National Goals on Health Equality

Issue Brief

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Consent and Decision-Making

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Introduction

Communities are becoming more **inclusive**. The way people with intellectual and developmental disabilities (IDD) are viewed as decision-makers has changed over time. People used to think people with IDD needed to be protected and have decisions made for them by family members or professionals. Many people now believe that people with IDD have the **human and civil rights** to make decisions for themselves. Research, policy, practice, and advocacy efforts can help people with IDD make their own decisions with the supports they need. People with IDD can and should be supported to take risks, learn from their mistakes, believe in themselves, and develop their own decision-making skills. These goals described here can help self-advocates, advocates, leaders, researchers, government agencies, policymakers, and professionals support people with IDD to be **self-determined** and live the lives they choose.

Inclusive Research, Policy, Practice, and Advocacy Goals

Researchers should work with people with IDD on their projects and support them to lead research. Researchers must find the best ways to check whether someone is ready to decide to participate in research and how they want to lead. Research teams must challenge systems, like university policies about who can lead research, to support and recognize people's abilities and to build ethical and evidence-based practices.

Professionals should work with people with IDD on issues that affect them and support them in taking leadership roles in advocating for changes in policies and practices to give them the chance to make decisions about their own lives.

Plain Language Summary

People with intellectual and developmental disabilities (IDD) should be able to make their own choices about their lives. In the past, other people would make all the decisions for them, but this has changed.

Now we know that people with IDD have the right to decide things for themselves, just like everyone else. They might need some help making choices, but that's okay. People with IDD should be able to try new things, make their own decisions, learn from their mistakes, and believe in what they can do.

There's a helpful way to support people with IDD called "Supported decision-making" (SDM). Instead of having someone else make choices for them, SDM lets people with IDD make their own decisions while getting help when they need it. SDM is different from guardianship, which is where someone else makes all their decisions.

To make society work better:

- People with IDD should start practicing making choices when they're young.
- Researchers should work together with people with IDD.
- Communities should include everyone.
- Laws should protect the rights of people with IDD to make their own choices.

Everyone needs practice to learn to make decisions. Sometimes people need help to make decisions. People with IDD may need help from others with decisions, but they can make choices about their own lives.

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Decision-making takes practice. From an early age, people with IDD should have the chance to make decisions. They should have support to make those decisions when needed. They should have the chance to learn from their good and bad choices, just like everyone else.

Supported Decision-Making Goals

Supported decision-making (SDM) is an alternative to guardianship for people with IDD. Instead of someone else making decisions for the person with IDD, SDM allows the person with IDD to make their own decisions. We don't know how many people with IDD are under guardianship because states collect data differently. Research shows that people who are under guardianship have fewer social relationships and are less likely to have jobs (Bradley et al., 2019). More research must be done so that everyone can agree on what SDM is and how it can be used. The support people need to make decisions may change as they practice and learn from their mistakes. The amount of support they need may also depend on how important a decision is (*see the stories about John thinking about donating a kidney and thinking about hand surgery*). Laws and regulations can help better define and support the use of SDM.

Conclusion

Research, practice, and policy must reflect the human and civil rights of people with IDD. Families and professionals should be educated about **consent** and decision-making in a way that highlights the views and experiences of people with IDD. The principles of SDM must be reflected in policies, practices, trainings, and supports to build a culture in which people with IDD grow their abilities to make decisions throughout their lives.

Two Stories About John

John is a young man with intellectual disability.

Major Surgery to Donate a Kidney

John's father is his legal guardian and asks the court to allow John to donate a kidney to John's brother, who needs a transplant to survive. The court appoints a lawyer, Ms. Jamison, to make sure that John understands what it would really mean to donate his kidney. Ms. Jamison asks John detailed questions about the surgery and its risks. She decides that John doesn't fully understand all the details and consequences, and she concludes John can't make this decision. Even though John knows he wants to help his brother and understands that it would involve an operation and a stay in the hospital to get better, he doesn't understand what donating a kidney would mean for his own well-being.

Minor Hand Surgery

John visits his doctor because his hand hurts. The doctor suggests a minor surgery. The doctor explains the operation in simple words and uses pictures to help John understand. John's father helps him think about how the surgery could help his hand feel better. John's father also helps him think about the things that could go wrong. John confidently tells his father and doctor that he wants to have the surgery.

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Reference

Bradley, V., Hiersteiner, D., St. John, J., & Bourne, M. L. (2019, April). *What do NCI data reveal about the guardianship status of people with IDD?* [National Core Indicators data brief]. National Association of State Directors of Developmental Disabilities Services & Human Research Services Institute. https://legacy.nationalcoreindicators.org/upload/core-indicators/NCI_GuardianshipBrief_April2019_Final.pdf

Definitions of Words Used in This Document

Consent: *Agreeing to* and refusing treatment are both part of a patient's rights. Patients have a right to make *informed*, voluntary decisions about their care. *That means they need to know the nature, risks, and benefits of their options.*

- Weiner, S. (2019, January 24). What "informed consent" really means. *AAMCNews*. https://www.aamc.org/news/what-informed-consent-really-means

Human and Civil Rights:
Human rights are rights we all have because we are human, and
Civil rights are rights we have in the United States of America.

- American Association on Intellectual and Developmental Disabilities. (2022). *Plain language summary of the 2022 joint position statement of AAIDD and The Arc on human and civil rights*. https://www.aaidd.org/docs/default-source/policy/pl-human-and-civil-rights.pdf

Inclusion means that all people—regardless of their abilities, disabilities, or health care needs—have the right to:

- Be respected and appreciated as valuable members of their communities.
- Participate in recreational activities in neighborhood settings.
- Work at jobs in the community that pay a competitive wage and to have careers that use their capacities to the fullest.
- Attend general education classes with peers from preschool through college and continuing education.

- Institute for Community Inclusion. (n.d.). *What we mean when we talk about inclusion*. https://www.communityinclusion.org/about/what-we-mean-when-we-talk-about-inclusion/

Self-determination is speaking up for our rights and responsibilities and empowering ourselves to stand up for what we believe in. This means being able to choose where we work and live and who our friends are; to educate ourselves and others and to work in teams to obtain common goals; and to develop skills that enable us to fight for our beliefs, advocate for our needs, and obtain the level of independence that we desire.

- Self-Advocates Becoming Empowered. (1997, November 1). *SABE definition of self-determination*. https://www.sabeusa.org/meet-sabe/policy-statements/self-determination

Supported decision-making (SDM) allows individuals with disabilities to make choices about their own lives with support from a team of people they choose. Individuals with disabilities choose people they know and trust to be part of a support network to help them with decision-making.

- Center for Public Representation. (n.d.). *About supported decision-making*. https://supporteddecisions.org/about-supported-decision-making/

The views and opinions expressed in this document were generated by independent teams at the National Goals Conference on Health Equity held June 8-9, 2024 in Louisville, KY, and do not necessarily reflect the official policy or position of any of the planning partners.