



Comprehensive Protection Needed for Individuals with Profound Developmental Disabilities at Risk of Abuse and Neglect



Maltreatment of individuals who are profoundly developmentally disabled is a problem that occurs across many settings and is investigated by human service workers and others. The prevalence¹ and incidence² of such maltreatment is unknown. While we know the numbers are considerable, there are no official national statistics. Several reasons account for this. First, there is no singular definition of developmental disability. Second, there is no nationwide uniform reporting system. Third, because of the nature of the victims, reporting is, by definition, aperiodic. Cognitive disabilities, in particular, afford opportunities for miscommunication or lack of communication and may thereby adversely affect a person's legal rights and compromise their safety and functioning.

The National Association of State Directors of Developmental Disabilities Services (NASDDDS) represents the nation's agencies providing services to children and adults with intellectual and developmental disabilities and their families. Its articulated guiding principles emphasize that "State service systems should be based on the principle that people with developmental disabilities have a right to:

- ♦ be treated with respect and dignity;
- ♦ be independent and make individual choices;
- ♦ participate in family, community, and work life;
- ♦ have opportunities to maximize their full potential; and
- ♦ receive outcome-based services and supports."³

Some states (e.g., CT, GA, MA, OH, and TN) have a stand-alone department responsible for service and protection functions of individuals with developmental disabilities. In other states, it is a mandate of the department of human services (e.g., AR, CO, IA, ID, IL, NC, ND, NJ, MN, MT, OK OR, SD, UT, and WA).⁴

Perpetrators of maltreatment against persons with developmental disabilities may be guardians, caregivers, neighbors or acquaintances, health care providers, family members, or other residents. Once again, because there is no uniform national data, we are unsure of their profiles and circumstances. We are uncertain of the exact risk factors associated with individuals who are developmentally disabled as victims of maltreatment.⁵

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The Illinois Department of Human Services, in its Residential Director Core Training, suggests that people with developmental disabilities may be at heightened risk for abuse and neglect because they:

- ♦ “May have a variety of care providers and may be reliant on physical assistance;
- ♦ Frequently are taught to be compliant to requests from caregivers or other authority figures;
- ♦ Are often isolated or living in institutional/group settings;
- ♦ Have not typically received training that addresses healthy intimate relationships and appropriate sexual activities;
- ♦ May not have been allowed privacy or had the chance to learn about the private areas of the body;
- ♦ May have limited communication skills, therefore making it harder to resist or disclose abuse;
- ♦ Often are not believed or viewed as credible (p. 6).”⁶

Clearly, better screening by department of human service investigators is needed to identify people with developmentally disabilities who are subject to abuse and neglect. A number of studies have been done⁷—all taking a step in the right direction—but additional studies are needed to determine optimal procedures department investigators can take in screening and assessing the incidence and effects of maltreatment events.

I am unaware of any validated tool specifically designed for human service department workers to assess persons with developmentally disabilities who are at risk for abuse or neglect. Whatever tools do exist appear to be adaptations from the fields of child abuse, adult protective services, or domestic violence.

It is time for state social service agencies responsible for serving and protecting individuals with developmental disabilities to develop and

implement comprehensive procedures. The Illinois Department of Human Services, some state courts,⁸ and others have recognized that, by virtue of their profound disabilities, some developmentally disabled adults are often (1) totally unable to protect themselves from abuse or neglect; (2) completely dependent on their caregivers and case managers for their personal safety; and (3) liable to be manipulated. These interrelated issues make it clear that the responsible state agencies must employ mechanisms to thoroughly screen the qualifications (education, training, and experience), character, competence, and suitability of prospective state-paid caregivers, and engage in conscientious case management and oversight of services being provided.

On a daily basis, children encounter an array of mandated reporters—teachers, health professionals, coaches, clergy, etc.—who serve as a layer of protection against abuse and neglect. In addition, vulnerable adults who are developmentally disabled, especially those living with a caregiver in a single-family home, are likely to encounter far fewer mandated reporters, thus depriving them of those layers of protection inherent in the child welfare system.

When developing protective mechanisms, the health, safety, and well-being of the client must be the paramount concern. Agencies may look to established standards and practices in child welfare systems for guidance, but only as the metaphorical “floor” of the mechanisms that should be employed, not the “ceiling.”

We know too well the profound indifference and criminality some predators display toward society’s most vulnerable people, especially when those vulnerable people are not sufficiently monitored by an oversight agency. Indeed, the more profound the developmental disability the more we must be concerned about

constitutional interests and human dignity. ■

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Reference Notes

1. The total number of people who have experienced maltreatment in a specified time period.
2. The number of new cases in a specified time period.
3. Available at <http://www.nasddd.org/about-nasddd>.
4. A complete list is available at <http://www.nasddd.org/state-agencies>.
5. See, for instance, Child Information Gateway. (March, 2012). The risk and prevention of maltreatment of children with disabilities. Available at <https://www.childwelfare.gov/pubs/prevenes/focus/focus.pdf>
6. Available at https://www.dhs.state.il.us/OneNetLibrary/27896/documents/By_Division/Division%20of%20DD/ResidentialDirectorCore/Module4RDCAbuseNeglect.pdf
7. See, for example, Bowman, R.A., Scotti, J.R. & Morris, T. (2010). Sexual abuse prevention: A training program for developmental disabilities service providers. *Journal of Child Sexual Abuse*, 19, 119–127; Sullivan, P.M. & Knutson, J. (2000). Maltreatment and disabilities: A population-based epidemiological study. *Child Abuse & Neglect*, (24)10, 1257–1273; Lumley, V.A. & Miltenberger, R.G. (1997). Sexual abuse prevention for persons with mental retardation. *American Journal on Mental Retardation*, 101, 459–472; Levy, H., & Packman, W. (2004). Sexual abuse prevention for individuals with mental retardation: Considerations for genetic counselors. *Journal of Genetic Counseling* 13(3), 189–205; Hassouneh-Phillips, D., & Curry, M. (2002). Abuse of women with disabilities: State of the science. *Rehabilitation Counseling Bulletin*, 45(2), 96–104.
8. *Caulfield v. Kitsap County*, 108 Wn. App. 242, 251–57, 29 P.3d 738 (Wash. 2001). See also *Hinckley v. Palm Beach County*, 801 So.2d 193, 195–96 (Fla. 2001).