

Nurse's Role in Providing Ethically and Developmentally Appropriate Care to People With Intellectual and Developmental Disabilities

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Purpose

The purpose of this position statement is to identify issues in the provision of ethically and developmentally appropriate care to people with intellectual and developmental disabilities (IDD).¹ Because of cognitive, physical, and communication challenges often faced by people with IDD, nurses must be sensitive to needs across the lifespan and in all settings. This position statement is written for novice nurses with little to no experience with people with IDD, and for expert nurses who have vast knowledge and experience with this population. Its intent is to support people with IDD, by respecting and understanding differences and enabling them to realize their full potential in health situations while building on existing strengths and skills as active, engaged citizens, so that others can benefit from their talents and abilities.

Statement of ANA Position

The American Nurses Association (ANA) believes that nurses must provide compassionate, comprehensive, and person-centered care to all people, inclusive of at-risk populations such as people with IDD who experience health disparities across practice settings. The nurse's primary commitment is to the patient, whether an individual, family, group, community, or population (ANA, 2015, p.5). By virtue of their disability, people with IDD often require support across the lifespan, which encompasses support for the individual, family, caregiver, and community. Nursing care for people with IDD should focus on individual

¹ Limitations in both intellectual functioning and adaptive behavior, which includes many everyday social and practical skills, are characteristic of intellectual disability. Intellectual disability originates before the age of 18. The most common syndromes associated with intellectual disability are Down syndrome, Fragile X syndrome and fetal alcohol spectrum disorder (FASD). Intellectual disability also co-occurs in nearly a third of people with autism spectrum disorder.

needs and strengths, rather than a diagnosis or label. Nurses are well positioned to advocate for the rights of people with IDD, as well as protect them from potentially harmful factors, such as victimization, abuse, neglect, and discrimination. Nurses should be aware that a restricted view of advocacy, focusing exclusively on either progress or challenges, may fail to address the spectrum of needs faced by people with IDD. Nurses can enhance the quality of life for people with IDD through advocacy efforts to break down traditional barriers, bias, stigmas, and stereotypes. Nursing care should focus on providing opportunities for people with IDD to participate in activities that promote self-determination and enhance quality of life. Nurses must provide care that enables people with complex care needs and difficulty with cognitive functioning to live fully with as much physical, emotional, social, and spiritual well-being as possible.

History/previous policy:

- 1982 *National Year of Disabled Persons* (ANA, 1982).
- 1983-1992 as the *Decade of Disabled Persons* (ANA, 1984).
- 1998 *Scope and Standards for the Nurse Who Specializes in Developmental Disabilities and/or Mental Retardation* (ANA, 1998).
- 2004 *Intellectual and Developmental Disabilities Nursing: Scope and Standards of Practice* (ANA, 2004).
- 2013 *Intellectual and Developmental Disabilities Nursing: Scope and Standards of Practice* (ANA, 2013).

Nursing Advocacy and Ethical Challenges in Decision Making

People with IDD experience a myriad of disparities related to health care and access to health care. It is not within the scope of this position to detail each of these. However, nurses must have knowledge and awareness of the potential for inequity in people with **intellectual and developmental disabilities (IDD)**. Although considerable progress has been made in the past fifty years, people with IDD still experience life expectancies approximately twenty years lower than the general population (Lauer & McCallion, 2015). While potentially influenced by factors associated with IDD, this inequity is exacerbated by modifiable determinants such as access to care, poverty, communication deficits, and self-advocacy challenges (Anderson et al., 2013). Emerging research also indicates that adults with IDD from ethnic and racial minorities have poorer health outcomes when compared to White adults with IDD (Mangana et al., 2016). This inequality in morbidity among people with IDD exists even if they are supported by state IDD service systems (Lauer & McCallion, 2015).

In addition to disparities of physical health, people with IDD also experience disparities of mental health. Mental health disorders are more prevalent among adults with IDD but are often undiagnosed or attributed to symptoms of IDD (Son, Debono, Leitner, Lenroot, & Johnson, 2018). This **diagnostic overshadowing** frequently occurs in people with IDD and therefore their mental health disorders are left untreated (Son, Debono, Leitner, Lenroot, & Johnson, 2018; Sutton & Gates, 2018). Access to mental health services for people with IDD is an additional complication due to poor utilization of service availability at both systemic and personal levels (Whittle, Fisher, Reppermund, & Trollor, 2018). It is critical for nurses to establish effective communication, adequate mental health screening, and collaboration with multidisciplinary professionals to identify barriers to person-centered mental health care for people with IDD (Whittle et al., 2018).

Self-Determination

Nurses must recognize that the presence of a disability does not automatically disqualify a person from participating in all decisions related to their care. Nurses need to be aware of the ethical and legal considerations related to self-determination for those with IDD. Balancing protection of at-risk people and respecting individual preferences requires nurses to have an understanding of the legal concepts related to informed consent, competency, capacity, guardianship, and guardianship alternatives. Ethical obligations emphasized in the *Code of Ethics for Nurses with Interpretive Statements* (The Code) include “respect for human dignity requires the recognition of specific patient rights, in particular, the right to self-determination” (ANA, 2015, p. 2). Encouraging self-determination for people with IDD can improve their quality of life, acknowledges their capabilities, and demonstrates professional respect for autonomy (Kerr & Linehan, 2015).

Decision-making capacity “is the ability ‘to understand and appreciate the nature and consequences of health decisions and to formulate and communicate decisions concerning health care’” (Veterans Health Administration, 2002, p. 2). Self-determination for people with IDD includes participation in decision making, unless a determination of incapacity has been made. When a patient lacks the capacity to make a decision about treatment, substitute decision makers are sought to strike a balance between respecting the autonomy of patients and protecting those with cognitive impairments (Appelbaum, 2007). Surrogate decision making is not without challenges, such as reluctance to make critical treatment decisions for others and the possibility that surrogates do not match patient preferences. Notwithstanding these issues, surrogates must impart the purest form of autonomy and respect for a patient’s self-determination. It is important to acknowledge that an assessment of capacity should be done on a frequent basis. Depending on the permanency of the condition, medications, or mental status changes, capacity may wax and wane (Jonsen, 2010).

Having an intellectual or developmental disability does not automatically mean the person lacks capacity or requires guardianship. With proper support, some people with IDD can be active participants in their own health care decisions. For example, supported decision making, unlike guardianship, is a process by which a third party helps a person with IDD make legally enforceable decisions (Kohn & Blumenthal, 2014). Proponents of supported decision making hold that it promotes autonomy, dignity, and self-determination (Kohn & Blumenthal, 2014). Supported decision making is most effective when the support person knows about the person’s disability and condition, is actively involved in the person’s life, and will make a decision in the best interest of the patient (ANA, 2012; “Informed Consent in Adults with IDD”, n.d.). Laws regarding supported decision making as well as various levels of guardianship vary widely among states. Nurses must be aware of and knowledgeable about the relevant laws in their state of practice. A comprehensive list of guardianship and supported decision-making laws by state is available in the reference section below.

It is important for the nurse to be cognizant of an IDD patient’s reproductive rights and access to family planning care. Nursing education regarding sexual behavior, contraception, and pregnancy should be openly discussed with the person with IDD and the family. Considerations for minors and people with IDD under the care of others must be acknowledged in an individualized and developmentally appropriate manner. People with IDD often face barriers to contraception, preconception counseling, and pregnancy due to disapproval of family members or caregivers (Fouquier et al., 2015). A parent or caregiver may object to sex education, rationalizing that the prevention of information may dissuade the person with IDD from sexual activity (Fouquier et al., 2015). Nurses must be vigilant in preserving self-determination and providing factual and developmentally appropriate sex education as an advocate for the respect of patient autonomy (Fouquier et al., 2015).

Caregiver Impact

It is critical that nurses recognize that a diagnosis of IDD impacts not only the person, but also the entire social structure that supports the person. Interpretive Statement 2.3 of The Code states that “Nurses have

the ethical obligation to ensure that all relevant persons, as moral agents, participate in patient care decisions” (ANA, 2015, p. 6). The quality of life for people with IDD can be enhanced by provisions of support within the family and the community (AAIDD, n.d.). In the United States, approximately 72% of people with IDD live in the community with the support of a family caregiver (Braddock et al., 2013).

Intellectual and developmental disabilities are chronic conditions. There is an interdependent relationship between the caregiver and the person with IDD, as well as a correlation between the level of support required and the challenges of caregiving (Lunsky, Tint, Robinson, Gordeyko, & Ouellette-Kuntz, 2014). Individuals who provide care to people with IDD may derive great satisfaction and positive consequences from their work (Martorell, Gutiérrez-Recacha, Irazábal, Marsà, & García, 2011). Caregivers may also experience fatigue associated with caregiving, which may adversely affect the “emotional, social, financial, physical and spiritual functioning” of the caregivers themselves (Mosley, Moodie, & Dissanayaka, 2017, p. 235; Yotani et al., 2014).

Caregiver impact is a “broad, multidimensional construct that reflects the unique experience of caregiving for individuals from different backgrounds, with differing levels of resilience and resources, facing distinctive illness-specific symptoms” (Mosley, et al., 2017, p. 235). We recognize the division of opinion about caregiver impact and want to acknowledge the research associated with caregivers of people with medically complex conditions. Research indicates that caregivers are at an increased risk of exposure to socioeconomic disadvantage, disability-related discrimination and stigma, and inadequate social services (Bhatia, Srivastava, Gautam, Saha, & Kaur, 2015). Although most people with IDD live in the community with the support of a family caregiver, older people with IDD are unlikely to be married and therefore have no spouse or dependents to care for them as they age (Ryan, Taggart, Truesdale-Kennedy, & Slevin, 2013). Therefore, parents continue to provide care, even as they are aging, resulting in mutually dependent relationships (Ryan et al., 2013).

It is important for nurses to not only assess the person with IDD, but also the vitality of their support system in order to maximize opportunities for personal growth. Nursing programs should consider adding coursework and clinical opportunities to promote quality care for the growing population of people with IDD. Nurses should acquire training and clinical exposure to enhance their skills in working with people with IDD. Nurses should be prepared to assist people with IDD with advanced care planning, emergency planning, and financial management, by providing (or referring to) appropriate resources. To that end, nurses must be aware of the community resources available and advocate for access to necessary resources by people with IDD, their caregivers, and those seeking to increase their skills and knowledge in working with this population.

Victimization and Criminalization

The Code states, “Nurses must always stress human rights protection with particular attention to preserving the human rights of vulnerable groups such as the poor, the homeless, the elderly, the mentally ill, prisoners, refugees, women, children, and socially stigmatized groups” (ANA, 2015, p. 33). People with IDD are disproportionately at high risk for violence, criminal acts, abuse, and neglect (Platt et al, 2017; Fogden, Thomas, Daffern, & Ogloff, 2016; Hillbrand, & Sondik, 2012; Petersilia, 2001). According to the US Census Bureau’s American Community Survey and the Department of Justice’s National Crime Victims Survey (NCVS), in 2014, the rate of violent victimization was 2.5 times higher for people with disabilities aged 12 to 65. Rates of victimization were similar for people over the age of 65 regardless of ability (Harell, 2016).

Types of Crimes

People with IDD are at risk for suffering unique forms of violence throughout their lives. A recent US study of 350 people with developmental disabilities found 76.6% reported at least one instance of abuse in their lifetime, such as physical abuse, disability-specific abuse, and sexual abuse (Platt et al., 2017). Disability-related hate crimes, i.e., crimes against a person because of their disability, are also on the rise (Sherry & Neller, 2016). Regrettably, people with IDD believe they are victimized because they have a disability (Harell,

2016), and abuse and exploitation are constant dangers and concerns for people with IDD and their families (Young, Dagnan, & Jahoda, 2016; Petersilia, 2001). Offensive behaviors by people with IDD, i.e., those considered antisocial, socially inappropriate, or defined as illegal, also occur (Nixon, Thomas, Daffern, & Ogloff, 2017; Feckelton, 2016; Fogden et al., 2016). However, it is much more likely that a person with IDD is a victim rather than a perpetrator of criminal acts (Nixon et al., 2017; Platt, et al, 2017; Fogden et al., 2016; Petersilia, 2001; Harell, 2016). People with IDD are most commonly victimized by their caregivers, support staff, or acquaintances (Fogden et al., 2016; Fisher et al., 2016), a fact that also plays a role in the reporting of crimes against people with IDD.

The nurse is expected to identify actual or potential risks to a patient's health and safety (ANA, 2015 Scope & Standards). Therefore, nurses must be knowledgeable about methods to assess and screen for abuse in people with IDD (Koetting et al., 2011). Koetting et al (2011) suggests that nurses should become familiar with the four R's: *routine screening*, realize an increased *risk* of abuse, *recognize* signs of abuse, and *report*, specifically when they are evaluating a person with IDD. Nurses must be trained and empowered to speak up and report their suspicions or evidence of abuse against people with IDD. Nurses must also encourage and support people with IDD in self-advocacy and autonomy to speak up for themselves when possible (Jenkins, 2012).

Nurses must be alert to and must take appropriate action in all instances of illegal or unethical practice or actions that place the rights or best interests of the patient in jeopardy (ANA, 2015). Safeguarding patients when health or wellbeing is endangered is also supported by the International Council of Nurses Code of Ethics (International Council of Nurses, 2012; Jenkins, Davies, & Northway, 2008). In addition to the ethical obligations to protect patients from harm, nurses must be aware of the legal obligations for reporting signs or suspicions of abuse and neglect. A list of mandatory reporting requirements by state can be found in the reference section below.

People with IDD are significantly less likely to have an official record or investigation of victimization and offending, as these crimes too frequently go undetected or are underreported (Fogden et al., 2016; Nixon et al., 2017; Pfeffer, 2016;). With few of these crimes being reported to police and ever fewer prosecutions, officials hesitate to pursue cases that rely on the testimony of a person with IDD, and negative interactions with police have been reported (Rava, Shattuck, Rast, & Roux, 2017).

When people with IDD do break the law, considerations that provide balance between the need to protect the community and effective containment care, e.g., rehabilitation and behavior modification versus imprisonment or execution, are required (Jones, 2007; Feckelton, 2016). In keeping with the profession's commitment to human rights, social justice, and preservation of human dignity, ANA's position statement on *Capital Punishment and Nurses' Participation in Capital Punishment* (2016) explains that the threat of execution is unlikely to deter people with IDD as they may not fully understand the gravity and nature of their alleged crimes. As such, people with IDD should not be subject to the death penalty. Numerous professional organizations have advocated the exempting of people with mental illness from the death penalty, including The American Bar Association Resolution 122A (2006), the American Psychiatric Association (2014), the American Psychological Association (2001), and the National Alliance on Mental Illness (2018). It is imperative that people with IDD be similarly exempted.

End-of-Life Considerations

There has been considerable advancement in delivery of optimal end-of-life care for the general population. People with IDD, however, face unique barriers in accessing palliative and hospice care, including delays in diagnosis of life-limiting conditions, providers' knowledge of this patient group, issues around communication, and ethical dilemmas related to informed consent (Dunkley & Sales, 2014). Although national and international organizations have developed position statements and consensus norms around the end-of-life process (American Association on Intellectual and Developmental Disabilities, 2010;

McCallion et al., 2017; Tuffrey-Wijne et al., 2016), access to and provision of equitable care remain as challenges.

Difficulties with communication and comprehension also affect the assessment and treatment of pain and other symptoms at the end of life in both children and adults. Symptoms may be attributed to the presence of IDD rather than physical ill-health or pain. While nurses are ethically obligated to “relieve pain and the suffering it causes,” they may lack knowledge of best practices. When a patient’s self-report of pain and other symptoms is limited or absent, appropriate validated assessment tools can be utilized (Solodiuk, J., Scott-Sutherland, S, Meyers, S., 2009; Herr, K., Coyne, P., McCaffery, M., Manworren, R., & Merkel, S., 2011).

Transitioning to palliative care/hospice requires education and collaboration among palliative care specialists, family members/trusted caregivers, primary care team members, and intellectual disability professionals (NHPCO, 2009; Tuffrey-Wijne et al., 2016). As team members, nurses are ethically obligated to “actively foster collaborative planning” in order “to provide safe, high-quality, patient-centered care” (ANA, 2015, p.6). Decision making about health care choices at the end of life is a fundamental right for individuals with IDD, including children, and they should be encouraged to express their preferences using appropriate advance care documents (AAIDD, 2010; McKenzie, N., Mirfin-Veitch, B., Conder, J., & Brandford, S., 2017). For those who are unable to convey their intentions, responsible family members and caregivers can be assisted in the process using appropriate supportive strategies (Watson, J., Wilson, E., & Hagiliassis, N., 2017; Georgetown, 2018).

Optimal nursing care at the end of life “enables the patient to live with as much physical, emotional, social, and religious or spiritual well-being as possible” (ANA, 2015, p.2). This care extends to the family and significant others and includes provision of grief and bereavement support. This support is also necessary for people with IDD who have experienced the death of a significant person. Although they may express their grief differently, their response to a loss is similar to that of the general population (Alcedo-Rodriguez, M., Cristobal. F., Gomez-Sanchez, L., Arias-Gonzalez, V., 2018; Young, H., 2017).

Summary

Research suggests that the attitudes of health care professionals are among the biggest barriers to people with IDD receiving equitable access to services (Lewis & Sternfert-Kroese, 2010; Hemm, Dagnan, & Meyer, 2015). The “fundamental principle that underlies all nursing practice is respect for the inherent dignity, worth, unique attributes, and human rights of all individuals” (ANA, 2015, p. 1). This is also supported by Article 25 of the United Nations Convention on the Rights of Persons with Disabilities, which holds that health care professionals are required to provide care of the same quality to people with disabilities as to others (U.N., 2007). It is imperative that nurses know how to provide care and make health care accessible to people with IDD, which by doing so can have a positive impact on service to this population (Hemm et al., 2015). Prior contact with someone with IDD predicts a more positive attitude and can negate misconceptions or stigma (Scior, 2011; Hemm et al., 2015). Improvements in training and curricula for nurses and all health care professionals, in addition to the promulgation of ethical standards for people with IDD, are potential interventions to enhance the quality of life and health experiences of people with IDD (Pelleboer-Gunnink, Van Oorsouw, Van Weeghel, & Embregts, 2017).

Recommendations

ANA recommends implementation of the following activities:

1. Nurses have an ethical responsibility to provide compassionate, knowledgeable, culturally sensitive, and developmentally appropriate care to people with IDD.
2. Nurses should cultivate **disability humility** and commit to competent care for people with IDD.

3. Nurses should advocate for publishers and editors to update language in educational materials to avoid outdated or offensive language.
4. Schools of nursing should incorporate didactic and clinical care of people with IDD to include not only the physical, but the cultural, spiritual, and emotional needs in nursing curriculum across the lifespan and in all practice settings.
5. State and national licensing organizations must increase content regarding the diagnosis, care, treatment, and needs of people with IDD in entry level or renewal examinations.
6. Nurses must advocate for human rights such as access to quality care, respect, dignity, and personhood across the lifespan of people with IDD.
7. Nurses must be critically aware of personal and institutional biases and act as change agents in favor of equitable health care regardless of ability or functional status.
8. Nurses and professional organizations should advocate for resources to support an enhanced quality of life for people with IDD.
9. Nurses must encourage and demonstrate civility and respect for those who care for people with IDD.
10. Nurses should collaborate with interdisciplinary teams and residential caregivers to develop training that bridges lifelong habilitative care practices with palliative, hospice, and end-of-life care that is needed at the end of life.
11. Nurses should advocate for an increase in safe and ethical research opportunities with informed consent for people with IDD.
12. Nurses must advocate for IDD support services and access to funding at the local, state, and national levels.
13. Nurses must be aware of caregiver impact and provide support to family members and caregivers.

Resources

The American Academy of Developmental Medicine and Dentistry (AADMD)

<https://aadmd.org/>

American Association on Intellectual and Developmental Disabilities

<http://aaid.org/>

American Association on Health and Disability

<https://www.aahd.us/>

The Arc of the United States

<http://www.thearc.org/what-we-do/public-policy/policy-issues>

Autism Speaks

<https://www.autismspeaks.org/>

Center for Parent Information & Resources

<http://www.parentcenterhub.org/>

Christopher and Dana Reeve Foundation

<https://www.christopherreeve.org/>

Complex Moral Issues: End of Life Decisions for Adults with Significant Intellectual Disabilities

<https://ucedd.georgetown.edu/complex/>

Cornell University Disability Statistics

<http://www.disabilitystatistics.org/>

Developmental Disabilities Nurses Association

<https://ddna.org/>

Disability Rights Education & Defense Fund

<https://dredf.org/>

Family Voices

<http://www.familyvoices.org/>

Georgetown University Center for Child and Human Development

Complex Moral Issues: End-of-Life Decisions for Adults with Significant Intellectual Disabilities

<https://ucedd.georgetown.edu/complex/>

Golisano Institute for Developmental Disability Nursing

<http://go.sjfc.edu/golisanoinstitute>

Health Care for Adults With Intellectual and Developmental Disabilities: Toolkit for Primary Care Providers

<http://vkc.mc.vanderbilt.edu/etoolkit/general-issues/informed-consent/>

Kennedy Institute of Ethics: Disability

<https://kennedyinstitute.georgetown.edu/cib/our-conversations/2017-disability/>

Lakeshore Foundation

<http://www.lakeshore.org/>

Minnesota Department of Administration: Council on Developmental Disabilities. Parallels in Time: A History of Developmental Disabilities

<http://www.mn.gov/mnddc/parallels/>

National Association of County Behavioral Health & Developmental Disability Directors

<http://www.nacbhd.org/>

National Disability Rights Network

<http://www.ndrn.org>

The National Leadership Consortium on Developmental Disabilities

www.nlcdd.org

National Task Group on Intellectual Disabilities and Dementia Practices

<https://aadmd.org/NTG>

Palliative Care for People With Learning Disabilities

<https://www.pcpld.org/>

Philadelphia Coordinated Health Care

<https://www.pchc.org/>

Robert Wood Johnson Medical School & The Elizabeth M. Boggs Center on Developmental Disabilities
Resources in Developmental Disabilities and Coping With Grief, Death, and Dying
<http://rwjms.rutgers.edu/boggscenter/documents/EndofLifeResources12013.pdf>

Rehabilitation Engineering and Assistive Technology Society of North America
<http://www.resna.org/>

Shaping the Future of Intellectual Disability Nursing in Ireland
<https://healthservice.hse.ie/filelibrary/onmsd/shaping-the-future-of-intellectual-disability-nursing-in-ireland-january-2018.pdf>

Spina Bifida Association
<http://spinabifidaassociation.org/>

Unite 2 Fight Paralysis
<https://www.u2fp.org/>

United Cerebral Palsy
<http://ucp.org/>

United Nations Convention on the Right of Persons With Disabilities
<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

University of New Hampshire Institute on Disability
<http://iod.unh.edu/resources-3>

University of Queensland Intellectual Disability Healthcare
<https://www.edx.org/xseries/intellectual-disability-healthcare>

World Health Organization World Report on Disability
http://www.who.int/disabilities/world_report/2011/report.pdf

Glossary

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| developmental disabilities | a group of conditions that begin during the developmental period or are acquired before age 22 and can affect cognitive ability, physical functioning, or both. While the term “developmental disability” encompasses intellectual disability, it also includes physical disabilities such as cerebral palsy or epilepsy, and some people can have a developmental disability and not have any intellectual functioning challenges. Some other examples of developmental disabilities are blindness, deafness and autism spectrum disorder. https://www.cdc.gov/ncbddd/developmentaldisabilities/facts.html |
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| diagnostic overshadowing | Symptoms of physical ill health are mistakenly attributed to either a mental health/behavioral problem or as being inherent in the person's learning disabilities http://www.intellectualdisability.info/changing-values/diagnostic-overshadowing-see-beyond-the-diagnosis |
| disability humility | learning about experiences, cultures, histories, and politics of disability, recognizing that one's knowledge and understanding of disability will always be partial, and acting and judging in light of that fact. https://journalofethics.ama-assn.org/sites/journalofethics.ama-assn.org/files/2018-11/msoc3-1812_1.pdf |
| intellectual disability | characterized by deficits in intellectual functioning and adaptive behavior, which covers many everyday social and practical skills. Intellectual functioning generally refers to intelligence, reasoning, problem solving, and learning, and one way to measure it is by an IQ test. IQ scores can be < 70 with some reporting up to 75 to characterize intellectual disability. This disability originates before the age of 18. Common syndromes that can be associated with intellectual disability are autism (in about of 1/3 of people diagnosed with ASD), Down syndrome, fragile X syndrome and fetal alcohol spectrum disorder (FASD). https://www.thearc.org/learn-about/intellectual-disability http://aidd.org/intellectual-disability/definition#.WMmod4WcHD4 |

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