


## *Special Publication*

### Councils on Developmental Disabilities Addressing Sexual Violence & Neglect



Developmental Disabilities Councils are part of the Developmental Disabilities Network as outlined in the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 2000 (DD Act). Councils across the United States and Territories work to address identified needs by conducting advocacy, capacity building, and systems change efforts that promote self-determination, inclusion, and integration. Councils play a unique role in making investments that impact the lives of people with developmental disabilities. This special publication highlights the work of select Councils on the topic of sexual violence and neglect.

## Introduction

Abuse, neglect, and exploitation are serious issues in systems of services and support for people with disabilities. Decades of research suggest an ongoing crisis; there is an alarmingly high rate of physical abuse, neglect, and sexual victimization among those with intellectual and developmental disabilities<sup>i ii iii</sup>, yet only a small fraction of these are reported,<sup>iv v vi</sup> and an even smaller fraction of persecutors are convicted<sup>vii viii</sup>. Studies from the early 1990's<sup>ix</sup> showed that people with developmental disabilities are 4 to 10 times more likely to experience abuse, particularly people with more profound intellectual disability, recent studies report similar findings<sup>xi xii</sup>. Although there have been targeted efforts to address this persistent issue, the field of services and supports for people with I/DD needs to better understand 1) when and how abuse and neglect occur for people with intellectual and developmental disabilities; and, 2) how to better support people to understand, avoid (if possible), report and heal.

To better understand these issues and support reporting and education activities, multiple Developmental Disability Councils have developed projects and partnerships aimed at preventing the abuse of people with disabilities and ensuring that they can report abuse and have their reports taken seriously, treated appropriately, and investigated fully. This paper will provide a brief review of the topic of sexual violence and neglect, and then highlight some work done in this area by various state developmental disability councils.

### What is Abuse & Neglect?

The National Adult Protective Services Association<sup>xiii</sup> defines abuse as a “form of mistreatment by one individual that causes harm to another person”. While neglect “includes failures by individuals to support the physical, emotional and social needs of people dependent on others for their primary care.” Abuse and neglect can include many forms of mistreatment. Specifically, abuse can be categorized as physical abuse, emotional abuse, isolation, financial or material exploitation, abandonment and sexual abuse.

### What Is Sexual Violence?

According to the Centers for Disease Control and Prevention<sup>xiv</sup>, sexual violence includes sexual assault and sexual abuse. Assault is a crime of violence, anger, power, and control where sex is used as a weapon against the victim. Assault includes any unwanted sexual contact or attention achieved by force, threats, bribes, manipulation, pressure, tricks, or violence. Sexual assault may be

## The Abuse Crisis:

### What the Research Shows

People with I/DD are 2.5<sup>xii</sup> to 10 times more likely to experience abuse<sup>ix</sup>.

People with I/DD are not only much more likely to experience abuse, they are likely to experience repeated abuse. One study estimates that 49% of people will experience 10 or more incidences of abuse<sup>x</sup>.

Researchers have found that that more than 90% of people with intellectual disabilities will experience some form of sexual abuse at some time in their lives<sup>ii</sup>. They estimate that 15,000 to 19,000 people with intellectual disabilities are raped each year in the United States.

Most incidences of abuse and neglect for people with IDD are not reported<sup>v</sup>. This is especially true for people receiving services in congregate settings where up to 85% of cases of abuse go unreported<sup>vi</sup>

When abuse is reported, most cases do not lead to prosecution or conviction. For instance, a study published by the Boston Globe found that while 70% of serious crimes against people without disabilities were prosecuted, only 5% of serious crimes against people with disabilities were<sup>vii</sup>.

People with more profound intellectual disabilities and people with higher support needs (who are more dependent on services) are more likely to be targeted for abuse and neglect<sup>ix</sup>

Almost all abuse is perpetrated by someone that a person with a disability knows; some research estimates up to 96%<sup>i</sup> of cases.

physical or non-physical and includes rape, attempted rape, incest, child molestation, and sexual harassment. Fondling, exhibitionism, oral sex, exposure to sexual materials (pornography), and the use of inappropriate sexual remarks or language also fall under the definition of sexual assault. Sexual abuse is similar to sexual assault, but is a pattern of sexually violent behavior that can range from inappropriate touching to rape. The difference between the two is that sexual assault constitutes a single episode whereas sexual abuse is ongoing. Sexual violence can occur in the home (sexual abuse of children, sexual assault by partners or relative), outside the home (in group homes or institutions), on the job, on transportation systems (while riding the bus or a taxi), and virtually anywhere.

### **Risk Factors for Individuals with I/DD**

Studies indicate that people with intellectual and developmental disabilities are at increased risk to experience abuse and neglect for several reasons. Specifically, the frequently reported risk factors for abuse, neglect, and sexual violence against people with I/DD are:

- Lack of education about sexual development and anatomy
- Lack of information on abuse awareness
- Lack of healthy relationship education
- Lack of social norm education
- Lack of age-appropriate friends<sup>xv</sup>

Another risk factor correlated with incidences of abuse and neglect and rates of reporting is the setting in which services are provided. People who receive institutional and congregate services and supports are likely to experience abuse<sup>xvi</sup>, but are less likely to report (or have someone report on their behalf)<sup>iv</sup>. Studies have shown that a disproportionate number of abusers are people who have a relationship with their victims specifically because of their disability<sup>xvii x</sup>. So, when people are supported in their communities, there are more opportunities for people to see and report abuse and neglect.

### **DD Councils Addressing Abuse & Neglect**

Developmental Disabilities Councils across the United States have engaged in efforts to better understand and mitigate issues that contribute to high rates of abuse and neglect for people with intellectual and developmental disabilities. Specifically, they have established work groups and initiatives and have funded research, programs and training geared towards building awareness and capacity to help providers, families, educators, people with disabilities and communities recognize, report and stop any and all abuse and neglect for people with I/DD. Several of those initiatives and opportunities are outlined below.

#### **Florida: The Abuse & Neglect Stakeholders' Workgroup**

The Florida Developmental Disabilities Council established the Abuse & Neglect Stakeholders' Workgroup in 2013 with the primary purpose of improving Florida's system of prevention, detection, and response to abuse and neglect for individuals with developmental disabilities.

The Stakeholder workgroup consisted of a total of 24 participants, which includes one (1) self-advocate; three (3) parents of individuals with developmental disabilities; two (2) public policymakers (the State Director of Adult Protective Services and the State Coordinator of the Agency for Persons with Disabilities Zero Tolerance Initiative); and eighteen (18) representatives of statewide organizations, waiver providers, and law enforcement agencies.

*"(The Workgroup) presented an opportunity to examine key national and global trends in abuse and neglect that helped guide and prioritize short and medium term planning across Florida." - Abuse & Neglect Stakeholder Participant*

The workgroup met for three years and developed recommendations for next steps that the Council can take to address abuse and neglect prevention for individuals with developmental disabilities. Specific recommendations identified included:

- Improving training for law enforcement and direct service personnel;
- Expanding education opportunities for individuals with intellectual and developmental disabilities;
- Raising public awareness on the identification of abuse and neglect of individuals with developmental disabilities; and,
- Conducting advocacy efforts to increase options for prosecutions or removal of abusers from service delivery systems for individuals with developmental disabilities.

*"I learned a lot about protecting myself." - Abuse & Neglect Stakeholder Participant*



### **Puerto Rico**

In recent years, the Puerto Rico DD Council (PRDD) has implemented five pilot projects on sexuality education and reproductive health care for individuals with I/DD and their families, resulting in over 800 people trained island-wide.

Projects included the Healthy Sexuality education program for adults with IDD that was implemented in collaboration with the Independence Living Center (MAVI). Through six interactive workshops, participants were educated about

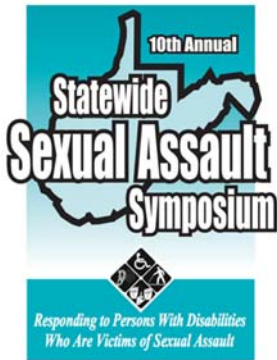
healthy sexuality, how to engage in healthy relationships, how to avoid pregnancies and sexually transmitted diseases, and how to prevent sexual assault. The information is presented through talks, films, and discussion activities and adjusts to the capacity of each individual. In addition, if necessary, group workshops are offered to parents to acquire the information and to follow-up in their homes on the concepts learned in the workshops. The program provides education to people with IDD, professionals, and to family members island-wide. The program led to the creation of support groups, which provided families with sex education and support for their family member with IDD.

PRDD also collaborated with the YAI Network in Puerto Rico to provide training on sex education and sexual health for adults with IDD and their families. A training model was created with Educavipro which integrated information on health sexuality education; prevention of abuse, neglect and sexual assault; and improving self-determination as part of sex health care education. At the end of the initiative, an educational magazine on sexual health was created to educate the community about the equal right individuals with I/DD have to live a sexually healthy life.

### **Hawaii**

The Hawaii DD Council (HIDDC) is involved with the Department of Health's (DOH) Maternal and Child Health Branch's (MCHB) Sexual Violence Primary Prevention Planning Committee that identified at-risk groups (youth and young adults, immigrants, people with disabilities, and Lesbian/Gay/Bisexual/Transgendered individuals). The DD Council and the Planning Committee also created profiles which showed risk factors related to poverty and discrepancies by island in rates of rape offenses. Prevention goals and strategies were addressed in three sections (Youth and Young Adults ages 10-21 years, Chuukese and Marshallese Communities, and Capacity Building). The Annual meeting, "Create, Enhance, Sustain," was held on October 30, 2014 to review the activities of the Community Action Teams (CAT) from Hilo, Hawaii; Maui; and Waianae, Oahu. The goal was to build individual and CAT capacity to implement effective sexual violence prevention efforts, to cultivate individual and CAT commitment and ability to evaluate sexual violence prevention efforts, and to develop and enhance CAT sexual violence prevention action plans.

As this population is at high risk for violence, the DOH’s MCHB and the Developmental Disabilities Division, along with the Hawaii State Coalition Against Domestic Violence have partnered to develop a curriculum and training to educate developmental disabilities case managers, domestic violence providers, and advocates on people with disabilities on domestic violence. It is estimated that initially 50 case managers and 30 domestic violence providers/advocates on Oahu will receive training through 2017.



### West Virginia

The West Virginia DD Council implemented the “Restoring Safety in a Vulnerable Population” (RSVP) project. This project sought to improve the health, safety, and welfare of children with developmental disabilities by improving the quality of interventions carried out by local multi-disciplinary investigative teams (MDITs). The RSVP Project was developed in response to growing concerns and factual evidence that children with developmental disabilities are at high risk of sexual and other forms of abuse, and that incidences of abuse and neglect are under-reported. Abuse prevention training will be conducted for a wide range of human services personnel. Additionally, long term public policy recommendations were developed, including necessary collaboration between the major responsible State and local agencies.

### Virginia

The Virginia Board for People with Disabilities (DD Council) invested in the Leadership for Empowerment and Abuse Prevention (LEAP) project. The LEAP’s project goal was to teach people with developmental and other disabilities about healthy relationships and how to better protect themselves from sexual assault, abuse, neglect, and violence. One of the main objectives of the project was to create a new curriculum on healthy relationships, abuse, neglect, and violence prevention that would meet the needs of Virginians with developmental and other disabilities. The project team evaluated existing curricula and found that existing curricula focused too much on placing the responsibility on the individual to prevent abuse and neglect rather than focusing on abuse prevention strategies and healthy relationships. The LEAP project developed its own unique training curriculum, created a 90-minute one-session overview of healthy relationships, and a curriculum of four 90-minute sessions. Project staff reached and scheduled 19 training sessions at key disability support agencies such as job clubs, day support programs, and residential providers. In total, eleven trainers were trained (including seven self-identified people with disabilities) and 519 people with disabilities were trained using the LEAP Curriculum. In addition, Council staff worked with the Sexual Assault & Domestic Violence Leadership Council. This Council represents service providers throughout Virginia and is critical to supporting individuals with developmental and other disabilities and service providers in the community now that the LEAP grant has ended.

**519 people with disabilities received Leadership for Empowerment and Abuse Prevention training**

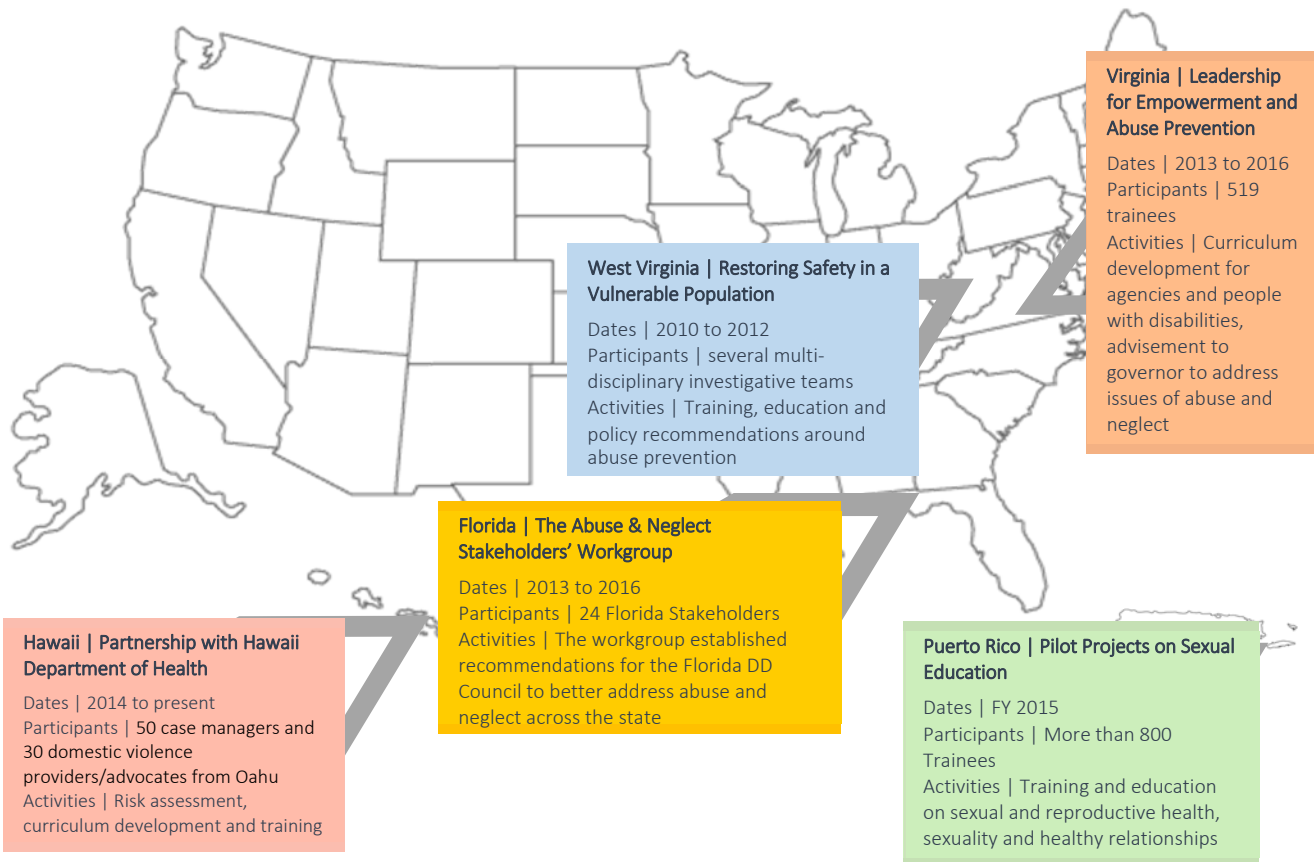
### Concluding Remarks

While DD Councils have committed a great deal of time, effort and resources to addressing issues of sexual abuse, neglect and exploitation for people with intellectual and developmental disabilities, there is still a significant amount of work to be done. Like other stigmatized groups<sup>xviii</sup>, people with disabilities are disproportionately at risk for abuse. Historical conceptualizations of people with disabilities that have diminished their humanity, continue to perpetuate the vulnerability of people with IDD; when people are seen as other, we can justify our actions to mistreat them. As long as *isms* prevail in our society (racism, sexism, ableism, etc.), people who experience discrimination will continue face higher risk of sexual abuse, neglect and exploitation.

DD Councils have the opportunity to address these atrocities head on; through research, training, programs and initiatives, DD Councils can continue to build states capacity to recognize and reduce abuse and neglect. The above initiatives and programs have shown that states can make progress, particularly when multiple agencies and entities (e.g. DD Councils, State offices, UCEDDS, etc.) collaborate.

One way that DD Councils might engage in a larger collaborative effort to address abuse and neglect is to follow the advice outlined in the National Association of State Directors of Developmental Disabilities Services (NASDDDS)<sup>xix</sup> recommendations to CMS to convene a workgroup to “develop core elements (and definitions) of abuse, neglect and exploitation (and other potential critical elements), similar to the core services definition... to provide a key framework for CMS expectations” around mitigating and monitoring abuse and neglect.

Whatever the efforts, DD Councils are uniquely positioned to support statewide enhancement of services, supports and lives of people with intellectual and developmental disabilities. To do this, they must continue to address the critical issues of abuse and neglect that affect too many people with IDD today.



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## References

- <sup>i</sup> Sobsey, D., D. Wells, R. Lucardie, and S. Mansell. 1995. *Violence and Disability: An Annotated Bibliography*. Baltimore, MD. Brookes Publishing.
- <sup>ii</sup> Baladerian, N. Coleman, T., & Stream, J. (2013). A report on the 2012 national survey on abuse of people with disabilities: Victims and their families speak out. *Spectrum Institute Disability and Abuse Project*
- <sup>iii</sup> Daigle, L. (2017). *Victimology: The essentials*. Sage Publications, New York, New York.
- <sup>iv</sup> Robinson, S., & Chenoweth, L. (2011). Preventing abuse in accommodation services: From procedural response to protective cultures. *Journal of Intellectual Disabilities, 15*, 63-74.
- <sup>v</sup> Wilson, C., & Brewer, N. (1992). The incidence of criminal victimization of individuals with an intellectual disability. *Australian Psychologist, 27*(2), 114-117.
- <sup>vi</sup> Powers, J.L., Mooney, A., & Nunno, M. (1990). Institutional abuse: A review of the literature. *Journal of Child and Youth Care, 4*, 81-95.
- <sup>vii</sup> *Boston Globe* (2001). In attacks on disabled, few verdicts despite evidence, law enforcement drops most cases, by R. Mishra. June 10. [Online] Available: [http://nl.newsbank.com/nl-search/we/Archives?p\\_action=print](http://nl.newsbank.com/nl-search/we/Archives?p_action=print)
- <sup>viii</sup> Sobsey, D. & Varnhaggen, C. (1991). Sexual Abuse and Exploitation of Disabled Individuals. *Child Sexual Abuse: Critical Perspectives on Prevention, Intervention, and Treatment*. Bagley, C.R. & Thomlinson, R.J. Editors. Wall & Emerson, Inc. Toronto. 1991
- <sup>ix</sup> Petersilia, J., Foote, J., & Crowell, N.A. (Eds.) (2001). *Crime Victims with Developmental Disabilities: Report of a Workshop*. Washington D.C.: National Academy Press.
- <sup>x</sup> Sobsey, D. & Doe, T. (1991). Patterns of sexual abuse and assault. *Sexuality and Disability, 9* (3), 243-259.
- <sup>xi</sup> Mikton, C., Maguire, H., & Shakespeare, T. (2014). A systematic review of the effectiveness of interventions to prevent and respond to violence against persons with disabilities. *Journal of Interpersonal Violence*,
- <sup>xii</sup> Harrell, E. (2017). Crime against persons with disabilities, 2009-2015- statistical tables. *Report from the U.S. Department of Justice, Office of Justice Programs*.
- <sup>xiii</sup> <http://www.napsa-now.org/get-informed/what-is-abuse/>
- <sup>xiv</sup> <https://www.cdc.gov/violenceprevention/sexualviolence/definitions.html>
- <sup>xv</sup> Fears, T. (2013). Sexual abuse of people with I/DD: A global scandal. *The Arc National Center on Criminal Justice and Disability*
- <sup>xvi</sup> Network Advocacy Information Service, Melbourne; French, P., Dardel, J., & Price-Kelly, S. (2010) *Rights denied: Towards a national policy agenda about abuse, neglect and exploitation of persons with cognitive impairment*, People with Disability Australia, Sydney.
- <sup>xvii</sup> Mansell, S., Sobsey, D. & Calder, P. (1992). Sexual abuse treatment for persons with developmental disabilities. Cited in Petersilia et. al. (2001), *Crime Victims with Developmental Disabilities: Report of a Workshop*. Washington D.C.: National Academy Press.
- <sup>xviii</sup> Sabina, C., Cuevas, C.A., & Schally, J.L. (2015). The influence of ethnic group variation on victimization and help seeking among Latino women. *Cultural Diversity and Ethnic Minority Psychology, 21*(1), 19-30.
- <sup>xix</sup> NASDDDS (2017) Response to Centers for Medicare & Medicaid Services 42 CFR Part 440 [CMS-2404-NC] RIN 0938-ZB33 Medicaid Program; Request for Information (RFI): Federal Government Interventions to Ensure the Provision of Timely and Quality Home and Community Based Services AGENCY: Centers for Medicare & Medicaid Services (CMS), HHS. ACTION: Request for information. [http://www.nasddds.org/uploads/files/NASDDDS\\_Response\\_to\\_CMS\\_LTSS\\_RFI\\_1.4.2017.pdf](http://www.nasddds.org/uploads/files/NASDDDS_Response_to_CMS_LTSS_RFI_1.4.2017.pdf)

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