

Autism, Neurodivergence and Transitioning to Adulthood: The Need for Supported Decision-Making and Supported Engagement

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Transition is both a verb and a noun. In its most general sense, it means, according to *The Merriam-Webster Dictionary*, “a change or shift from one state, subject, place, etc. to another,” and the “period or phase in which such a change or shift is happening.” A more medicalized definition of transition is “a purposeful, planned process that addresses the medical, psychosocial, educational and vocational needs of adolescents and young adults with chronic medical conditions, as they advance from a pediatric and family-centered to an adult, individual focused health care provider.”¹

Transition, however, encompasses more than chronic medical conditions. We also recognize that various transitions occur throughout our lifetime, but the shift from adolescence to adulthood creates unique challenges and opportunities. This transition takes years and is a process, not an event. Key markers of transition include housing, employment, education, voting, driving, health care, marriage and contracting.

Critical to each of these markers of adulthood is the legal ability — and requirement, in many instances — to make these decisions for oneself, which can be both challenging and fortifying. Determining how such decisions are made — and who can make them — is essential during the transition period. The determination of who has the authority to make decisions is particularly pronounced for autistic and neurodivergent individuals. Some of them may have intellectual challenges, while others will not — but might be presumed to have limited capacity.

‘FALLING OFF THE CLIFF’ INTO ADULTHOOD

According to the latest data from the U.S. Centers for Disease Control and Prevention (CDC), approximately 1 in 36 children have been identified as autistic.² Both data and services related to autism have focused primarily on children, and thus the transition to adulthood for autistic individuals and their families is often described as “falling off the cliff.” This metaphor describes the abrupt move from a model of entitlement with a full range of coordinated social and medical services to a model of mere eligibility for services at the state and federal levels.

Although a model of entitlement can pose challenges for autistic individuals in accessing services, a model of eligibility poses even greater barriers. As Anne Roux, director of Research and Policy Impact at A.J. Drexel Autism Institute, and her collaborators have stated:

Upon exiting secondary school, youth and

their families must navigate a complex and fragmented system of eligibility for adult services, which include Vocational Rehabilitation (VR), Developmental Disability (DD) services, safety net benefits like Supplemental Security Income (SSI), public health insurance like Medicaid, and Medicaid waivers, which cover services and supports not typically available through health insurance.³

While nearly 40% of autistic people have an intellectual disability (ID),⁴ according to the CDC, that alone does not necessarily render one incapable of making their own decisions. Even without an ID, an individual's level of executive functioning can inhibit their ability to identify, apply for and access services. Additionally, the capacity for decision-making may wax and wane, and the types of decisions that must be made can range from minor to significant. For instance, the decision to consent to a flu shot may be less onerous than the ability to consent to major surgery.

Moreover, an autistic individual may have the ability to express their goals and values with certain clinicians but not others. Scheduling, planning and participating in medical and dental visits may be easier or more difficult, depending on one's executive functioning skills. At all times, however, the autonomy and dignity of the autistic person must be respected. Therefore, a range of decision-making options are available to consider as one moves from childhood to adulthood and throughout one's life span.

MECHANISMS FOR DECISION-MAKING

Being diagnosed with autism or as neurodivergent does not automatically render one incapable of making one's own decisions. The presumption is often made, especially for those with an ID, that a parent or family member is the legal guardian when, in fact, they may not have taken the legal steps to become the person's guardian. A recent *Frontiers in Psychiatry* article advises clinicians to be aware and cautious of any disability bias:

[C]linicians may hold implicit stigmatizing

views of autistic adolescent and adult clients, especially those with co-occurring intellectual disability and/or language impairment. This harmful perspective may contribute to the assumption that these clients are unable to direct their own treatment and result in deriving treatment goals from caregivers', rather than clients', presenting concerns.⁵

Guardianship, however, is often seen as a last resort, as the guardian assumes all legal decision-making authority for the individual, and replacing a guardian involves a complex legal process. Additionally, guardianship may not respect the goals and values of the individual, especially if the individual can express, verbally or otherwise, their own values and preferences. Some of those values and preferences may not always be ideal. However, we afford discretion to neurotypical adults to make poor decisions. Poor decisions do not necessarily mean that an individual lacks capacity.

Supported decision-making is a way to further enhance autonomy, respect dignity, ensure a commitment to the individual's best interests, and promote shared decision-making.

Measures that are more inclusive of an autistic individual's autonomy (with or without an ID) include the following legal tools: a power of attorney for health care, a power of attorney for finances/property, and/or a newly emerging legal model of supported decision-making (SDM).

SDM embodies the disability rights motto "nothing about us without us." This seemingly simple statement captures the powerful notion that critical decisions, especially ones around health care, should not be made for autistic or neurodivergent individuals. Rather, as much as possible, they should be at the center of health care decision-making as well as other major life decisions, including where to work and where to live.

Currently, half of U.S. states have enacted supported decision-making laws, with Florida becoming the most recent state in July 2024.⁶ SDM

occurs when “people use trusted friends, family members and professionals to help them understand the situations and choices they face, so they may make their own decisions — [it] is a means for increasing self-determination by encouraging and empowering people to make decisions about their lives to the maximum extent possible.”⁷

This alternative to guardianship and other more formal legal interventions mirrors the way most adults make decisions: by consulting with friends, family and trusted advisors when facing serious health care decisions. SDM is a way to further enhance autonomy, respect dignity, ensure a commitment to the individual’s best interests, and promote shared decision-making.

For example, the law in Washington, D.C., defines SDM as:

[A] process of supporting and accommodating an adult with a disability in order to: (A) Assist the adult with a disability in understanding the options, responsibilities and consequences of life decisions; and (B) enable the adult with a disability to make life decisions, without impeding the self-determination of the adult with a disability or making decisions for the adult with a disability.⁸

SUPPORTED DECISION-MAKING: A VARIABLE FRAMEWORK

While some variability exists from state to state on how supported decision-making works, including who can and cannot be named as a supported decision-maker, the general intent of such laws is not only to prioritize the preferences of the person for whom a decision is being made, but to allow that person to make decisions for themselves. A guardian, for example, may consider the preferences and views of a ward when making a decision, but the guardian is, by law, the ultimate decision-maker. Also of note is that in those states with SDM laws, “only Illinois limits the adult in an SDM agreement to a person with developmental or intellectual disabilities. All other states allow adults with disabilities ... to receive support in SDM agreements.”⁹

SDM statutes lend formality to what are often informal arrangements, set parameters to ensure that exploitation is not occurring, and identify the range of decisions in which such agreements may be effectuated. An excellent resource for learning more about SDM is the Center for

Public Representation, which has extensive information on SDM and even has a sample SDM agreement form on its website.¹⁰ Additionally, the American Bar Association has published a chart, current through 2023, of state statutes on SDM. The chart includes how states define SDM, what an SDM agreement is, how and when such agreements can be terminated, conflicts of interest and reporting requirements for third parties who suspect abuse.¹¹ The goals are to demystify the process as much as possible and to make SDM more accessible for decision-makers and their supporters.

THE NEXT STEP: SUPPORTED ENGAGEMENT

Supported decision-making is essential to respecting individual choices, and the growing attention to the voices of those for whom decision-making may be challenging is long overdue. Those decisions, however, must be effectuated. Therefore, we attest that we need to expand to a concept we refer to as supported engagement.¹² This is the next step in ensuring that “nothing about us without us” is operationalized beyond individual decisions.

This new conceptual framework acknowledges that supported decision-making is only the start. SDM recognizes that autistic and neurodivergent individuals may need the support of a trusted friend, parent or peer to help make health care and other important life decisions. Making such decisions is important, but the goal is to ensure that these individuals have flourishing lives.

Supported engagement argues that the need for support does not suddenly disappear when adolescents become adults. In fact, a greater need for support, or varying degrees of support, may arise in adulthood. Supported engagement recognizes the individual needs of autistic adults but also recognizes the obligation of the state and other organizations to provide services, as well as the right of autistic and neurodivergent individuals to participate in engaged ways to identify those services. As part of the community and the larger social fabric, their engagement in setting policy and legislation that impacts them is a matter of social justice.

Organizations such as the Autistic Self Advocacy Network emphasize self-advocacy but also recognize the need to have more just laws and policies.¹³ Our conceptual framework of supported engagement recognizes that autistic and

neurodivergent individuals have differing needs for support. It recognizes the individuality of each person but also recognizes that the people living with these diagnoses need services that are accessible, coordinated and effective so they can enjoy and contribute to society as fully as possible.

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NOTES

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