

Healthcare Self-Advocacy

Self-Advocacy in Healthcare for Individuals with I/DD

Melvin Nobles

University of Alaska-Anchorage

2015–16 LEND Fellow

As of 2013, according to the American Community Survey conducted by Cornell University, 5 percent of the US population identifies as having a cognitive disability. For Alaskans reporting cognitive disability it is 4.4 percent. A previous study completed in 2008 showed that the incidence of developmental disability reported in children is 1 in 6. . (Boyle et al.,2011; Erickson, Lee, von Schrader, 2015). With the incidence of developmental disabilities being at this level, it presents special challenges for both healthcare providers and the individuals seeking services who have developmental disabilities. Through a literature review, this paper will examine what families and individuals who experience intellectual and developmental disabilities (IDD) need to know or do to be strong self-advocates in health care decisions and interactions.

Review of existing literature finds a limited amount of research and information from the perspective of the individual with IDD. Most research and review has been from the perspective of the medical provider and what they can do to improve services to individuals with IDD. However, several main areas of concern are presented that can assist individuals and their families in being better medical self-advocates. These areas are: communication, education, record keeping, time limitations, and use of additional advocacy resources.

In a review of healthcare delivery concepts conducted by Ervin, Hennen, Merrick and Morad (2014), it is noted that significant barriers exist that affect the access to, and the quality of healthcare received by individuals. One of these barriers is communication. It is additionally addressed that individuals with IDD often have trouble communicating what their healthcare needs are, and often need someone to assist them in this communication. Even when this is accomplished the healthcare provider may not respect the individual's input, and may not implement what is requested (Ervin, et al 2014; Perry et al, 2014). Communication is also addressed as not just an issue for the individual with IDD, but for the medical provider as well. People with IDD and their caregivers have addressed that medical providers don't always communicate in ways that are effective for the individuals to understand (Mastebroek, Naaldenberg, Lagro-Janssen, de Valk 2014).

Education is a second area of concern. Again this is a concern not just for the individual with IDD and their caregiver, but also for the medical provider. Medical providers have voiced concerns that people with IDD are often accompanied to appointments by caregivers with limited education in general and with little to no medical knowledge. This reduces the likelihood of the medical provider getting quality information about the status of the person being seen. Medical providers have also admitted their own lack of knowledge about IDD and associated illnesses (Mastebroek , et al 2014). Much of this lack of knowledge on the part of medical providers can be attributed to the fact that no medical school programs have accreditation required curricula in IDD (Ervin , et al 2014).

A third area of concern is record keeping and information sharing. Poor quality of health information related to the individual with IDD due to direct care staff turnover and communication difficulties has been identified by primary care physicians. Medical providers have recommended that individuals maintain a central health record at their home that can be updated between visits and brought to appointments. Providers and caregivers have agreed that there is a need to work together to share information and ensure that thorough background information is available for appointments (Lennox , Van Driel , van Dooren 2014; Mastebroek , et al 2014).

A fourth area of concern is time limitations. Many people with IDD and their caregivers report that they are given too little time for appointments to fully give or receive necessary information to ensure the best possible care. Time given for appointments is insufficient to account for communication difficulties and to allow for caregivers to ask questions. Medical providers recognize time constraints as a problem as well. People with IDD realize that doctors are very busy but feel that sufficient time is necessary to get the best possible care which would benefit from extended appointment times (Mastebroek , et al 2014; Perry , et al 2014).

A final area of concern is knowledge of additional information and advocacy resources. In the article *Patient and Family Advocacy: Working with Individuals with Comorbid Mental Illness and Developmental Disabilities and their Families*, McGinty, Worthington, and Dennison present their views on the topic based on their own experience working with individuals with

developmental disabilities as a parent, a psychiatric intern, and as a child/adolescent psychiatrist and community service agency board member. In review it seems logical that many of the issues raised could also transfer to primary care. Parents feel that they should be encouraged to advocate for their children and provided with information about local support agencies and advocacy agencies. From the psychiatrist perspective it is seen as a valuable resource to provide parents and individuals with information about local and national support and advocacy agencies such as The ARC, NAMI, Autism Speaks, and others (McGinty , Worthington , Dennison 2008).

In conclusion, this literature review found several important strategies for individuals who experience IDD and their families to help them overcome some of the barriers to the best possible healthcare. These strategies include: informing the primary care physician of any communication difficulties and needs prior to the initial appointment; researching their specific disability and related health concerns in order to be educated and well informed on the subject to even possibly assist as a resource to the physician; maintaining extensive, well-organized, up to date records of their own healthcare to have available to the physician; requesting longer appointment times and preparing what needs to be presented to the physician prior to the appointment to maximize the time available; and researching agencies and support groups related to their disability for general information, support, and advocacy services and sharing these resources with their physician. Use of these strategies should serve to greatly improve the overall healthcare experience for individuals who experience IDD and their families.

## References

- Boyle, C.A., Boulet, S., Schieve, L.A., Cohen, R.A., Blumberg, S.J., Yeargin-Allsopp, M. Kogan, M.D. (2011). Trends in the prevalence of developmental disabilities in US children, 1997-2008. *Pediatrics*, 127(6), 1034-1042. doi:10.1542/peds.2010-2989
- Erickson, W., Lee, C., von Schrader, S. (2015). Disability statistics from the 2013 American community survey (ACS). Ithaca, NY: Cornell University Employment and Disability Institute (EDI). Ervin, D.A., Hennen, B., Merrick, J., & Morad, M. (2014). Healthcare for persons with intellectual and developmental disability in the community. *Frontiers in Public Health*, 2, 83. <http://doi.org/10.3389/fpubh.2014.00083>
- Lennox, N., Van Driel, M.L. and van Dooren, K. (2015), Supporting primary healthcare professionals to care for people with intellectual disability: a research agenda. *Journal of Applied Research in Intellectual Disabilities*, 28: 33–42. doi: 10.1111/jar.12132
- Mastebroek M., Naaldenberg J., Lagro-Janssen A.L., deValk, H. van Schrojenstein Lantman (2014) Health information exchange in general practice care for people with intellectual disabilities—A qualitative review of the literature. *Research in Developmental Disabilities* Volume 35, Issue 9, September 2014, Pages 1978–1987
- McGinty K., Worthington R., Dennison W. (2008) Patient and family advocacy: working with individuals with comorbid mental illness and developmental disabilities and their families. *Psychiatric Quarterly* September 2008, Volume 79, Issue 3, pp 193-203
- Perry, J., Felce, D., Kerr, M., Bartley, S., Tomlinson, J. and Felce, J. (2014), Contact with primary care: the experience of people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 27: 200–211. doi: 10.1111/jar.12072