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Supporting Autonomy for Patients with Intellectual Disability: Principles for Care Providers

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Abstract

Individuals experiencing intellectual disabilities (ID) often experience restricted autonomy. The prima facie core ethical principle of autonomy provides the fundamental basis for assuring self-determination for all persons, regardless of disability. This is affirmed by article 12 of the United Nations Convention on the Rights of Persons with Disabilities. However, ethical challenges arise from tension between prima facie principles, in this circumstance, between the mandate for autonomy and goal of nonmaleficence. This commentary reviews these concepts and recent research exploring intrinsic and extrinsic factors that enhance autonomy in persons with ID. Practical recommendations are provided to assist care providers in being intentional in anticipating challenges and in guiding their patients with ID and their families toward optimal degrees of autonomy.

Keywords

Intellectual disability, Autonomy, Maleficence, Choice opportunity, Recognition respect

Introduction

At least 13% of the United States population has an intellectual disability (ID) [1]. There are many adverse consequences to having an ID compared to the general population, including lower employment rates and earnings, difficulty developing and maintaining social relationships such as marriage, and overall lower quality of life and life satisfaction [1-4]. Persons with disabilities also experience poorer health outcomes overall including higher rates of tobacco use and obesity [1-4]. Finally, individuals with ID often suffer from restricted autonomy, and existing concepts and systems designed to foster and ensure their autonomy are often not well understood and may be difficult to implement [5,6].

As healthcare providers, we frequently care for people with intellectual disabilities and witness these disparities firsthand. Children with ID experience their own set of challenges that vary widely depending on level of ID, family structure and socio-economic factors, psycho-cultural environment, educational resources, and access to medical and habilitative care [6,7]. Many, but by no means all, such children grow up in a supportive environment, but their disability may lead to a greater degree of reliance on other people and social resources. This may lead to circumstances in which personal autonomy is increasingly at risk of being compromised as one approaches adulthood [8].

Children with intellectual disabilities transitioning from pediatric to adult medical care and adults who support them such as their parents, guardians, teachers, or caretakers find themselves in an ethically complex position. This multifaceted transition faces legal, developmental, social, and emotional challenges [9]. This process affects the patient, their caregivers, and other supportive adults including their health care providers [6-9].

Health care providers and the professional societies that represent them have made concerted efforts to facilitate successful transition from pediatric to adult models of medical care [10,11]. Still, many providers feel uncomfortable when it comes to guiding and supporting their patients with ID and their families in transitioning from adolescence to adulthood, particularly when it comes to fostering and ensuring the

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highest level of autonomy for each person with an ID [6,12,13].

In this article, we review this problem, explore the ethical, philosophical, legal, and practical implications that underlie it and provide guidance for pediatricians, family physicians and other health care providers who seek to foster the autonomy of their patients with ID.

CASE 1: Johanna: Young woman with ID and epilepsy following treatment of childhood ALL

- Cared for by same pediatric neurologist since 8 years of age
- History of intractable epilepsy (partial impaired awareness seizures)
  - Fully controlled on epidiolex and clobazam
- History of encephalopathy followed by mild ID
  - Following treatment of ALL in early childhood
- Mild ID (~ fsIQ 62)
  - Particular problems with language comprehension
- Mild to moderate difficulties with executive function
- Very shy, reserved
  - She seems "gullible" and would be at risk of being "taken advantage of" by others
- No other neurological impairments
- Very supportive, informed and cautious/concerned parents
- Lives in smaller community

Once 18 years of age, parents assume guardianship and power of attorney.

At 24 years of age, Johanna lives with parents, participates in church activities and church-based social groups, enjoys singing but has limited independence, an otherwise limited social life and is not employed. She voices being happy.

CASE 2: Seth: Young adult man with Tuberous Sclerosis Complex*

- Cared for by same pediatric neurologist since infancy
- History of infantile spasms and childhood epilepsy- in remission
  - No longer requiring antiseizure medications
- Mild ID (~fsIQ 65)
- Mild to moderate difficulties with executive function
- Mild to moderate difficulties with social judgment
  - As an adolescent greets his neurologist as: "Hey Buddy, how's it going?" and claps him on the back.
- Very supportive and informed parents (father, mother and step-mother)

Once 18 years of age, parents and Seth come to visit indicating they have talked together about Seth having a vasectomy. They are aware of 50% chance of having a child with TSC. Seth himself tears-up talking about this and expresses his desire to have this procedure.

At age 21, Seth gets married. His wife also has mild ID. They live independently with thoughtful and caring support from immediate family. He works for his father (who owns a construction company). His wife works independently.

Finally, Seth and his wife want to start a family. He returns to his pediatric neurologist on his own and expresses his desire to have his vasectomy reversed.

*Cases are actual patients cared for by the author (FF) with minor details altered to assure confidentiality.

The Four Basic Principles of Medical Ethics

For providers and caretakers to better ensure autonomy for people with ID, it is helpful to review the basic principles of medical ethics, and to understand how other core ("prima facie") principles may potentially inhibit a person's full assumption of autonomy.

The four prima facie principles of medical ethics, their interplay and practical implementation were most lucidly discussed by Gillon [14] (based on the work of Beauchamp and Childress [15]). These are: 1) Respect for autonomy, 2) Beneficence, 3) Nonmaleficence, and 4) Justice. These four principles, with attention to their scope of application, provide a fundamental method for approaching ethical dilemmas in healthcare.

Autonomy refers to the patient's right to control her body. Each person must be allowed to make her own decisions, even if supportive family members, guardians or the care provider may disagree with her choices. A medical professional may advise and educate the patient and family to properly inform them, but persuasion or coercion in any manner violates the autonomy principle. All persons, including those with ID, have the right to independently make decisions based on personal beliefs and values [14,16-18]. Shared decision-making is based on the principle of autonomy [8,16].

Beneficence refers to the obligation of medical professionals to do all possible to benefit the patient [14,19]. All recommended medical decisions intend to do the best for the patient. In the context of this discussion, beneficence encompasses a provider's obligation to understand the principle of autonomy and its legal ramifications.

Nonmaleficence states that medical providers should "do no harm." They must consider the consequences of every individual decision. Even if a choice is beneficial in some ways, potential harm to the patient or others must be weighed against it. Thus, they must provide the best net medical benefit with minimal harm [8,14,19].

The justice principle states that all medical decisions should be fair and decided with impartial judgment. This principle demands equitable allocation of healthcare resources and treatments [14,19]. Challenges arise when considering the care of individuals with ID, as data indicates that such individuals are often marginalized, have fewer resources and experience limited access to optimal care [16-18].

Challenges and ethical dilemmas arise when considering the scope of application for each of the prima facie principles, specifically when cardinal principles conflict with one another. Particularly relevant to the subject of this paper, balancing autonomy with beneficence and nonmaleficence is especially challenging for patients with intellectual disability [8]. For many patients with ID, substantial autonomy may predispose to risks of harm to themselves or others, potentially violating the nonmaleficence principle [6,7,20].

For example, in Case 1 (see textbox), Johanna's family is vigilant in protecting her from harm. Her parents are highly motivated by the principle of nonmaleficence. Given her intellectual disability, her difficulty with language comprehension, her shy and gullible nature, she is no doubt at greater risk of sustaining harm from unscrupulous individuals. Her parents worry that as a young woman she could be "taken advantage of," be sexually assaulted and/or be faced with an unplanned pregnancy. She could easily be exploited financially by dishonest individuals. Hence, her parents are reluctant to have her participate even in "sheltered" work environments or group home settings in which she could have greater autonomy. In her case, the principle of autonomy is potentially compromised by concerns for nonmaleficence.

In Case 2 (see textbox), a supportive and thoughtful family is successful in providing their young adult child with ID with an optimal degree of autonomy following a principle of "supportive decision making" (see below; [20]). He lives independently, is gainfully employed (albeit with his father), makes most of his own financial and social decisions (though supported by his parents) and marries. During follow-up visits he is upbeat and appears fulfilled. It is true that later he regrets a serious decision he made with the support of his parents. However, such changes of heart or unforeseen consequences of well-intentioned decisions affect all persons, regardless of disability.

Established Conventions Sanctioning Respect for Autonomy

In 2006, the United Nations released a formal statement, the Convention on the Rights of Persons with Disabilities [21] (henceforth referred to as "The Convention"). It is the first international human rights treaty that addresses disability rights globally. The Convention lists 50 articles that provide statements and instructions for "States Parties" agreeing to safeguard the rights of persons with disabilities, whether intellectually, physically, mentally, or sensory impaired. These articles affirm that all persons have all categories of rights, can be active members of society, and are capable of making decisions. It also clarifies where adaptations may be needed to assure that persons with disabilities are able to successfully exercise their rights [21].

Article 12 emphasizes the need to "recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life," and should be supported in this right [16,21]. The document continues by stating that persons with disability have a right to "full inclusion and participation in the community." Specifically, State Parties must ensure that persons with disabilities be able to marry and choose where and with whom they live with "on an equal basis with others" [16,21].

This established Convention has many powerful implications [8,16,21,22]. Impaired mental capacity does not justify curtailing legal capacity. Furthermore, The Convention clarifies that specific adaptations should be made to guarantee these rights are respected: Persons with disabilities should have access to the full range of assistive devices and resources as well as the community support services necessary to "prevent isolation or segregation from the community" [21]. In addition, the Convention states

that children with disabilities (Article 7) must also enjoy "all fundamental freedoms on an equal basis with other children." Their views should be given consideration equal to that of all other children commensurate with their age and maturity [21]. It states clearly that the best interests of the child shall always be a primary consideration.

Consequently, existence and acceptance of the Convention confers a high level of responsibility on us as citizens to assure those rights for persons with even the most severe degree of intellectual disability [8,16,22]. As health care providers, we have the opportunity to play a pivotal role in encouraging and guiding our patients, their families and caretakers to adhere to and foster those essential human rights for our patients with intellectual disability [7,8,16,17,20]. We should avail ourselves of our knowledge and positions of respect and authority to better advocate for broader acceptance and implementation of these recommendations in our own communities.

Two Models of Decision Making

Medical providers should support and assist patients with intellectual disability and their families in making decisions surrounding their health care and psychosocial wellbeing. In addition, they can inform families and patients regarding the legal and practical implications of intellectual disability when transitioning to adulthood [6,7,17,19]. At this critical juncture, health care providers can guide families and patients toward approaches that optimize autonomy for individuals with ID.

Two models of decision-making exist: **Substitute** and **supported decision making** [4,13]. The **substitute, or surrogate, decision making** approach was foremost before the UN Convention. In the United States, this approach is implicit in our legal basis for guardianship and power of attorney and hence substitute decision making remains predominant [4,8].

Supported decision making represents an alternative approach to decision making that may foster a greater degree of patient autonomy [4,6,16]. The UN Convention on the Rights of Persons with Disabilities, Article 12 promotes supported decision making to ensure the autonomy of individuals with disabilities. According to this approach, it is the responsibility of the patient's chosen support network to optimize the individual's ability to make autonomous decisions by seeking to understand as best as possible their actual desires, wishes and goals [4-6,16,20]. In addition, the team should strive to facilitate the individual's ability to achieve those goals. If the person's degree of ID is such that they are completely unable to communicate their desires, it remains the group's goal to ensure in as much as possible that the ID individual's inferred wishes, goals, and desires be respected and met [4-6,16,20]. Supportive decision making strives to follow the dictum, stated in the Convention, that "the best interests of the child shall be a primary consideration" [21].

Proactively Fostering Autonomy for Persons with Intellectual Disability: What Data Exists to Guide Practitioners?

How can we as health care providers proactively foster autonomy for our patients with intellectual disabilities? Research devoted to addressing this question offers substantial evidence-based guidance for care teams and practitioners (Table 1) [6,23,24].

Factors/approaches that lead to a greater degree of autonomy or foster self-determination in patients with intellectual disability (Table 1) can be divided into *intrinsic* and *extrinsic* categories. Intrinsic factors (or *nature*) are characteristics of the individual, though these may be modifiable or influenced by environmental factors (*nurture*). Extrinsic factors (*nurture*) consist of environmental/ educational and other outside influences that modify an individual's capacity for self-determination [25].

Table 1: Approaches/factors promoting autonomy.

Approaches (Extrinsic); Factors (Intrinsic)
Extrinsic
Community-based non-congregate environments
Availability (provision) of choice opportunity
Decision-making training
Teaching of self-determination skills
Provision of autonomy support
Implement/practice shared decision making
Involvement in transition planning process
Intrinsic
Higher level of intelligence (higher IQ)
Better developed social abilities/adaptive behavior
Fewer or lack of associated disabilities

The key intrinsic factors influencing autonomy (see Table 1) seem relatively self-evident. The degree of intellectual disability is of course critical [26]. It stands to reason-and is borne out by the data - that lower IQ, particularly functional IQ, is associated with more restricted capacity for self-determination and hence autonomy [6,26].

Regardless, providers can encourage supportive decision making for all patients with ID, no matter the severity. Most individuals with "mild ID" should be able to exercise considerable autonomy and may lead relatively independent lives, particularly if assisted by the "supportive decision-making" model [25]. However, with more severe levels of intellectual disability, greater assistance is needed to ensure against harm, and more creative efforts are required on the part of support individuals to understand or determine the likely wishes of the disabled individual [6,16]. Having multiple people on the support team is ideal to best meet the balance of autonomy and nonmaleficence [20,27]. Both verbal and nonverbal means of communication will prove valuable. Additional creative approaches may be needed, and best judgement should be used to assess the patient's desires and understanding of any conversation or communication. Finally, even greater resourcefulness and commitment are needed for patients with severe intellectual disability [20,27]. Members of the support group will need to use nonverbal communication to best interpret or invoke the wishes of the individual. The person who has lived with the patient the longest is typically most capable of making these judgements. If interpretable communication cannot be attained, the "best interest" principle should be followed [17,18].

As with the level of ID, better developed social abilities and adaptive behavior correlate with greater capacity for self-determination and autonomy [4,6,23]. While some of these attributes are intrinsic personal characteristics (as in autism, for instance), these may be more amenable to environmental influences than is the level of intellectual functioning as such (see below). Hence home, school, and community programs designed to foster social skills, effective communication, problem-solving and so forth may provide great benefit and enhance an individual's capacity for effective self-determination [6,13,23-25,28]. Finally, associated physical, emotional or mental-health challenges (or disabilities) such as autism, cerebral palsy, anarthria/dysarthria, impaired behavioral regulation and limitations in executive function may further interfere with the goal of autonomy [17,18].

Methods or approaches shown to foster autonomy in individuals with ID are also summarized in Table 1. A major objective is to better their self-determination, thereby gaining a greater sense of wellbeing [6]. Studies indicate that youth with higher self-determination at the time of high school graduation experience higher rates of employment, greater independent living, and a higher quality of life [2,6,16]. While it is established that persons with ID have less self-determination than their non-disabled counterparts, persons with intellectual disability may become more self-determined with optimal support and interventions.

Studies indicate that individuals with ID experience far fewer opportunities to make decisions and to practice exercising control in their lives. "Choice opportunity" predicts degree of self-determination better than any other known factor [6,29]. Thus, one of the cardinal extrinsic factors or approaches for optimizing autonomy in individuals with ID is the provision of "choice opportunity" [29]. This involves formal programs that provide individuals with ID with training in decision-making and exercising skills essential for self-determination. These specific programs allow individuals to practice shared decision making, problem-solving, and self-awareness in a safe and supportive environment [6,29]. Medical providers can be instrumental in providing choice opportunity in one particularly important setting, namely the "transition process" of moving from pediatric to adult models of medical care [10,11]. This circumstance provides an ideal opportunity for individuals with ID and their support persons to practice decision-making in a supportive and guided setting.

Other extrinsic factors linked to improved autonomy include characteristics of the living environment. In general, community based, "non-congregate" living settings are more likely to foster autonomy than "congregate" settings [6]. (Congregate refers to organized and regulated group homes, nursing homes, other "institutional" settings and so forth). Congregate settings by their nature tend to be less personalized and more structured and regulated. Staff and support individuals in such congregate settings are more likely to be influenced by specific rules and regulations. They may be more inclined to be motivated by the principle of nonmaleficence, ensuring no harm comes to wards under their care and supervision, than in fostering autonomy [6,10,27].

Proactively Fostering Autonomy for Persons with Intellectual Disability: Roles for Medical Providers?

As suggested above, healthcare providers have a unique opportunity to encourage and foster the autonomy of their patients with ID. Specific steps available to providers are identified in Table 2.

The health care provider may choose to address principles of autonomy as soon as a patient is recognized to have an ID. The goal of fostering autonomy can then become precedent and routine in ensuing conversations. Early exposure of the family to the concept of supportive decision making is important. Healthcare providers may encourage guardians to view the autonomy of their child as equal to other children's. The provider can gently provide information, reflection, and feedback when encountering questions and hesitancy towards fostering the child's independence.

Together with the caretakers and patient, healthcare providers can explore ways in which self-determination may be fostered by optimizing choice opportunity in the home and school environments [29]. Providers may guide families toward programs that enhance social abilities and adaptive behavior, such as school- or center-based social skills training programs [6,13]. Engaging other team members such as

Table 2: Practical steps for health care providers to foster autonomy in patients with ID.

- Begin discussions regarding autonomy at first opportunity
- Engage guardians in discussions regarding autonomy as a fundamental moral principle
- Encourage guardians to:
  - Consider their child with ID as equal to other children with respect to right to self-determination
  - Anticipate future of their child with ID as an adolescent, young adult, etc…
    - Encourage them to envisage and strive for the highest degree of autonomy possible
  - Prepare for a journey that includes learning to interpret their child's volition/wishes/opinions as best as possible
  - Anticipate situations in which there will be tension between drive for autonomy and protection from harm
- Expose caretakers to the concept of "supportive decision making"
- Explore ways of fostering autonomy with caretakers and patients (together if possible)- see Table 1
- Explore parents/caretakers fears about the provision of autonomy
- Discuss autonomy vs. risks of harms (and put in perspective)
- Gently provide reflection/feedback when encountering positive or negative approaches to fostering (or not) a child's autonomy.
- Make families aware of factors that foster autonomy in individuals with ID
  - Formal instruction/interventions to foster self-determination
  - Optimizing the environment
  - Training/supporting those providing support
  - Ongoing provision of "choice opportunity"
  - Involve child with ID in educational and transitional planning and goals.
- Guide families toward resources for "supported decision making"
  - https://www.aclu.org/documents/supported-decision-making-resource-library
- Advocate for such services in your community.

Table 3: Resources for persons with ID and their support persons.

https://www.parentcenterhub.org/intellectual/
https://www.aaidd.org/news-policy/policy/position-statements/autonomy-decision-making-supports-and-guardianship
https://www.aaidd.org/education/video-library (videos on self-determination)
https://www.raisecenter.org/
https://www.pacer.org/transition/learning-center/independent-community-living/self-determination.asp
https://ttac.odu.edu/intellectual-disabilities/self-determination-skills-resources/
https://www.letsgettoworkwi.org/index.php/lgtw-project-resources/self-determination-resource-library/

social workers, psychologists, community health care workers and patient-led support organizations may be particularly valuable in guiding families toward resources that foster self-determination and supported decision making. Examples of such resources are provided in Table 3.

To better prepare individuals for transition to adulthood, caretakers should be encouraged to envision the best future for their child, and to do so through ongoing communication. When they anticipate the child as an adolescent, young adult, and beyond, they should strive to see her achieving the highest degree of autonomy possible. This vision should consider the patient's own opinions and wishes as best as possible. In fact, the philosopher Matthew Burch [8] argues that failure to provide a person with ID such "recognition respect" may in-itself result in maleficence. Consistent ignoring of or discounting an individual's wishes and repeatedly disrespecting their choices results in the "denial of their legal capacity" [8]. This demonstrates a lack of respect for the person's autonomy, and hence of her value as an autonomous human being. Burch argues that this "denial of recognition respect" in effect constitutes or conveys a denial of the "moral worth" of the individual and of her "dignity as a person" [8]. He astutely points out that repeated experiences of this sort may lead to a "destruction of a person's sense of self-worth" [8] which in itself constitutes a serious harm (maleficence) equal to or potentially more serious than the feared harms that overprotection seeks to mitigate.

The transition from adolescence to early adulthood

offers the support team, healthcare providers and patient the opportunity to openly and honestly consider the future [10,11,13,24]. The individual should be supported in setting educational and translational goals, developing specific plans to achieve them, and actively working towards attaining them. This process basically involves practicing "choice opportunity" [29]. During these planning interventions, it is important for all team members to listen to the individual's thoughts with neutrality, irrespective of their degree of agreement. The team should seek to respect the person's vision while helping to ensure safe and realistic expectations including gaining insight into the potential consequences of her choices and adjusting plans to a sensible time frame [20].

In such interactions, the healthcare provider is in a privileged position to provide ideas and information considering the patient's wishes. An ideal provider will avoid being overly paternalistic or detached, and will strive to be exploratory and dynamic, setting an example to everyone on the team. Empowering the patient to be in control of their life and healthcare as much as is realistically possible strongly upholds the prima facie principles of autonomy and beneficence [14].

Returning to cases 1 and 2, based on considerations discussed above, it is possible that in Johanna's case, the young woman in Case 1, earlier efforts to engage parents in considering the value of autonomy relative to nonmaleficence could have been helpful. In the setting of her healthcare visits during adolescence, her provider could have more openly explored her parents' and the patient's ideas, hopes and fears regarding these principles. The provider could have modeled efforts to provide Johanna with "choice opportunity" regarding her healthcare as such, and to explore her vision of her future as an autonomous adult. This could have provided opportunities for her and her parents to consider these wishes and goals together and to select options in accordance with her wishes tempered by realistic expectations and considerations for her safety. In case 2, such an approach was fostered by Seth's parents' forward thinking and implicit desire to respect their son's autonomy. This resulted in a remarkably fulfilling early adult life for their son with mild ID, one in which one could argue the challenges he and his family encountered were no different than those of any family.

Conclusion

Autonomy and self-determination remain inviolate human rights for all persons, regardless of their physical or intellectual capacities. However, in daily life the prima facie principle of autonomy may often be compromised by overly zealous adherence to another prima facie moral principle, namely that of nonmaleficence. Supportive family members, guardians, healthcare providers, teachers and other engaged community members understandably wish to protect persons with ID from harm to which they may be at greater risk given associated challenges in comprehension, communication, and judgement. However, fundamental moral principles affirmed by the UN Convention on the Rights of Persons with Disabilities insist that persons with ID should enjoy full autonomy equal to all other persons.

Practically, healthcare providers can play a critical role in ensuring that patients with ID for whom they care achieve the optimal degree of autonomy of which they are capable. Healthcare providers may foster such self-determination by educating patients and families regarding these principles early in their therapeutic relationship. They can consistently engage patients in "choice opportunity" throughout their provision of care, particularly during the process of transition to adult healthcare. They should strive to ensure that their patients with ID receive needed "recognition respect" and that in turn caretakers are aware of the often-unrecognized harm that can result from denial of such "recognition respect" and the resulting loss of a person's sense of self-worth. Finally, providers can put families and patients in touch with valuable educational and community resources and can advocate for individuals with disabilities within their community. Thus, the healthcare provider has a unique opportunity to serve a valuable role when it comes to fostering the autonomy of individuals with ID. We hope this document may serve as a guide for healthcare professionals to allow them to optimally meet this important opportunity.

References

1. Erickson W, Lee C, von Schrader S (2017) Disability Statistics Report.
2. Alonso-Sardón M, Iglesias-De-Sena H, Fernández-Martín LC, et al. (2019) Do health and social support and personal autonomy have an influence on the health-related quality of life of individuals with intellectual disability? BMC Health Serv Res 19: 1-10.
3. Guralnick MJ (2017) Early intervention for children with intellectual disabilities: An update. Journal of Applied Research in Intellectual Disabilities 30: 211-229.
4. Sullivan William F, Heng J (2018) Supporting adults with intellectual disabilities to participate in health care decision making. Canadian Family Physician 64: 32-36.
5. National Council on Disability (2019) Turning rights into reality: How guardianship and alternatives impact the autonomy of people with intellectual and developmental disabilities.
6. Wehmeyer ML, Abery BH. (2013) Self-determination and choice. Intellect Dev Disabil 51: 399-411.
7. Bogossian A, Majnemer A, Racine E (2020) Contextualized autonomy in transitional care for youth with neurologic conditions: The role of the pediatric neurologist. J Child Neurol 35: 536-542.
8. Burch M (2017) Autonomy, respect, and the rights of persons with disabilities in crisis. J Appl Philos 34: 389-402.
9. Verhoof E, Maurice-Stam H, Heymans H, et al. (2012) Growing into disability benefits? Psychosocial course of life of young adults with a chronic somatic disease or disability. Acta Paediatr 101: e19-e26.
10. Camfield P, Camfield C, Pohlmann-Eden B (2012) Transition from pediatric to adult epilepsy care: A difficult process marked by medical and social crisis: transition from pediatric to adult epilepsy care. Epilepsy Curr 12: 13-21.
11. Iyer A, Rajendran S (2016) Epilepsy: Addressing the transition from pediatric to adult care. Adolesc Health Med Ther 7: 77-87.

12. Disability Rights Pennsylvania. Chapter 1 : Decision-Making By People With Intellectual Disabilities : The Importance of Self-Determination N.D, 7443: 1-6.

13. Vatland C, Strickland-Cohen K, Loman S, et al. (2011) Promoting self-determination for adults: A practice guide. A National Gateway to Self-Determination.

14. Gillon R (1994) Medical ethics: Four principles plus attention to scope. BMJ 309: 184.

15. Beauchamp TL, Childress JF (2001) Principles of biomedical ethics. (5th edn), Oxford: Oxford University Press; 2001.

16. Devi N (2013) Supported decision-making and personal autonomy for persons with intellectual disabilities: Article 12 of the UN convention on the rights of persons with disabilities. J Law Med Ethics 41: 792-806.

17. Racine E, Larivière-Bastien D, Bell E, et al. (2013) Respect for autonomy in the healthcare context: Observations from a qualitative study of young adults with cerebral palsy. Child Care Health Dev 39: 873-879.

18. Shevell MI (1998) Clinical ethics and developmental delay. Semin Pediatr Neurol 5: 70-75.

19. Ronen GM, Rosenbaum PL (2017) Reflections on ethics and humanity in pediatric neurology: The value of recognizing ethical issues in common clinical practice. Curr Neurol Neurosci Rep 17: 39.

20. Bigby C, Whiteside M, Douglas J (2019) Providing support for decision making to adults with intellectual disability: Perspectives of family members and workers in disability support services. J Intellect Dev Disabil 44: 396-409.

21. United Nations (2006) Convention on the rights of persons with disabilities and optional protocol. Treaty Series 2006: 37.

22. Megret F (2008) The disabilities convention: Human rights of persons with disabilities or disability rights? Hum Rights Q 30: 494-516.

23. Hilberink SR, van Ool M, van der Stege HA, et al. (2018) Skills for growing up-epilepsy: An exploratory mixed methods study into a communication tool to promote autonomy and empowerment of youth with epilepsy. Epilepsy Behav 86: 116-123.

24. McPherson L, Ware RS, Carrington S, et al. (2017) Enhancing self-determination in health: Results of an RCT of the ask project, a school-based intervention for adolescents with intellectual disability. J Appl Res Intellect Disabil 30: 360-370.

25. Emond Pelletier J, Joussemet M (2017) The benefits of supporting the autonomy of individuals with mild intellectual disabilities: An experimental study. J Appl Res Intellect Dis 30: 830-846.

26. Gaumer Erickson AS, Noonan PM, Zheng C, et al. (2015) The relationship between self-determination and academic achievement for adolescents with intellectual disabilities. Res Dev Disabil 36: 45-54.

27. Modula MJ (2022) The support needs of families raising children with intellectual disability. Afr J Disabil 11: 1-9.

28. Frielink N, Schuengel C, Embregts PJCM (2018) Autonomy support in people with mild-to-borderline intellectual disability: Testing the Health Care Climate Questionnaire-Intellectual Disability. J Appl Res Intellect Dis 31: 159-163.

29. Vicente E, Mumbardó-Adam C, Guillén VM, et al. (2020) Self-determination in people with intellectual disability: The mediating role of opportunities. Int J Environ Res Public Health 17: 1-15.

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