

Issue Brief- A Report to the National Council of Independent Living Centers



2004 NCIL Conference, Washington DC



Voices Across America: Communities Coming Together to End Crimes Against People with Disabilities

*A report to the National Council of
Independent Living Centers*

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On June 12, 2004 two focus groups were held at the National Independent Living Conference in Washington DC. Approximately 60 people with a variety of disabilities, 13 male and 47 female, attended the two groups. The purpose of the focus groups was to facilitate discussion on crimes against people with disabilities, with a specific focus on domestic violence, sexual assault and abuse by personal assistants. Each of the groups addressed the following questions:

- *“What drew you to participate in this focus group?”*
- *“Are you seeing issues of violence against people with disabilities being addressed in your Center?” If so how? If no, why not?”*
- *How would you like to see violence against people with disabilities addressed at your Center? At NCIL?”*

“I’m a program coordinator and within the last 6 months there have been 3 incidents of abuse of our clients. For one of our consumers, the police simply gave the abuser a ‘talking to.’”

-Focus Group Participant

There were a variety of reasons conference attendees decided to take part in the focus groups:

- A number of participants said they wanted to gain more insight into the issues of abuse against people with disabilities.

- Several participants have seen a number of their consumers facing violence/abuse and hoped to get assistance in dealing with these issues.
- A few participants stated that they were survivors of violence/abuse and hoped to apply their personal experiences in the focus group process.
- Most participants joined the focus group because they felt strongly about ending abuse and saw these issues as an important part of their jobs at their Centers for Independent Living.
- One participant stated that her Center was currently involved in a Department of Justice grant that is addressing violence against women with disabilities.

WHAT ARE THE ISSUES?

In both of the focus groups sessions, facilitators offered the following background material, as a way to introduce the subject on violence and abuse against women and men with disabilities.

Incidence of Abuse Toward Women and Men with Disabilities

- In the U.S. about 20% of individuals experience some form of disability (U.S. Census 1992).
- About 9 million individuals with disabilities use some form of Personal Assistance Services (Litvak et. al. 1987):
 - Paid or unpaid / formal or informal
 - Family members, intimate partners, friends, strangers
- Many women and men with disabilities face additional risk of abuse by people who give them assistance.
- Sobsey and Doe (1991) found that as many as 83% of women with developmental disabilities were victims of sexual assault.
- Nosek, Young & Rintala (1995) study found that women with physical disabilities:
 - 62% experienced some form of abuse in their lifetime
 - Intensity and duration of abuse was higher for women with disabilities

- Powers et. al. (2002) study found that women with physical and cognitive disabilities:
 - 67% experienced physical abuse in their lifetime
 - 53% experienced sexual abuse in their lifetime
- Little information is currently available on men's experiences.
- Mandatory abuse reporting data suggests that men and women may be at similar risk for abuse and violence (Brown, Stein and Turk 1995; Marchetti & McCartney, 1990).
- As many as 32% of men with developmental disabilities are victims of sexual assault (Sobsey & Doe, 1991).
- Survey data from current study regarding men with disabilities (Powers, et al, 2002) found that :
 - 65% of the men with disabilities reported they experienced physical abuse in their lifetime;
 - 24% experienced sexual abuse in their lifetime

Effects of Abuse (Women)

- Impedes employment 30%
- Impedes caring for health 64%
- Impedes independent living 61%

Effects of Abuse (Men)

- Impedes employment 14%
- Impedes caring for health 23%
- Impedes living independently 16%

Some additional issues discussed by the focus group participants during the NCIL 2004 Conference included:

- In states that are considered wilderness areas, domestic violence is a huge issue. There are many people with disabilities living in very isolated

communities, which is a problem because there is not a place to go where people can be anonymous [or get help].

- Many participants shared that the domestic violence shelters in their states are not wheelchair accessible and this is a big problem. In addition, the time limits that are placed on shelter users makes it hard, because even if a person can get into a domestic violence shelter, they can't stay very long and often have to leave and go back with the abuser.
- Federal domestic violence laws define abusers as intimate partners; currently, these federal domestic violence laws do not acknowledge abuse by caregivers as a form of domestic violence.

“Violence awareness and prevention – needs to be an integral part of what we do in our CIL”

-Focus Group Participant

When participants were asked how their Centers were addressing violence against people with disabilities some of the innovative programs we found included:

- In response to seeing a lot of psychological and relationship abuse and neglect, one Center uses their PASS program to provide abuse awareness training/education in consumer's' homes and in the Center office.
- Another Center hosted a Sexual Assault community workshop, which included a self-defense class.
- Building relationships with the religious communities and utilizing pastors and church members for transportation needs of victims of violence/abuse.
- One participant said that in her state, the abuser had murdered a woman with a disability. This murder prompted their Center to provide community training on issues of violence against people with disabilities.
- Another participant related a current situation in which their Center is working with a consumer who is experiencing spousal abuse - this abuser is well known in the community.
- The Center that currently has a grant to address violence/abuse against women with disabilities meets once a month with domestic violence

agencies to work on needs (i.e. transportation) of consumers who are being abused. They also take part in cross training activities with their local domestic violence advocates who are also working with people with disabilities who are experiencing violence and abuse.

- Another Center does ongoing training about domestic violence and offers community workshops to spread information about domestic violence interventions.
- One Center offers a 6-week course each year to educate consumers with developmental disabilities. The courses include sexuality education, information on appropriate behaviors and role-plays.

VIOLENCE/ABUSE... IS IT OUR RESPONSIBILITY?

“Sometimes, I don’t think CILs think it’s our job [to deal with abuse issues].”

-Focus Group Participant

In 1978, Congress authorized the Title VII Independent Living Services and Centers for Independent Living in response to concerns that people with severe disabilities, who were not participating in vocational rehabilitation services, could benefit from other services that would support their efforts to become/remain independent in the community. Independent living services help people with disabilities obtain independence and control over their own lives; maximize leadership, empowerment, independence and productivity of individuals with disabilities and their integration and inclusion into the mainstream. The Rehabilitation Act defines a center for independent living as a consumer-controlled, community-based, cross-disability, nonresidential private nonprofit agency, designed and operated within a local community by individuals with disabilities.

Centers for Independent Living provide services and advocacy by and for persons with all types of disabilities to create opportunities for independence and assist individuals with disabilities to achieve their maximum level of independent functioning. Centers are authorized to provide Independent Living services in accordance to a State Plan for Independent Living (SPIL), which is developed by the Statewide Independent Living Council in partnership with the State Vocational Rehabilitation agency. A Center works with an individual to achieve their self-identified goals through peer counseling, skills training, advocacy, information and referral and other independent living services. Centers for Independent Living promote and practice the independent living philosophy of:

- Consumer control
- Self-help and self-advocacy

- Development of peer role models
- Equal access of individuals with significant disabilities to society and to all services, programs, activities, resources, and facilities, whether public or private.

Each Center for Independent Living provides at least four independent living core services: advocacy, peer support, independent living skill development and information and referral. Depending on the center's planning priorities and available funding they may also provide:

- Counseling
- Housing modifications
- Assistance in finding accessible housing
- Rehabilitation technology
- Mobility training
- Interpreters and readers
- Personal assistance including attendant care
- Needs surveys
- Education and training for participation in community activities
- Transportation
- Therapeutic treatment
- Social and recreation services
- Services to youth to promote self-esteem and self-empowerment
- Services for children
- Preventive services
- Disability awareness in local communities

With all of this to do, where does violence/abuse awareness and education fit in? To answer this question we need to look at how violence/abuse actually affects all aspects of the services you are currently offering. Remember that The Rehabilitation Act requires Centers to facilitate in the development and achievement of the IL goals selected by the individuals you are serving. A consumer living in a violent/abusive home will have difficulty achieving their goals. They may miss appointments because their abuser controls their every move. It may be hard for them to advocate for themselves since their self-esteem has been shattered at the hands of an abuser. They may experience times when the symptoms of their disabilities are exacerbated or a new disability is acquired because violence/abuse takes a toll on the mind, body and soul. The Rehabilitation Act also requires centers to:

- Provide services on a cross-disability basis to individuals with a variety of disabilities
- Provide services to those individuals that are unserved and underserved
- Work to increase the availability and improve the quality of community options for independent living

- Increase their communities' capacity to meet the needs of individuals with disabilities
- Develop funding sources beyond that afforded by the Rehabilitation Act.

When an individual is living in a violent/abusive household they are often kept isolated by their abuser. This is also true for people with disabilities who are living in abuse situation. In addition, to the isolation and entrapment created by the conscious choice of the abuser, many agencies that serve victims of violence/abuse are not accessible to people with disabilities. These combined barriers make it nearly impossible, for the person being abused to leave.

Violence/abuse issues **are** disability issues and we need to make sure that these issues are addressed in every aspect of our programming and service delivery. But how do we start? Is it a separate issue or will it fit into your existing Center activities and SPIL?

FOUR CORE SERVICES PROVIDED BY CENTERS FOR INDEPENDENT LIVING

We can begin addressing the problem of violence/abuse in our four core services: advocacy, peer support, independent living skill development and information and referral. Suggestions for how this can be done include:

Advocacy:

1. Currently the federal laws on domestic violence limit their definition of an abuser to an intimate partner. Intimate partners include, spouse, a former spouse, a person who shares a child in common with the victim or a person who cohabits or has cohabited with the victim. While some States may use different definitions others will follow the federal model. The federal definition of an intimate partner, however, excludes personal assistants and caregivers that may be perpetrators of violence and abuse.

Lobbying efforts are needed to amend state and federal statutes that exclude abusers defined as personal assistants / caregivers to increase the awareness that similar tactics of power and control is used by personal assistants as well.

“...Consumers come to us with abuse, we contact the shelters but when we tell them the people have physical disabilities...they say they can’t help them.”
-Focus Group Participant

2. Domestic violence, sexual assault and other victim services are often inaccessible to people with disabilities that have experienced violence/abuse. Action needs to be taken to hold these services providers

accountable to the Americans with Disabilities Act and Section 504 (since most of these victim agencies receive federal Violence Against Women Act dollars). We can no longer sit by and let these agencies discriminate against people with disabilities; there needs to be a joint effort to hold them accountable.

“In our state, shelters are not wheelchair accessible. We need to know what shelters can do and what CILs can do, so we can work together.”

-Focus Group Participant

3. Increased government and private funding that can be devoted to increase service development, so agencies (disability and victim services) have the resources to address the problems of violence/abuse in the lives of people with disabilities.

Peer Support:

1. Utilizing your current peer support program by expanding it to include peers who are survivors of violence/abuse to work with consumers who are trying to get out or deal with violence/abuse.

“Training in our CILs and PASS programs has to increase our contact with consumers by having mentors go into the consumers home.”

-Focus Group Participant

2. Running support groups for people with disabilities who have been victims of abuse.
3. Collaborating with local victim services for cross training. Having peers learn about victim advocacy and victim advocates learn about disability advocacy.

Independent Living Skills Development:

“Educate consumers about their rights, reporting laws and educate CILs about mandatory reporting laws...keep educating.”

- Focus Group Participant

1. Independent Living Centers who are providing independent living skills classes can add violence/abuse prevention to their existing curriculum.

2. Independent Living Centers that are providing skills training to individuals who are transitioning from high school or college can add violence/abuse prevention skills to their existing curriculum.

***“Self-defense classes for people with disabilities.”
- Focus Group Participant***

3. Teaching consumers who are transitioning from nursing homes or other institutions how to protect themselves from possible violence/abuse at the hands of caregivers and other service providers, family, strangers, etc.
4. Educating the community about the violence/abuse of people with disabilities including:
 - Aggressive community education to raise awareness of this issue
 - Sensitivity training for sexual assault and domestic violence agencies, the police, district attorney, etc.
 - Cross training with violence/abuse service providers and disability agencies.
 - Violence awareness for general public through skits, educational forums, theatre (such as Encore).
 - Training judicial and criminal justice personnel to apply and interpret laws fairly.

***“As a personal assistant agency we can educate consumers how to screen out potentially abusive PCWs.”
- Focus Group Participant***

Information and Referral:

1. Expanding your information and referral database to include detailed descriptions (i.e. accessibility features, services provided and areas served) of the violence/abuse providers in your area will help you to refer individuals who are being abused to the correct agency.
2. Knowing where to refer consumers who are being abused in institutional settings or by caregivers (i.e. ombudsman, bureau of quality assurance, protection and advocacy, adult protective services, etc.).
3. Providing violence/abuse agencies with information on where they can locate interpreters, personal care attendants, adaptive equipment, etc..

“Make sure staff know who to get in touch with when abuse occurs”, “We need to offer resources and support for emergency PA services so that a person that is abused has alternative service.”

-Focus group Participant

OTHER SERVICES: Questions to ask yourself:

Assistance in finding accessible housing and housing modifications- Do your consumers know about the different ways they can become the victim of a scam? Do they know what to do to prevent becoming a victim?

Rehabilitation technology- Safety devices and home alarm systems included?

Mobility training- Is safety training and crime prevention included in this training?

Interpreters and readers- Do you know who has experience with abuse issues or who has information about the legal system?

Personal assistance including attendant care- Are background checks done? Do consumers know what to do if violence/abuse occurs by their personal assistant?

Needs surveys- Do you ask your consumers questions about violence/abuse? Do you ask your consumers if they feel safe at home, with the people they know, at their worksite, and with the people who give them assistance?

Education and training for participation in community activities- Do you include public safety in your education and training?

Transportation- if you have worked to bring accessible transportation to your area, have you worked to see if it is safe for your consumers to wait at the bus stops? Are the paratransit drivers screened for criminal records?

Therapeutic treatment and counseling- Do you ask consumers questions about violence/abuse? Let them know that the abuse/violence they are experiencing is **NOT** their fault, that they have options for seeking help. Encourage survivors to tell someone they trust.

Social and recreation services- Do you have outreach material on violence/abuse of persons with disabilities? Do you hold informal classes on abuse prevention? Do you offer self-defense as part of your recreation programs?

Services to youth to promote self-esteem and self-empowerment- Do you provide IL skills to youth and do you include violence/abuse awareness and prevention education for youth?

Services for children- Do you provide IL skills to children and youth, and do you include violence/abuse awareness and prevention education for children/youth?

Preventive services- Violence and abuse can cause disability, in preventative services; do you address this issue?

Disability awareness in local communities- Have you done any disability awareness to police, victim services, your district attorney, etc.?

When participants were asked how they would like to see violence/abuse against people with disabilities addressed at their Centers and at NCIL their ideas included:

- The CILS across the country should be active in the community and bring the issues of violence against people with disabilities to the forefront. One way to do this would be via teleconference.
- CILS should provide safety training with the sheriff's office and invite all consumers and individual officers. Maybe we need to do this with our prosecutor's office.
- Additionally, CIL's could work closely with their local domestic violence and sexual assault agencies / advocates. Work with these domestic violence and sexual assault programs to become accessible - in terms of structural, programmatic, attitudinal and communication accessibility. Provide training to domestic violence shelters about working with people with disabilities; offer these agencies / programs information about accessibility features. This will help everyone.
- Focus group participants agreed that teaching consumers about violence and abuse was a priority; this education would need to include identifying the signs of abuse and violence and identifying abuse from caregivers. The following skills are important for consumers to know: how to recruit, hire, train and fire caregivers; how to identify "red flags" of potential abusers; ways to be effective employers, and communicating relaying how they want their work done. Consumers and staff need to learn ways to develop safety plans and identify people in the community who should receive reports of abuse. Consumers need to be educated about their rights to live a life without violence and the Centers need to learn about mandatory reporting laws. Center staff also needs to be educated about

the resources in the community and the seriousness and pervasiveness of violence and abuse of people with disabilities.

- There is a need for more safe spaces...housing...we need more safe houses. NCIL needs to talk about to legislators about federal allotments and additional housing so that more resources are available to consumers who need a safe, fully accessible place to go if they need to leave an abusive relationship or situation.
- Community outreach and advocacy on violence/abuse issues needs to take place. Pressure should be put on the attorney general's office and others to make this a priority.
- Centers need to encourage persons with disabilities who are sexually or physically abused to report this abuse to law enforcement, domestic violence / sexual assault advocates, or someone they can trust who would be supportive and listen to their story. Staff can go with their consumers to report the violence and be an advocate. Encourage consumers to call the police and file complaints of violence/abuse.
- Staff needs to know who to get in touch with when abuse does occur.
- Centers need to collaborate with all stakeholders in a community, including developmental disability providers, physical disability providers, etc.
- Resource and support for emergency personal care assistance services need to be developed for people who are being abused by caregivers.
- Participants would like NCIL to be aware of the issues of abuse and to understand that violence/abuse is both a community and a national problem.
- Focus group participants said they would like NCIL to help create legislation around these issues; NCIL needs to be our national voice for the prevention and increased awareness of people with disabilities.
- Since NCIL has a number of different committees, staff with an interest in violence/abuse can get involved in these sub-committees and bring the issues into the committee.
- NCIL should put violence/abuse on their agenda, and to continue to offer workshops on violence/abuse at the national conference.
- NCIL could develop booklets to help with education, raising awareness of violence and abuse and collaborations and develop open-caption videos

- NCIL could talk to law and policy makers to include caregiver abuse in the definition of domestic violence. They could also advocate for minimum sentencing guidelines at the local and national level.
- NCIL should build national coalitions with national organizations that deal with violence/abuse.
- NCIL should demand that domestic violence shelters become accessible (increasing physical, attitudinal, communication and programmatic accessibility). These shelters need to be working with people with disabilities. Demand that federal funding sources make sure that the programs they are funding are complying with the ADA and 504.

While the facilitators and participants are well aware of all the work that Independent Living Centers currently do and the priorities set by SILCs and NCIL, we do see that violence/abuse needs to start being addressed on both a local, state and national level. We do not feel that every Center needs a special program to deal with violence/abuse, but instead, these important issues can be intertwined into the work CILs, SILCs and NCIL are already performing.

REFERENCES

Brown, H., Stein, J., & Turk, V. (1995). The sexual abuse of adults with learning disabilities: Report of a second two-year incidence survey. Mental Handicap Research, 8(1), 3-24.

Litvak, S., Zukas, H., & Heumann, J.E. (1987). Attending to America - Personal assistance for independent living: A survey of attendant service programs in the United States for people of all ages with disabilities. Berkely, CA: World Institute on Disability.

Marchetti, A.G., & McCartney, J.R. (1990). Abuse of persons with mental retardation: Characteristics of the abused, the abusers, and the informers. Mental Retardation, 6, 367-371.

Nosek, M.A., Young, M.E., & Rintala, D.H. (1995). Barriers to reproductive health maintenance among women with physical disabilities. Journal of Women's Health, 4(5), 505-518.

Powers, L.E., Curry, M.A., Oschwald, M., Maley, S., Saxton, M., & Eckels, K. (2002). Barriers and strategies in addressing abuse: A survey of disabled women's experiences. Journal of Rehabilitation, 68(1), 4-13.

Sobsey, D., & Doe, T. (1991). Patterns of sexual abuse and assault. Journal of Sexuality and Disability, 9, 243-259.

United States Census Bureau. (1992). United States National Census. Available: <http://www.census.gov>

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The facilitators for these focus groups are all recipients of Department of Justice grants. Representing agencies from across the country and across disciplines.

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