple.edu)

2. DisAbled Women's Network of Canada; Sobsey and Doe, 1991.

3. *Augmentative and Alternative Communication* is available from BC Decker Inc, 20 Hughson Street South, 10th floor, P.O. Box 620, LCD 1, Hamilton, Ontario, Canada L8N 3K7 or from the ISAAC Secre-

tariat, 49 The Donway West, Suite 308, Toronto, Ontario, Canada, M3C 3M9.

4. Chenoweth, L. (1995), "Community ignorance keeps hidden abuse flourishing." Griffith University, Australia, Media Information Office of External Relations, available online at <http://members.shaw.ca/road2healing/abusedef.htm>

5. Information about the *Speak Up* project is available at [www.aacsafeguarding.ca](http://www.aacsafeguarding.ca) or from [speakup@sympatico.ca](mailto:speakup@sympatico.ca)

6. *Assistive Technology* (Volume 14, Number 1). For a copy of this publication, you can e-mail the

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Thank you to all of the guest authors.



*Continued from page 2*

to be the ones who abuse or victimize us and that this abuse is likely to occur in familiar settings.

Eighty-eight percent of the victims in the survey told someone about the crime or abusive situation, but only 28% ever told the police. And only one person reported that the offender was arrested and convicted!

Individuals said that crime and abuse had a large effect on their life. Of the 18 individuals who reported abuse or crime against them, 89% said they were emotionally hurt, 39% said they were physically hurt and 11% reported losing valuable property or money.

The *End the Silence* study results are consistent with research which shows that people with disabilities probably experience a higher rate of crime and abuse as compared to people without disabilities, that their abuse tends to be chronic, and that they tend to know their perpetrators.<sup>2</sup>

The accompanying articles in this issue of *Alternatively Speaking* suggest four ways that individuals with severe communication disabilities can better protect themselves from abuse and crime. These articles talk about (1) recognizing danger (2) speaking out (3) accessing adult vocabulary and (4) advocating for equal justice.

### Conclusion

Nobody had ever looked at the rate of crime and abuse against people who use AAC. That's why

the *End the Silence* study is so important. It shows everyone what the AAC community already knows: Abuse and crime against people who use AAC happen too often. We hope our study draws attention to this problem and starts the community thinking about ways to end the silence for all victims.

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The full results of the *End the Silence* research project have been published in the June 2003 issue of the AAC journal, *Augmentative and Alternative Communication*.<sup>3</sup>