# Recommendations of the Consent and Decision-Making Strand from the National Goals 2024 Conference

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**Note**

In this journal article, we use a mixture of terminology when referring to intellectual and developmental disabilities. A common form of description has been called “person-first.” This is when the person (e.g., adult) appears before the condition (e.g., intellectual and developmental disabilities). At the time of this writing, terminological issues have not been settled. To honor the advocates and professionals in the field, we use person-first terminology with the primary descriptor being intellectual and/or developmental disabilities.

## Abstract

This article presents the recommendations developed by the Consent and Decision-Making Strand at the National Goals conference, a platform for leaders in the intellectual and developmental disabilities (IDD) field to advance research, advocacy, policy, and practice. Over the past decade, self-advocacy efforts, strengths-based approaches, and evolving societal perspectives have contributed to some progress in autonomy and decision-making rights for people with IDD. However, persistent ableist norms coupled with oppressive and systemic barriers continue to limit the human and civil rights to consent and decision-making for people with IDD. Recommendations to advance change include: (1) building a culture of consent, (2) creating clear policies for Supported Decision-Making (SDM), (3) advancing inclusive research practices that empower people with IDD to participate and lead in all aspects of research they choose, (4) innovating with technology to enhance autonomy while ensuring privacy and security, and (5) leveraging data to change education, training, and systems. These recommendations provide a framework for transformative change needed to ensure equitable, inclusive, and accessible consent and decision-making opportunities for people with IDD.

*Keywords:* consent, decision-making, intellectual and/or developmental disabilities, Supported Decision-Making, self-determination

# Recommendations of the Consent and Decision-Making Strand from the National Goals 2024 Conference

In 2015, leaders in the intellectual and developmental disabilities (IDD) field identified recommendations to advance research, policy, and practice related to self-advocacy and self-determination over the next 10 years (Shogren et al., 2015). Since this platform of national goals was established, significant advances have been made in self-advocacy and self-determination research, policy, and practice. This work has been driven by (a) change initiated and sustained by the self-advocacy movement, (b) growing recognition of the importance of strengths-based approaches to supporting people with IDD (e.g., Burke et al., 2020; Shogren et al., 2025; Wehmeyer, 2025), and (c) the emerging shared citizenship paradigm in the IDD field (Schalock et al., 2022). However, despite progress over the past decade and sustained efforts by self-advocates as well as statutory and constitutional proclamations, ableist norms persist and people with IDD continue to experience unnecessary limitations to their self-determination, inclusive of their civil and human rights to provide consent and make decisions (e.g., Hatch et al., 2015; King, 2023).

Barriers to the transformative change needed to shift away from ableist norms currently associated with consent and decision-making are fundamentally tied to how these rights are often viewed in society. In particular, consent is often considered from a procedural lens (e.g., answering a set of questions to earn the right to consent) for a specific person rather than based on the broader cultural value placed on the right for *all* people in a society to provide consent and make decisions. People with IDD, in particular, are often held to higher expectations for demonstrating their capacity, rather than systems being held accountable to accommodate diverse support needs (e.g., cognitive and communication support needs; Peterson et al., 2020;

Peterson et al., 2021). This inequitable situation in which people with IDD are held to a higher standard than the people or systems that impose the standard is often known as the Disability Double Standard (Snow, 2016). For example, only members of the IDD community are tested on their understanding of participant consent forms to demonstrate their capacity to decide whether to participate in research. While there is growing research and advocacy for policies and practices that support a shift away from a procedural perspective of consent and decision-making (e.g., Supported Decision-Making [SDM]; Shogren et al., 2019), cultural and societal change in how consent and decision-making are viewed is necessary for sustainable systems change.

Another barrier to transformative change related to consent and decision-making across research, policy, and practice centers around guardianship and its prevalence within the IDD community (Jameson et al., 2015; Kanter, 2015; National Council on Disability, 2019). Research on the impact and outcomes of guardianship and its alternatives (e.g., SDM) is limited by a lack of consistent and longitudinal data. Relatedly, the lack of clear definitions and consistent approaches to SDM creates major barriers, which are compounded by state-level variation in laws and policies. Additionally, with regard to consent and decision-making in practice, efforts to build decision-making skills are often focused during the time a person reaches the age of majority (18 years in 47 U.S. states) rather than being integrated across the life course. Given the need for transformative change, in this article, the co-authors detail a process for creating recommendations for the next 10 years of research, policy, and practice for consent and decision-making within the IDD community and then describe those recommendations to guide leaders in the IDD field in promoting a culture of equitable, inclusive, and accessible consent and decision-making.

## Methodology

## Process

In June 2024, the American Association on Intellectual and Developmental Disabilities (AAIDD) convened the National Goals conference to provide an opportunity for leaders in the IDD field to evaluate the current state of knowledge and identify recommendations for research, practice, and policy across nine topic strands, including consent and decision-making. Members of each topic strand were tasked with developing recommendations for the next 10 years that would make the most significant impact on research, policy, and practice. To achieve this goal, members assigned to each topic strand, including the Consent and Decision-Making strand which is the focus of this article, convened in-person over two days. The co-authors of this article were members of the Consent and Decision-Making strand and were identified by AAIDD as leaders in research, advocacy, policy, and practice. Prior to the conference, Consent and Decision-Making strand members were encouraged to critically consider discussion questions and come prepared to discuss them at the in-person convening, including:

1. What are the big debates (What do we disagree on?)
2. What are the big unanswered questions (What we do not know that we need to know?)
3. What are the big challenges in definitions, methods, measurement, and evidence (What kinds of things do we need to agree on to be able to move forward?)
4. What are the next (most important) research questions that need to be answered?
5. What are the critical policy and practice issues that need to be addressed?

## Values

At the start of discussions at the conference, Consent and Decision-Making strand members collectively identified the need to establish agreed upon values that would be the foundation for further discussions and associated recommendations. Ethical conversations in the

IDD field about consent and decision-making are often based on normative judgments. Thus, strand members felt it was critical to establish shared values that centered on disability empowerment to guide discussions and the development of products from the conference, including this journal article. These values are particularly important as the historical and continuing dialogue concerning consent and decision-making for people with IDD has been dominated by deficit-based models and shaped policies, services, and supports and often not included the voices of those most impacted (Shogren et al., 2024). Members of the strand identified a shared commitment to applying a social-ecological approach that fundamentally aligns with the principles of diversity, equity, inclusion, and social justice for *all* people, including people with IDD. As such, the five values that guided the development of the recommendations for research, practice, and policy from the Consent and Decision-Making strand are described below.

The first value emphasizes that all people, inclusive of people with IDD, have a human and civil right to autonomy and self-determination. Advocacy led by people with disabilities and their supporters has led to growing federal and international recognition (e.g., Americans with Disabilities Act of 1990, United Nations Convention on the Rights of Persons with Disabilities) of the rights of people with disabilities, including people with IDD, to autonomy and self-determination in society. This value aligns with how the co-authors collectively agree that disability is a valued part of the diversity of human experience. The second value underscores that people with IDD can also be professionals who should be driving systems that impact research, policy, and practice now and in the future. Self-advocates and people with lived experience have the expertise, skills, knowledge, and experience to lead within all systems. For example, it is imperative to challenge the ethicality of IDD research that does not incorporate lived expertise of researchers with IDD. The third value advocates for the presumption of agency in decision-making to promote high expectations and dignity found in "experiencing risk-taking of ordinary life" (Perske, 1972, p. 195). Current practices in the IDD field often emphasize a problematic dichotomy of competency, where someone has full or no agency. This ignores the nuance of inclusive and interdependent decision-making practices and the ways that *all* members of society rely on some decision-making support. As such, this value highlights how the Consent and Decision-Making strand members believe that the burden of proof must be shifted away from the person with IDD proving their decision-making capacity, toward systems that acknowledge and provide the supports people use to make decisions and communicate their inherent agency over their lives.

The fourth value stresses the importance of plain language for all. Plain language is a tool for inclusion that can be useful for everyone regardless of reading level, disability status, or language proficiency. Particularly within the IDD community, plain language ensures full inclusion of people with IDD within both the process and outcomes of communicating research, policy, advocacy, and practice. For example, one of the products from the Consent and Decision-Making strand includes an Issue Brief in plain language (Strickler et al., in press). It is critical for researchers, policymakers, and practitioners within the IDD field to facilitate plain language in all shared materials so information is accessible to all professionals and community members engaged in research, policy, and practice. Finally, the fifth value emphasizes that Supported Decision-Making (SDM) is for all. Everyone uses SDM, and as a person's support needs change over the life course (e.g., transition from high school to college/university, retirement, aging related support needs), the types of supports needed will also change. Although supports for decision-making may, in some circumstances, look different for the IDD community, people with IDD should have the same rights to SDM. It is vital that when considering the ways SDM is supported, those with power and privilege are held accountable to creating the diverse supports needed by different community members, inclusive of people with IDD.

## Positionality

As advocates, educators, professionals, and researchers with decades of experience in the IDD field, we recognize that our perspectives on consent and decision-making are shaped by our individual and shared positionalities. Our strand team, primarily women who work in university settings, includes attorneys, self-advocates, teacher educators, and other professionals engaged in disability-related research, advocacy, and community engagement. We bring diverse lived experiences, including neurodivergence, parenting children with support needs, and navigating complex health needs. We acknowledge that our group is predominantly white, with some representation from the African-American, Iranian, and Jewish communities, and that we lack sufficient representation of the broad perspectives of the IDD community. While we are committed to Disability Justice, we recognize the limitations of our perspectives and the need for ongoing reflection, accountability, and advocacy for greater representation as these recommendations are implemented and reconsidered in the future.

Guided by these values, and using the discussion questions listed above, Consent and Decision-Making strand members reflected, discussed, and identified five recommended directions for future research, advocacy, policy, and practice. The recommendations were those the strand members concluded could have the maximum impact on policy and practice to address the major challenges in the IDD field related to consent and decision-making. The recommendations of strand members are summarized and elaborated on by co-authors of this article who were all strand members in the section that follows.

# Recommendations

## Recommendation 1: Build a Culture of Consent

Consent is often considered through a procedural perspective (e.g., a form that documents whether a person consents). To promote autonomy for people with IDD as it relates to consent and decision-making, p**rioritizing the supports needed by the IDD community to build decision-making capacity, creating a culture of consent** is imperative**.** In this first recommendation, Consent and Decision-Making strand members identified broad societal perspectives that must shift to promote transformative change for people with IDD regarding consent and decision-making. First, social perspectives must change, in ways aligned with the shared citizenship paradigm (Schalock et al., 2022), so the assumption is that people with IDD have the capacity to consent in medical, legal, relational, and all other decisions about their lives, as opposed to assuming they cannot take on these roles. This could lead to transformative change in how the consent process is conceptualized and open possibilities for increased accessibility and alignment with individual support needs in specific situations. It can also open up possibilities for the preferences of people with IDD to be centered, building decision-making capacity and participation, even in situations when the person does not currently have legal capacity to consent (McDonald et al., 2024; Strickler & Havercamp, 2023).

Second, procedures to assess a person's capacity to consent, and need for substituted decision-making, are often binary examinations that occur at a single point in time, leading to legal guardrails on who will be the final decision-maker across situations and time. These binary disregards the contextual elements of capacity and the fluidity of decisions (Khemka & Hickson, 2021). While someone might not be considered to have capacity based on specific assessments, their lived experience still gives them expertise that a legal guardian or power of attorney does not have. Capacity should always be presumed, and because someone cannot consent within a specific situation does not mean they do not have capacity to be involved in the consent process. In building a culture of consent, the burden of establishing capacity for consent and decision-making needs to be shifted away from the individual and towards systems to ensure that individuals are given ample opportunity through education, supports, and accommodations including adapting typical protocols for consent, creating plain language explanations, and expanding opportunities to be involved in the consent and decision-making process (Horner-Johnson & Bailey, 2013; Strickler & Havercamp, 2023). Additionally, questions related to capacity are often focused on the capabilities of the individual and not on the skills of those assessing or seeking to obtain consent (Dunn et al., 2024). Part of this shift necessitates greater training and skill building for professionals on how to create accessible consent and decision-making procedures.

Third, proving the capacity to consent is often a burden put onto the IDD community inequitably. When non-disabled people need to have medical decisions explained to them, choose to engage in “risky” behaviors despite health consequences, or fail to comprehend the documents they sign, the decision-making capacity and autonomy is not questioned as it is for the IDD community. The removal of the right to consent through plenary guardianship or other arrangements, often leads to removing the focus on a strengths-based approach. Thus, broader societal change in how legal agency is understood and viewed as an inherent right to be supported within the IDD field is needed.

Finally, over the lifecourse, support networks (e.g., families, educators, medical professionals) can support the development of decision-making capacity (Khemka & Hickson, 2021), balancing risk while creating opportunities for learning and growth. This lifetime of practice and skill-building supports a culture of consent, a perspective self-advocates have advocated for, which is the recognition that with opportunities, high expectations, and supports, people with IDD are equally as capable as any other member of society to be involved in making decisions about their lives (e.g., Charlton, 2000; Weintraub, 2025). To build a culture of consent for *all*, it is critical to expand the process of building decision-making capacity to be more inclusive across the lifecourse.

## Recommendation 2: Identify Universal Definition and Policies for Supported Decision-Making

Current reforms advancing the recognition of legal capacity of adults with IDD are closely tied to SDM (Glen, 2023; Parker, 2016). For example, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is universally recognized as the landmark document promoting and protecting the human rights of people with IDD, including their right to "the support they may require in exercising their legal capacity" as stated in Article 12. However, the CRPD does not explicitly define supports for legal capacity or SDM (United Nations, 2006). This has created a void filled by varied interpretations and implementation approaches (Then et al., 2018). For instance, some definitions highlight support for autonomy as a contrast to substitute decision-making (Devi, 2013), while others focus on the process by which support is provided (Dinerstein, 2012). This has led to SDM being understood and applied in various ways in practice, ranging from informal support from friends and family to formal agreements (Blanck & Martinis, 2015; Parker, 2016; Then et al., 2018). Different approaches to SDM are often built around distinct concepts. For example, sometimes the focus is on legal capacity or the right to be recognized and make legally binding decisions. Other times, the focus is on decision-making capacity or the steps that go into decision-making across contexts with a greater focus on assessing support needs for different decisions over time (Parker, 2016).

Within the United States, these diverse interpretations and implementation approaches to SDM, lacking a single, clear definition have led to distinctly different approaches regarding SDM legislation. Some states, for example, recognize SDM as a legitimate and valuable practice without establishing specific associated legal mechanisms or protections. This approach aims to encourage the use of SDM and increase awareness of its potential benefits for people with IDD as an alternative to guardianship without legal mechanisms (Glen, 2023). Other states have focused on Supported Decision-Making Agreements (SDMAs) and legislation that grants legal recognition and enforceability to SDM. Such formal agreements are between a person with IDD and their chosen supporters specifying how the supporters will assist in decision-making. Several states have adopted this approach, passing laws that recognize SDMAs (National Resource Center for Supported Decision-Making, 2025). While this approach creates a more concrete legal framework for SDM, it also introduces new complexities, such as defining the capacity to enter into an agreement, the scope of supporter authority, and potential conflicts of interest or exploitation (Glen, 2023). The lack of clear philosophical and legal frameworks and supporting structures results in inconsistent service provision and, in the worst case, could lead to more guardianship appointments if there are not adequate supports for implementing SDM, undermining its core principles (Bigby et al., 2022; Glen, 2023).

Given these issues, there is ongoing debate about the role of SDM as an alternative to guardianship and whether the two concepts can coexist or complement one another. This debate is rooted in the tension of balancing protection and autonomy. The crux of the argument against guardianship derives from the CRPD and the idea that any form of guardianship is inconsistent with Article 12 and the spirit of SDM, as it undermines the right to choice by transferring decision-making authority to a third party instead of planning for needed supports for legal agency (Devi, 201; Glen, 2023; United Nations, 2006). From this perspective, SDM and guardianship represent fundamentally different and conflicting paradigms. Guardianship, particularly plenary guardianship is rooted in a paternalistic approach, prioritizing protection and risk aversion, often limiting individual choices (Parker, 2016). In contrast, SDM focuses on empowerment, recognizing individual agency and supporting people in making their own decisions, even if those decisions involve risk (Glen, 2015). Combining these approaches may dilute SDM's essence and perpetuate the power imbalance inherent in guardianship (American Association on Intellectual and Developmental Disabilities & The Arc, 2016; Glen, 2023).

Others acknowledge the potential benefits of SDM while maintaining that guardianship remains necessary in certain situations, and that despite its flaws and the emergence of alternatives like SDM, guardianship is likely to remain a part of the legal landscape (National Council on Disability, 2018). Guardianship is perceived as providing essential protection for people who may lack the capacity to make certain decisions or are highly vulnerable to exploitation (National Guardianship Association, 2017). The case is also made that SDM principles can be incorporated into guardianship practice, encouraging guardians to involve people in decision-making whenever possible and respecting their preferences within the guardianship framework (National Council on Disability, 2018; National Guardianship Association, 2017).

The ongoing reforms and debates around Supported Decision-Making (SDM) and guardianship informed the strand’s recommendation for **identifying a clear definition as well as engaging in consistent implementation and robust education initiatives for SDM.** Establishing a single, agreed-upon definition of SDM could provide numerous benefits, including a broader shared understanding among stakeholders, expanded legal recognition, consistent standardized applications and models, greater normalization of its use, and better data collection and evaluation systems to understand the impacts of SDM. This committee does not endorse any single existing SDM implementation model but instead encourages a deliberative process led by individuals with intellectual and developmental disabilities to merge what has been learned. One example worth closer examination is New York, recently highlighted by the United Nations for its state-led effort and dedicated funding (United Nations Department of Economic and Social Affairs, 2024, p. 291). New York's Article 82 of the Mental Hygiene Law legally recognizes SDM agreements developed through a standardized process, mandates third-party acceptance with liability protections, and supports implementation and education efforts overseen by the state developmental disabilities agency (New York Mental Hygiene Law Article 82, 2022, NYSBA Committee on Disability Rights, 2024). Closer examination and inclusive research on the outcomes and effectiveness of such existing efforts can support and enhance the wider development of consistent, meaningful models. By addressing these challenges and involving individuals with lived experiences in the development of more consistent SDM implementation, we can better support the autonomy and decision-making capabilities of people with disabilities, ensuring they have the opportunity to lead more self-determined and fulfilling lives.

## Recommendation 3: Promote Inclusive Research

Increasingly, researchers in the IDD field advocate for partnering with and advancing the leadership of people with IDD in conducting research to foster innovation and create more meaningful outcomes for everyone (Spong & Bianchi, 2018). Throughout history, a lack of involvement of people with IDD has led to unethical research as well as research not valued by the community (Ouellette, 2024). Although some systems of protections are in place to minimize harmful practices (e.g., Institutional Review Boards), this protectionism can directly conflict with the autonomy, self-determination, and inclusion of the IDD community within research practice (Friesen et al., 2023). As such, members of the Consent and Decision-Making strand advocate for **expanding participation for people with IDD to include *all* aspects of the research process they choose, including but not limited to, shaping research priorities, leading research activities, and participating in dissemination.** In this section, the co-authors describe specific aspects of the research enterprise in which systemic changes are needed to promote equity and advance inclusive research. It is important to note that these aspects are in no way exhaustive of all research processes that require systemic changes; however, moving forward on the areas identified below could enhance inclusive research related to consent and decision-making in partnership with the IDD community.

To ensure members of the IDD community are empowered to decide whether they want to participate in the research process, informed consent practices should be redesigned to prioritize accessibility and inclusion, ensuring that research is equitable and open to as many adults with IDD as possible. Traditional informed consent processes often rely on standardized criteria to assess decision-making capacity, which can exclude people with IDD by categorizing them as a vulnerable population rather than recognizing their diverse abilities and support needs (DeCormier Plosky et al., 2022). This overlaps with considerations related to SDM discussed in the previous recommendation. However, a growing emphasis places the onus of ensuring inclusion across marginalized populations both as research participants, but also as research team members to develop a clear and supportive consent process (McDonald et al., 2024; McDonald & Kidney, 2012; Vogt, 2024). In other words, the accessibility and adaptability of consenting procedures will invariably impact a person’s assessment of capacity, and research teams have an ethical obligation to ensure consenting processes are as accessible as possible. To achieve this, research teams and systems that support them should no longer categorically exclude research participation of the IDD community; rather, they should assume capacity to consent and develop standardized practices for increasing the accessibility of the consenting process (McDonald et al., 2024), including engaging the IDD community in developing and implementing consent procedures.

Research involving the IDD community should be conducted by inclusive research teams with people with IDD in leadership roles. Inclusive teams must go beyond tokenism, emphasizing genuine partnerships and a commitment to diverse team composition (Bigby et al., 2014; Di Lorito et al., 2018; Ghaderi et al., 2023). Collaborative research methods, such as Community-Based Participatory Research (CBPR) and Participatory-Action Research (PAR), should be utilized to ensure a wide range of perspectives and voices within the IDD community are represented (Chinn & Balota, 2023; McDonald, 2017; Rix et al., 2020). Further, funding agencies should use their power and privilege to promote and require the active engagement of people with IDD in identifying research priorities, designing and conducting research, and sharing research findings. Relatedly, many people within the IDD community hold intersecting racial, cultural, gender, class, and sexuality identities, which may compound barriers to participation (Green et al., 2024; Santinele Martino & Fudge Schormans, 2018). As such, efforts must be made to ensure the voices of the entire IDD community are included and valued.

To facilitate this shift, IRBs must adopt more inclusive approaches to mitigating harm that do not diminish the autonomy and self-determination of the IDD community on research teams. This requires reexamining traditional concepts of vulnerability to better align with principles of equity and inclusion, ensuring protections are not inherently paternalistic (Friesen et al., 2023; McDonald et al., 2015; Santinele Martino & Fudge Schormans, 2018). Additionally, IRBs should also promote active participation from those directly impacted by research decisions, embedding the perspectives of people with IDD throughout the review process (Anderson, 2023; Bigby et al., 2014; Li & Grady, 2023).

Finally, research findings must be shared with the broader IDD community through meaningful collaboration with IDD research partners. Dissemination should target diverse stakeholders in various locations and formats, ensuring the information reaches both the core research population and the wider community (Parent-Johnson & Duncan, 2024). Accessible materials are essential and should include plain language, languages other than English, and alternatives to traditional academic articles (Parent-Johnson & Duncan, 2024). When publishing in academic settings, co-researchers or researchers with lived experience must be equal collaborators, ensuring their voices are authentically represented (Riches et al., 2020; Strnadová & Walmsley, 2018). These collaborators should also play a central role in community-facing dissemination efforts, with systems in place to provide the supports necessary for their full participation. Instead of simply adapting existing frameworks, the priority must be on transforming dissemination structures to promote accessibility, equity, and full inclusion. This will require change in research and funding structures, as well as training and dissemination practices and norms.

## Recommendation 4: Innovate with Technology

Across a broad range of fields, including IDD, growth in technology can enable innovation as well as introduce potential risks, and the possibilities for innovation and risk apply to consent and decision-making for people with IDD. Members of the Consent and Decision-

Making strand focused on two areas in considering recommendations for technology innovation group discussions: (a) the potential impact of technological innovation on autonomy and (b) the potential impact of technological innovation on privacy. This recommendation centers on **encouraging leaders in the IDD field to innovate with technology to support autonomy for people with IDD, including consent and decision-making, while also critically examining how emerging technologies potentially impact risk and privacy for people with IDD.** Rapid advancements and integration of computing, artificial intelligence (AI), and communication technologies have the potential to transform how people with IDD can be autonomous in how they are supported to make decisions and exercise their human and civil right to consent as these technologies are changing how people acquire, process, and share information (Rashid & Kausik, 2024). For *all* people, but particularly people with IDD, access to comprehensible information and communication supports is crucial to make informed decisions and consent while building self-determination across contexts (e.g., home, work, school, community).

Emerging technologies, including adaptive interfaces, generative AI, and personalized decision-support systems, can support access to information, expression of capacity and communication of consent and assent. These advancements have the potential to efficiently actualize the “born accessible” term used in technology design and engineering which described the possibilities of the full integration of universal design principles into new developed technology (Wehmeyer et al., 2021). Enhanced accessibility via technology can open new markets and job opportunities (Damianidou et al., 2018), lower healthcare costs (Lancioni et al., 2023), and ultimately enhance the self-determination and quality of life of people with IDD (Tassé et al., 2020). As such, investing in inclusive technology that is universally designed is not only an ethical imperative to ensure people with IDD have the human and civil right to consent and make decisions, but it is also an economic and social opportunity.

Despite recognizing the potential positive impact technological innovation can have in the IDD field as it relates to consent and decision-making, the co-authors also feel it is important to consider the potential impact on privacy and associated risks particularly if inclusive design is not used and if people with IDD are not supported to be a part of and lead discussions about design and implementation. In particular, during group discussions, members highlighted that in order to uphold civil rights and personal dignity, privacy and security safeguards must be prioritized when developing and deploying technologies as breaches in privacy can undermine a person's autonomy (O'Brolchain, 2018). However, the prioritization of these safeguards should not overprotect or paternalize people with IDD by removing dignity of risk. Engaging with technology as it becomes ubiquitous in society is (a) a human right and (b) a pathway to valued outcomes, including the development of meaningful relationships, promotion of problem-solving and decision-making skills, and increased quality of life (Blatt, 1987; Ward, 2005). Integrating increasing understanding of ways to support the dignity of risk for people with IDD (Bumble et al., 2022) and growing advancements in technological innovation has the potential to exponentially enhance the opportunities and supports for people with IDD to be autonomous and make decisions while leveraging needed supports, including technology.

## Recommendation 5: Leverage Data to Transform Education, Training, and Systems

In the next decade of IDD research, advocacy, policy, and practice related to consent and decision-making, a data-driven approach will be essential for transforming education, training, and systems. Central to this approach is tackling the lack of a consistent and longitudinal data collection system that tracks relevant information on consent and decision-making (National Council on Disability, 2019). For example, research findings consistently demonstrate worrisome correlates to guardianship, including diminished educational achievement and opportunities (Millar, 2009; Smith & Stein, 2020), and decreased likelihood to marry, work in the community, have employment as a goal, live in the community, and be involved in making life choices (Bradley et al., 2019). However, at this point, there is no consistent data system that tracks (a) the use of guardianship and associated alternatives (e.g., SDM) for people with IDD, (b) the outcomes for people with IDD when they are effectively supported to consent and make decisions, and (c) potential disparities that are perpetuated by systemic barriers.

For example, most states do not collect thorough data on adults with guardians, their guardians, or the guardian-client relationship (Tompkins et al., 2024). With a specific focus on outcome-related data, members of the Consent and Decision-Making strand discussed the need for research on the impact of different uses of SDM (e.g., informal use within family context, legal use such as SDMAs) on a myriad of practical outcomes (e.g., health, self-determination, quality of life). Relatedly, another critical area for further research is strengths-based consent and decision-making assessment and interpretation practices. Traditionally, assessments have been tied to capacity determinations, often used in ableist ways to limit the decision-making power of people with IDD. As such, there is a need to further understand the purpose of assessment as it relates to consent and decision-making and determine if assessment in these areas can be decoupled from capacity determinations, such as the Supported Decision-Making Inventory (SDMI; Shogren et al., 2017) which measures areas in which a person needs support in decision-making.

Members of the Consent and Decision-Making strand advocate for **developing and evaluating ways information on consent and decision-making can be shared through education and training initiatives that are data-driven.** For example, given the estimated three-fold increase in adults in the United States with guardians between 1995 and 2011 (Reynolds, 2002; Schmidt, 1995; Uekert & Van Duizend, 2011), attention and resources should be directed to understanding the factors that may have influenced this increase. These factors could be policy-related, such as the Individuals with Disabilities Education Act’s transfer-of-rights requirement that mandates school professionals inform parents/guardians that their rights to make educational decisions for their child transfers to the child when they reach the age of majority (Raley et al., 2020). The National Council on Disability (2019) identified the “school-to-guardianship pipeline,” or the hypothesis that school professionals frequently recommend guardianship as the primary or only option when students reach the age of majority due to a lack of information and training (Jameson et al., 2015). However, other influences during school-age years include parent-to-parent communications that share information and perspectives about guardianship (Landa et al, 2023). Overall, members of the Consent and Decision-Making strand strongly encourage research that examines how constituents with valued roles in consent and decision-making for people with IDD—including people with IDD, family members, educators, healthcare professionals, legal advocates—understand and communicate options related to guardianship and its alternatives as well as build expectations for human and civil rights for people with IDD through education and training.

## Conclusion

The recommendations made by the Consent and Decision-Making strand stresses the urgent need for systemic change to promote consent and decision-making rights and opportunities as well as innovative research, policy, and practice in the IDD field. Such work must occur in partnership with, and led by, people with IDD who are experts on supports needed for consent and decision-making. By striving to shift societal perspectives through building a culture of consent, establishing clear policies related to SDM, and embracing inclusive research and technological advancements, equitable and inclusive consent and decision-making for people with IDD is possible. Moving into the next decade of IDD research, advocacy, policy, and practice, it is essential that people with IDD are not only included in decision-making processes but are recognized as leaders in professional roles who shape the policies and practices that impact their lives.

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