

ASAN's Invitational Summit on Supported Decision-Making and Transition to the Community: Conclusions and Recommendations

Statement of Purpose

This paper discusses the Autistic Self Advocacy Network's "Invitational Summit on Supported Decision-Making and the Transition to the Community," held on October 18th and October 19th, 2016. From the summit and a series of follow-up interviews, ASAN derived recommendations for how self-advocates, lawyers, parents, government officials, and other stakeholders can use supported decision-making to decrease institutionalization and improve the integration of people with disabilities into the broader community. The White Paper provides recommendations for the use of supported decision-making in four aspects of successful community living: Housing, Relationships and Natural Supports, Healthcare, and Long-Term Services and Supports.

Introduction

International law protects our right as adults with disabilities to make our own decisions. Article 12 of the Convention on the Rights of Persons with Disabilities, adopted by the United Nations General Assembly in 2006, states that "States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life."¹ Article 12(3) of the Convention holds that parties to the Convention must provide people with disabilities with "the support they may require" to make decisions, regardless of what that support is.² 177 countries are parties to the Convention and 161 countries are signatories.³ Nonetheless, people with disabilities are denied the right to make choices in almost every country through guardianships.

Guardianships greatly constrain the decision-making power of people with disabilities. A person with a disability under a plenary (or full) guardianship cannot choose where to live, where to work, who to be friends with, and who to marry without their guardian's consent. In fact, the guardian often makes decisions for the person with a disability, without considering their wishes. Legal scholars have compared plenary guardianship to civil death.⁴ Some guardians can make intimate personal decisions about a person's life without even knowing the person, as in the case of professional guardians who have dozens of people with disabilities as wards.⁵

1 Convention on the Rights of Persons with Disabilities art. 12, December 13, 2006, U.N. Doc A/RES/61/106, 6, 2515 U.N.T.S. 3, 78. The Convention came into force on May 3, 2008.

2 Convention on the Rights of Persons with Disabilities, *supra* note 1, at 78.

3 *United Nations Treaty Collection Depository: Status of Treaties*, https://treaties.un.org/Pages/ViewDetails.aspx?s-rc=TREATY&mtdsg_no=IV-15&chapter=4&lang=en&clang=en (last visited May 15, 2018).

4 See Robert Dinerstein, *Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Supported Decision Making*, Human Rights Brief, Jan. 2012, at 9; H.R. Rep. No. 100-641, at 8 (1987) ("The typical ward has fewer rights than the typical convicted felon ... By appointing a guardian, the court entrusts to someone else the power to choose where they will live, what medical treatment they will get and, in rare cases, when they will die").

5 National Council on Disability, *Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination* 34 (2018) ("... professional guardians provide these services to large caseloads of individuals").



The Autistic Self Advocacy Network seeks to advance the principles of the disability rights movement with regard to autism. ASAN believes that the goal of autism advocacy should be a world in which autistic people enjoy equal access, rights, and opportunities. We work to empower autistic people across the world to take control of our own lives and the future of our common community, and seek to organize the autistic community to ensure our voices are heard in the national conversation about us. Nothing About Us, Without Us!

Guardianships are notoriously difficult to remove. Ryan Keith Tonner, a man under guardianship in the United States, attempted unsuccessfully for years to eliminate his guardianship through litigation, even though his guardian died in 2007 and he had made decisions without a guardian in the years after her death.⁶ Jenny Hatch, a woman placed under guardianship who was sent to live at a segregated group home, was only able to remove her guardianship after an extensive legal case that involved the assistance of multiple disability rights organizations and a national campaign.⁷

In many countries, guardianships are also a barrier to the full integration of people with disabilities into society. Lawyer and advocate Dana Kořínková, of the advocacy organization QUIP in the Czech Republic, reported that the Czech Republic's public guardians often prefer that their wards remain in institutions. She says: "It is easier for the guardian to manage their assets and care, since all the care is then provided by an institution and people's autonomy and opportunities for actions are significantly restricted."

Guardianships are not sufficient, even with reforms, to protect the assets and privacy rights of people with disabilities. While many states and countries have pursued modifications to their guardianship statutes,⁸ these reforms tend to add additional, less restrictive forms of guardianship (such as limited guardianship)⁹ and procedural protections¹⁰ rather than reduce the risk that the guardian will abuse and exploit the person with a disability. The existence of limited guardianship and the additional due process protections added over the last several decades have done little to reduce the overuse of plenary guardianship on people with disabilities.¹¹

Supported decision-making arose as an alternative to guardianship during the last several decades.¹² Supported decision-making is a system through which people with disabilities elect either one person or numerous people (with more than one person being ideal) to help us understand the decisions we need to make without supplanting our right to make decisions.¹³

Ten to twenty years before the rise of supported decision-making as an alternative to guardianship, there began what New York family court judge Kristen Booth Glen in 2012 called a "paradigm shift" in how we think

6 Megan Morgan, *The Arc of Texas, Alternatives to Guardianship for Adult Texans with Intellectual and Developmental Disabilities 3* (August 2015), <http://www.thearc.org/file/Guardianship-White-Paper.pdf> *In Re: Guardianship of the Person and Estate of Ryan Keith Tonner, an Incapacitated Person, Petitioner*, 513 S.W.3d 496, 498-99 (Tex. 2016).

7 *Julia S. Ross and Richard W. Ross v. Margaret J. Hatch*, No. CWF120000426P-03, available at: http://jennyhatchjusticeproject.org/docs/justice_for_jenny_trial/jhip_trial_final_order.pdf (Va. Cir. Ct. Newport News, Aug. 2, 2013) The final 2013 court order in Jenny Hatch's case created a temporary guardianship with her chosen friends as guardians, with the goal of terminating the guardianship in one year and transitioning it to a supported decision-making arrangement instead.

8 *See, e.g.*, Eleanor Crosby Lanier & Rose Nathan, *Adult Guardianship in Georgia: Are the Rights of Proposed Wards Being Protected? Can We Tell?* 16 *Quinnipac Probate Law Journal* 249, 253-57 (2003) (describing the United States state of Georgia's attempts to reform their guardianship statutes); Bizchut, *Supported Decision Making Service for Persons with Disabilities: Service Model 58, 59, 60* (2017), <http://bizchut.org.il/he/wp-content/uploads/2017/06/Support-system-Model-Bizchut.pdf> (describing changes made to Israeli guardianship law by the Knesset in 2016 which make it more difficult to impose guardianship by defining specific rights that the person under guardianship has); *Latvia Abolishes Plenary Guardianship*, Mental Disability Advocacy Centre (December 5, 2012), <http://mdac.org/en/05/12/2012/latvia-abolishes-plenary-guardianship> (showing Latvia abolished plenary guardianships but kept partial or limited guardianships).

9 Leslie Salzman, *Guardianship for Persons with Mental Illness: A Legal and Appropriate Alternative?* 4 *St. Louis University Journal of Health Law & Policy* 279, 294 (2011) (explaining limited guardianships).

10 Lanier & Nathan, *supra* note 8, at 253-57; Mental Disability Advocacy Centre, *supra* note 8.

11 Nina A. Kohn, Jeremy A. Blumenthal, Amy T. Campbell, *Supported Decision-Making: A Viable Alternative to Guardianship?* 117 *Pennsylvania State Law Review* 1111, 1118 (2013); Samantha Crane, *Is Guardianship Reform Enough? Next Steps in Policy Reforms to Promote Self-Determination Among People with Disabilities*, 8 *Stetson University Journal of International Aging Law & Policy* 177, 187-89 (2015); Leslie Salzman, *Rethinking Guardianship (Again): Substituted Decision Making as a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act*, 81 *University of Colorado Law Review* 157, 174-78 (2010) (finding that guardianship reforms have not had much of an impact on the number of plenary guardianships issued by United States courts).

12 Kristen Booth Glen, *Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship, and Beyond*, 44 *Columbia Human Rights Law Review* 93, 119-39 (2012) (describing the shift in thinking which led to the development of supported decision-making).

13 Inclusion Europe, *Key Elements of a System for Supported Decision Making* (2008), <http://www.supporteddecisionmaking.org/sites/default/files/Key%20Elements%20of%20a%20System%20for%20Supported%20Decision-Making.pdf>.

about people with disabilities.¹⁴ This new paradigm holds that a person's disabilities should in no way prevent them from being an active participant in society, and that one's impairments should never lead to their unjust segregation in an institution.¹⁵ The Supreme Court case *Olmstead v. L.C.* in the United States reinforced this paradigm by holding that unnecessary institutionalization violated the Americans with Disabilities Act and that confinement in an institution unnecessarily limits the ability of people with disabilities to participate in the social world.¹⁶ The United States' federal government has made institutionalization less likely through the Center for Medicare and Medicaid Services' (CMS) provision of Section 1915(c) home and community-based services (HCBS) waivers,¹⁷ which allow people to receive supports necessary for independence in the community, and state-by-state implementation of the Supreme Court's ruling in *Olmstead*.¹⁸

The deinstitutionalization movement is intersectional and international. Disability Rights International¹⁹ and the nonprofit Lumos,²⁰ for instance, are international organizations that work to reduce the institutionalization of children and people with disabilities in multiple countries. Disability rights organizations, which advocate for people with disabilities to have the same capacity to make choices as all other citizens, exist worldwide, from Turkey's RUSIHAK²¹ to the Mental Disability Rights Initiative²² in Serbia.

We believe that the two movements — supported decision-making and deinstitutionalization — can benefit one another. A significant number of studies since 1990 have shown that people with disabilities are happier, healthier, and less likely to be institutionalized when we have a greater number of opportunities to make decisions for ourselves.²³ ASAN hypothesized that supported decision-making could help people with disabilities leave institutions and better integrate us into our communities.

ASAN held a two-day summit on October 18th and 19th, 2016, which brought together disability rights advocates, professionals, and stakeholders from around the world. Our attendees had a wide variety of experiences and expertise, from parent advocates from the United States to self-advocates from Bulgaria and experts on legal capacity from Mexico. The summit attendees discussed present-day supported decision-making and institutionalization in their countries and how it related to four components critical for successful integration into the community: **Health Care, Relationships and Natural Supports, Housing, and Long-Term Services and Supports**. We called these four components “Elements of Community Integration” at the summit and described them in the following way to indicate their importance:

First, affordable, disability-accessible housing integrated within the community is crucial to ensuring that persons with disabilities have places to live other than in institutional settings.

¹⁴ See Glen, *supra* note 12, at 107-28 (explaining that since the 1970s and late 1980s, there has been a move away from a medical model of disability, in which people with disabilities were believed to be inferior and institutionalized “away from society,” toward a belief in integration and a social model of disability).

¹⁵ See Glen, *supra* note 12 at 126-34; Mary C. Cerreto, *Olmstead: The Brown v. Board of Education for Disability Rights: Promises, Limits, and Issues*, 3 Loyola Journal of Public Interest Law 47, 59 (2001).

¹⁶ *Olmstead v. L.C.* by Zimring, 527 U.S. 581, 600, 601 (1999).

¹⁷ *Home and Community Based Services 1915(c)*, Center for Medicare and Medicaid Services (CMS), <https://www.medicare.gov/medicaid/hcbs/authorities/1915-c/index.html> (last visited May 14, 2018).

¹⁸ U.S. Department of Justice, Civil Rights Division, *Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and Olmstead v. L.C.*, https://www.ada.gov/olmstead/q&a_olmstead.htm (last visited May 14, 2018).

¹⁹ Disability Rights International, <https://www.driadvocacy.org/> (last visited May 14, 2018).

²⁰ Lumos, <https://wearelumos.org/> (last visited May 14, 2018).

²¹ RUSIHAK, <https://www.rusihak.org> (last visited May 14, 2018).

²² Mental Disability Rights Initiative of Serbia, <http://www.mdri-s.org/> (last visited July 13, 2017). English-language speakers interested in MDRI-S' work should read the publications in the “Publications in English” section.

²³ Michael L. Wehmeyer & Susan B. Palmer, *Adult Outcomes for Students with Cognitive Disabilities Three-Years After High School: The Impact of Self-Determination, Education & Training in Mental Retardation & Developmental Disabilities*, 38 *Education & Training in Developmental Disabilities* 131, 139-40 (2003); Tina M. Anctil et al., *Academic Identity Development Through Self-Determination: Successful College Students with Learning Disabilities*, 31 *Career Development for Exceptional Individuals* 164, 172-73 (2008); Ishita Khemka et. al., *Evaluation of a Decision-Making Curriculum Designed to Empower Women with Mental Retardation to Resist Abuse*. 110 *American Journal of Mental Retardation* 193, 193-204 (2005); Michael L. Wehmeyer & Michelle Schwartz, *Self-Determination and Positive Adult Outcomes: A Follow-Up Study of Youth with Mental Retardation or Learning Disabilities*, 63 *Exceptional Children* 245, 250-55 (1997).

Second, any person in the community requires a network of personal relationships and natural supports within that community. These networks allow people to rely upon their fellow community members when they need help.

Third, any person in the community must receive healthcare services within their community. Without proper health care from sources within a community, a person cannot maintain an independent life there.

Fourth, many people with disabilities need certain services and supports in the community in order to perform activities of daily living. Some may need personal care attendant services to perform activities of daily living and live and work in the community. Others may need daily health care or vocational rehabilitation services.

The summit was divided into four segments, during each of which the summit attendees discussed how supported decision-making related to one of the four elements of community integration. Each segment was divided into **a panel**, where a 4-5 person panel of experts discussed their work as it related to the topic; **break-out discussion groups** during which the summit attendees split into groups of 6-7 people and discussed the topic among themselves; and finally **breakout presentations** where the summit reconvened and each breakout group presented what their discussion group talked about to all other attendees.

After the summit, we followed up during November 2016-January 2017 with several of our summit panelists, including all of our international invitees. They described to us their experience at the summit and offered further comments. They also described past work they had done on supported decision-making and any barriers preventing the use of supported decision-making that they encountered. We specifically wanted to follow up with our international participants and with participants who had significant experience helping people with disabilities transition from institutional settings.

From these events, we have developed a list of recommendations for how disability rights advocates can best utilize supported decision-making to support the community integration of people with disabilities and our transitions from institutional settings into the community.

ASAN's Recommendations for Effective Use of Supported Decision-Making in Deinstitutionalization and Community Integration²⁴

Housing

Recommendation 1:

Disability-friendly landlords are sometimes the difference between successful and unsuccessful use of supported decision-making in housing. The disability rights community (particularly the I/DD community) should take deliberate steps to engage with the landlord community around supported decision-making.

Many of our OSF summit attendees discussed the importance of well-informed, disability-friendly landlords to deinstitutionalization and community integration. They were particularly concerned about situations in which less well-informed landlords might act as a barrier to the use of supported decision-making in housing.

Their first concern was whether the landlords would accept that people with disabilities using supported decision-making are responsible for their own rent and are qualified to sign a rental agreement. In the experience of several summit invitees, landlords may feel that people with disabilities with guardians are more “reliable” than those with supporters, even if such a belief is groundless. For example, as Alison Barkoff, an attorney for the Bazelon Center for Mental Health Law at the time of the summit, noted, “if someone shows up with a supported decision-making agreement, most likely the landlord will impose requirements -- like a guarantee that they can pay -- that they do not impose on other people. Landlords may not be as focused on legal capacity per se as doctors or banks may be, but disabled tenants will likely still run into unnecessary housing barriers.” Invitees also felt that landlords might evict the person with a disability due to concerns related to the person’s disability. Several attendees spoke of situations in which behavior reasonably related to a disability, such as hoarding and excessive noise, could be used as a pretext for eviction. Many attendees felt that in such a situation, decision-making supporters of the person with a disability would need to help the person understand the potential negative consequences of their actions (such as evictions due to hoarding unnecessary objects in a way that interferes with overall cleanliness) while still acknowledging their right to make those decisions. Several summit attendees referred to this as giving the person with a disability “the dignity of risk.” Supporters could also help people investigate options to minimize these consequences, such as placing unnecessary items into storage.

Landlords who *are* willing to work with people with disabilities who are using supported decision-making can significantly aid in the resolution of disability-related concerns or disputes. Leslie Salzman, a professor at Cardozo School of Law and Director of Clinical Legal Education at the school, described a Section 8 housing case where an older woman forgot to renew her application for Section 8 housing benefits, due to disability. When the woman attempted to re-apply for a Section 8 housing voucher, with the help of her daughter, the government agency administering the vouchers refused to accept the application because the daughter signed it and was not the woman’s guardian. The landlord in the case was highly supportive. The landlord was willing to accept the tenant’s portion of the rent payment even without Section 8 benefits and willing to allow the daughter to sign the lease. The landlord’s support contributed to the resolution of the case in the woman’s favor.

Attendees also discussed a trend in the United States in which people with psychiatric disabilities were increasingly accepted as decision-makers in their own right by landlords. For example, the supported housing

²⁴ Most of the quotes, videos, and pamphlets we reference in this section were either presented to all attendees during the Autistic Self Advocacy Network’s supported decision-making summit or to ASAN during subsequent interviews conducted from November 2016 - January 2017. For example, Hana Solařová, a Project Manager at the international organization Lumos, handed out copies of the pamphlet “Moving to My New Home” at the summit, as examples of Lumos’ efforts to incorporate supported decision-making into their deinstitutionalization work. There are some sources in this White Paper that were not brought up at the summit, but support our recommendations. The quotes used in this White Paper may be approximate. The quotes either come from notes written by ASAN staff members on what the attendees said at the summit, or from notes written by ASAN staff members on the follow-up interviews we conducted with attendees after the summit. Anyone whose words are in quotation marks in the White Paper was given an opportunity to review and either approve or ask us to omit their quote or quotes.

movement promotes the use of housing rental subsidies for people with psychiatric disabilities, along with services that help to “secure and maintain housing, to restore or develop independent living skills, to obtain and keep employment, and to maintain . . . health.”²⁵ A person with a psychiatric disability using supportive housing has their name on the lease and all rights and responsibilities associated with tenancy.²⁶ Clients retain control over their daily schedules and are not required to accept any service they do not want to receive.²⁷ Supportive housing, according to the Center on Budget and Policy Priorities, is highly underutilized compared to the number of people with psychiatric disabilities that need it.²⁸ Nonetheless, people with intellectual and developmental disabilities (I/DD) are less frequently accepted as decision-makers. Certain attendees suggested that advocates could apply the same principles used in supportive housing for people with psychiatric disabilities to people with I/DD.

Policy Recommendations:

- ◆ Conduct outreach to local landlord associations and the local landlord community about people with disabilities and supported decision-making. Advocates can invite landlords and landlord associations to disability rights events, advise that they join advisory committees on disability, and offer expertise on supported decision-making. This may be particularly effective if the advocate is in a country that has ratified the CRPD or that has laws or judicial precedents concerning supported decision-making.
- ◆ Encourage policy on the national level that provides landlords with positive incentives to offer affordable housing. For example, in the U.S., advocates should work to expand access to the Section 8 housing vouchers that help low-income people afford rent payments, including people with disabilities.
- ◆ Re-examine supportive housing programs for people with psychiatric disabilities. Determine whether similar principles and supports would be useful for helping people with other disabilities (especially people with intellectual and developmental disabilities) to access housing.

²⁵ National Council on Disability, Home and Community Based Services: Creating Systems for Success at Home, at Work, and in the Community, app. A at 1, 2 (2015), <https://www.ncd.gov/publications/2015/02242015> (describing how supportive housing works).

²⁶ Ehren Dohler et. al., Center on Budget & Policy Priorities, Supportive Housing Helps Vulnerable People Live and Thrive in the Community 2 (2016), <https://www.cbpp.org/research/housing/supportive-housing-helps-vulnerable-people-live-and-thrive-in-the-community>.

²⁷ *Id.*

²⁸ *Id.* at 9.

Recommendation 2:

Advocates should encourage their countries' national housing agencies to release guidance addressing how landlords and the real estate community should respond to people with disabilities who have supporters instead of guardians.

For example, in the United States the Department of Housing and Urban Development (HUD) enforces both the Fair Housing Act and the Americans with Disabilities Act (to the extent that it pertains to housing), and has the authority to issue guidance on both laws.²⁹ Under the Fair Housing Act, a landlord cannot refuse to lease to a person with a disability solely because that person has a disability.³⁰ The landlord also cannot require that a person with a disability adhere to different lease terms than a person without a disability.³¹ Summit participants reported that many landlords in the U.S. were uncomfortable with renting to a person with a disability solely because the person did not have a guardian. A similar bias may exist cross-culturally.

Policy Recommendation:

- ◆ Disability rights advocates should coordinate with other fair housing advocates. They should draft a letter calling on their national housing agency to issue laws or guidance (depending on the country) stating that landlords and real estate brokers must: (a) acknowledge the decisions of a person with a disability who does not have a guardian; (b) acknowledge the person with a disability has competency to sign a lease or mortgage; and (c) allow the presence of a supporter at all meetings as a reasonable accommodation for the lessee or mortgage-holder.

Recommendation 3:

Supported decision-making will not help many people with disabilities enter the community unless there is affordable, accessible housing available to us. Disability rights advocates should support efforts in their countries/regions to promote access to affordable housing. Affordable housing must be physically accessible to people with disabilities. It should also include features that can accommodate people who have support needs related to their executive and cognitive functioning in addition to physical access needs. Advocates should also promote access to types of affordable housing that are consistent with the cultural context and use of housing in their countries or regions.

When people with disabilities leave institutions, we will not be able to live in the community without access to affordable housing. However, affordable housing is in limited supply in almost every country, even for people without disabilities.

Affordable housing may differ from country to country due to the cultural context and use of housing in each country. For instance, in many places in the United States, the cultural expectation is that a household consists of single adults, couples, or two parents and their underage children. Once the children reach adulthood, they are expected to leave their family home. Households are not expected to include grandparents, other extended family members, friends, or live-in supporters. Another cultural expectation in some communities in the United States is that each individual member of society will be fully self-sufficient or only dependent on a few other people, and will live in a home that they own. The same cultural expectations are not necessarily present in other countries, or in all cultural groups in the United States. For example, in some communities it is expected that several generations of a family live together in one house or apartment. One summit attendee said that

²⁹ *Disability Rights In Housing*, U.S. Department of Housing and Urban Development, https://www.hud.gov/program_offices/fair_housing_equal_opp/disabilities/inhousing (last visited May 14, 2018).

³⁰ *Id.*

³¹ *Id.*

we can't just think of "two parents and a white picket fence" anymore when we think of how people live, as the United States is becoming an increasingly diverse country. Similarly, advocates cannot assume that housing norms in one country will apply in other countries.

The kinds of affordable housing available to people with disabilities also differs by country. According to Dana Kořínková of the advocacy organization QUIP, affordable housing and access to community-based supports can both be difficult for people with disabilities to attain in the Czech Republic. As of the time of this article's publication, there is no law governing "social housing" — low-cost housing specifically available to people with significant financial need — in the Czech Republic. According to Kořínková, Czech Republic human rights advocates have worked for years to pass the Social Housing Act,³² but the Act has not yet been passed. She explained that while it is possible in *some* municipalities for people with disabilities (or other people of low income) to obtain housing at a reduced cost, this is not true in every city and town in the country. In most places, people with disabilities must attain apartments in the same manner as people without disabilities. The person's disability pension may not be enough to cover the cost of rent alone. In 2015 the Czech Republic approved a plan, the "Social Housing Strategy of Czech Republic 2015-2020," which is designed to foster the development of a government-wide social housing program in the Czech Republic.³³

These affordable housing limitations may contribute to the slow pace of deinstitutionalization in the Czech Republic. According to Kořínková, while the Czech Republic has ratified the CRPD, most deinstitutionalization, especially the deinstitutionalization efforts supported by the government, has consisted of moving people with disabilities in the Czech Republic from larger institutions to group homes--- effectively re-institutionalizing them. In the best-case scenario, individuals moving from an institution are able to share rented apartments. While there are some effective deinstitutionalization initiatives at the regional level, and service providers that are better at complying with the CRPD than others, more often there is little or no support for people who decide to leave institutions in the country. People with disabilities leaving institutions may additionally face a lack of community-based support services.

In the United States, summit attendees discussed the lack of good quality non-segregated housing for people with disabilities. According to one of our summit attendees, in the United States "there are real safety issues associated with living where affordable housing is built--- affordable housing may be constructed in very dangerous or poorly maintained areas in a city." Some of these safety concerns may be more perceived than actual: affordable housing units are often located in neighborhoods with a higher Black and/or Hispanic/Latino population than average,³⁴ which white people with disabilities and/or their parents may incorrectly perceive as less safe neighborhoods. However, in the U.S. affordable housing is often constructed in relatively low-opportunity³⁵ areas, which may also discourage the use of affordable housing for some people with disabilities.³⁶ Summit attendees discussed whether these issues contributed to the placement of some people with disabilities in disability-specific, segregated settings by their families. They also discussed how some parents' low expectations for their children contributed to their children's placement in such settings instead of in affordable housing or other housing in the community.

³² *The new Social Housing Concept in Czech Republic: Key elements and first reactions from our member organisation*, SCMBD, Housing Europe (November 3, 2015) <http://www.housingeurope.eu/resource-578/the-new-social-housing-concept-in-czech-republic>.

³³ *Id.*

³⁴ Philip Tegeler et. al., *Opportunity and Location in Federally Subsidized Housing Programs: A New Look at HUD's Site and Neighborhood Standards as Applied to the Low Income Housing Tax Credit 8* (2011), <http://www.prrac.org/pdf/OpportunityandLocationOctober2011.pdf>.

³⁵ Opportunity refers to "environmental conditions or resources that are conducive to healthier, vibrant communities and are more likely to be conducive to helping residents in a community succeed." *Id.* at 5.

³⁶ See Philip Tegeler et. al. at 3, 5, 8 (noting the difficulty in enforcing HUD standards which require that affordable housing be located in areas with some opportunity, and that most affordable housing is still located in high-poverty areas — one strong indicator of a low-opportunity area).

Affordable housing must be *accessible* as well as affordable. Dr. Clarissa Kripke, Director of Developmental Primary Care at the Office of Developmental Primary Care at the University of California, reported, in her interview and commentary on the summit, that the greatest challenge may be providing affordable, accessible housing for those who have significant physical disabilities and/or high support needs. She wrote that we must have homes available that can accommodate unusual access needs, such as gurney wheelchairs and ceiling lifts for those with little or no mobility in their limbs. Dr. Kripke explained that there is also a need for homes that meet accessibility needs related to a person's executive or cognitive functioning, such as homes with features that reduce visual or auditory distractions or that are designed to make it easier for the person and (if present) their support staff to navigate the home. Additionally, ASAN notes that smart home technology (such as refrigerators that order food once they become empty, smart lighting and sprinkler systems, etc.), remote monitoring and telehealth, and other home modifications and accommodations could increase the accessibility of the home for people with mental disabilities.

Supported decision-making advocacy by itself may not be sufficient to resolve the many problems people with disabilities face when looking for affordable and accessible housing. However, supported decision-making advocates can contribute their knowledge of the preferences and access needs of people with disabilities to the broader affordable housing conversation. Professor Lauren Onkeles-Klein, a practitioner-in-residence at American University Washington College of Law at the time of the summit,³⁷ suggested that “there are problems with affordable housing for *everybody*. They stifle what can be done with supported decision-making in the realm of housing. In some ways, we just need to join with the people who are fighting for affordable housing generally – that allows room for supported decision-making to breathe.”

Policy Recommendations:

- ◆ Housing for people with disabilities must be affordable and accessible. Advocates should invest time and effort into technologies that will both reduce the cost of housing and make it more accessible to people with disabilities, especially those moving from institutional settings into the community.
- ◆ Advocates should be mindful of the cultural norms and overall housing situation in their countries and regions (or the countries or regions in which they are advocating) when determining which laws and other reforms will benefit the people with disabilities living there. Whether housing is considered affordable or not depends on the particular cultural context of housing in that country, including: (a) that country's standard living arrangements, e.g. whether family homes are typically nuclear or multi-generational; (b) the age and circumstances in which the typical adult member of that society starts a new household; (c) the availability of homes and apartments in that country to people without disabilities; (d) the support systems available in that country, the availability of housing subsidies in that country, and other concerns.
- ◆ Advocates should continue to fight for laws and policies that allow people with disabilities to be able to afford to live in our communities, such as European social housing for low-income people or the United States' Section 8 vouchers. Advocates should ensure that social housing projects are not disability-specific and that such housing is integrated into the broader community. Disability rights advocates should lend their aid to affordable housing advocates working on these issues in their countries.

³⁷ Professor Onkeles-Klein subsequently joined the faculty at the University of the District of Columbia David A. Clarke School of Law.

Recommendation 4:

Successful transitions from an institution to housing in the community involved tailoring the home to the person's specific needs and slowly introducing the person to the idea of living outside the institution. They additionally involved the use of supported decision-making. Advocates should use these approaches when helping people who were previously institutionalized decide where they want to live.

Several of our summit attendees successfully helped people with disabilities transition from institutions and group homes into homes of their own. We believe these successes were due to three components present in each attendee's process: the methodical use of supported decision-making principles to ensure the person's wishes were forefront, the presumption that the person with a disability had the ability to choose where they wanted to live, and the persistent efforts to communicate with the person, even if communication took a long time. ASAN believes that silence does not mean absence when it comes to the opinions and preferences of people with disabilities.³⁸ A provider's present-day inability to determine a person's perspective does not mean that the person lacks a perspective.³⁹ Each of the attendees who described their work to us believed that people with communication-related disabilities have perspectives, wishes, thoughts, and dreams of our own and acted on that belief.

The transitions were also successful because each home was tailored carefully to the needs of the person with a disability. The summit participants did *not* assume that everyone with the same disability had the same housing needs, as that assumption likely would have led to failure. Instead they adhered as much as possible to the stated likes, dislikes, preferences, and opinions of the person with a disability.

Hana Solařová, a Project Manager at Lumos, an international organization working to end the institutionalization of children around the world, described how her organization used supported decision-making to prepare children with disabilities for life in the community. Lumos held "case conferences" that brought Lumos caseworkers, the child with a disability, and the child's supporters together to prepare to help the child move from an institution into the community. These interactive case conferences are designed to elicit the input and preferences of the child on where they would like to live, by presenting the material in the manner that is easiest for the child to understand.

However, as Solařová explained, the interactive case conferences are just one part of the process for preparing the child for life outside the institution. Lumos' staff ensures that all children, including children with disabilities, understand what it means to leave the institution and enter the community by introducing one aspect of life outside the institution at a time. It also introduces these concepts to previously institutionalized children with disabilities in forms that they will understand. Lumos introduces the real world to these children initially by explaining it using easy-read picture books⁴⁰ and diagrams, and later by photographs and slow, gradual contact with the world outside the institution. Solařová said that, often, the only home the child knows is the institution, and the child "expects to live in the institution until the end of life."

Lumos staff also advise the parents of the child (when Lumos intends to move the child back in with their parents) on how to make the child's new home more familiar and comfortable (e.g. asking the parents to use the same bath soap used at the institution). Lumos' staff are trained in a "comprehensive diagnostic method

³⁸ For a more detailed description of this perspective, and the source of the phrase "silence is not absence," which we used in a modified form in this paper, see Ruti Regan, Anachnu, When Listening is Complicated: Skills for Honoring the Individual Perspectives of Every Person with Disabilities, presentation at 16th Annual Developmental Disabilities: Update for Health Professionals Conference (March 2017), available at: <https://www.uctv.tv/shows/When-Listening-is-Complicated-Skills-for-Honoring-the-Individual-Perspectives-of-Every-Person-with-Disabilities-32191>.

³⁹ *Id.*

⁴⁰ "Moving to my New Home" is an easy-read picture book for children designed to show them what they can expect when they move from an institution into the community. It is available on Lumos' website in five languages at <https://www.wearelumos.org/resources/moving-my-new-home-0-14/>. Solařová also provided us with several more examples of Lumos' easy read pamphlets, which help children who have been in institutions for years learn everything from emotional regulation to the basic structure of the family in their country.

aimed at finding the level of communication of each child,” which helps them ensure the child understands the transition at hand to the maximum extent possible.

Gail Godwin, Executive Director of Shared Support Maryland, a support coordination service for people with disabilities, works with an older population but uses very similar methods. In one of our subsequent interviews, Gail Godwin provided us with an example where she helped to move a 25-year-old man, who had lived in an institution since he was a teenager, into housing in the community. According to Ms. Godwin, they spent “a lot of time getting to know him, understanding his preferences for things like temperature and favorite color and preferences for voice.” Without this effort to discover the man’s preferences and adhere the home to his needs, the man’s transition would likely have been unsuccessful. The man with a disability also hired his own staff and found his own roommate. Ms. Godwin says that the key to successful supported decision-making for people with disabilities is that you “cannot force it,” and that you must allow as much time for the person to respond as they need.

Barbara Brent, Director of State Policy at the National Association of State Directors of Developmental Disabilities Services (NASDDDS), spoke about the necessary process:

“Risk is not just about safety, but about making friends and what’s enjoyable for the person. Exploration is important. The community can be alien to people who have lived in institutions for most of their lives. [It is necessary to] translate what’s important to that different environment, such as by saying ‘It’s important that I be around a lot of people, but they don’t all have to live with me.’”

Policy Recommendations:

- ◆ Successful transitions from an institution into the community should not be rushed. They should occur methodically and involve careful planning and deliberation to ensure the transition is understood by the person with a disability and suits the individual’s needs.
- ◆ People with disabilities who have trouble communicating need to be given time to express their wishes and preferences.
- ◆ Presuming competence in supported decision-making means acknowledging and accepting that many people with disabilities do not communicate in the same way, or at the same speed, as people without disabilities. We recommend that support providers accept all behavior as a potential means of communication, and make every effort possible to reach the person with a disability.
- ◆ People with disabilities also need to be given the time and support services necessary to adjust to living outside the institution. Successful use of supported decision-making is not *solely* a matter of establishing effective communication.
- ◆ Successful transitions that use supported decision-making require a willingness to work with the person with a disability over the long term. People who have lived in institutions their entire lives may not have learned important independent living skills and may be frightened of community living at first. Supported decision-making can only aid in deinstitutionalization if supporters help people who have been institutionalized develop these skills.

Relationships and Natural Supports

Recommendation 1:

Peer modeling and peer support are critical when it comes to introducing persons with disabilities to supported decision-making. People who have been institutionalized benefit from examples of peers who have achieved independence. Advocates should promote the use of peer modeling and peer support.

Peer modeling and peer support programs have a critical role to play in deinstitutionalization. By providing institutionalized people with disabled role models who are successfully living in the community with supports, the former can see that they, too, are capable of community living. A peer can also introduce an institutionalized person to the self-advocacy and decision-making skills that are necessary if the person wishes to utilize supported decision-making.

Max Barrows, Outreach Director of Green Mountain Self Advocates (GMSA), strongly advocated for the widespread use of peer modeling and peer support programs at the summit. GMSA is made up of a network of 23 local groups throughout the U.S. state of Vermont, whose members are advocates with developmental disabilities. As Outreach Director, Max Barrows provides training, technical assistance, and support to self-advocacy groups in Vermont. He also provides support to GMSA's summits and leadership training programs. Barrows said:

“Peer to peer connections are very important. It helps people with disabilities get over the barrier of being afraid to speak up for themselves. If advice is coming from a peer, the person with a disability is less likely to feel the advice has been sugar-coated.”

Barrows says that supported decision-making must start young in order to be effective. Barrows says:

“We need to have conversations about supported decision-making with families of persons with disabilities. Education is key. There are too many people telling people what to do rather than giving them the information they need to make a decision.”

Barrows' insights are based in his experiences working with a large number of high school students with disabilities. GMSA hosted a Youth Summit in which young people with disabilities led and participated in activities that helped them learn self-advocacy and make decisions for themselves.⁴¹ Green Mountain Self Advocates also regularly presents a Vermont Leadership Series of trainings, jointly with the Vermont Developmental Disabilities Council and Vermont Family Network, in which self-advocates and their family members learn leadership and advocacy skills (including supported decision-making strategies) together.⁴² Family members are encouraged to help their child understand decisions but not to take over for their child.

Kapka Panayotova, one of the founders of the independent living movement in Bulgaria, Director of the Center for Independent Living - Sofia (CIL Sofia), and current acting President of the board of the European Network on Independent Living (ENIL), describes peer support as “one of the most powerful tools for change.” As the head of CIL Sofia, Panayotova runs a peer-led organization that has transitioned people with disabilities out of institutions. In her presentation at the Relationships and Natural Supports panel, Panayotova described a project (specifically the project at a group home in Lukovit, Bulgaria) in which CIL Sofia worked with young people with disabilities and attempted to move them from large group homes into the community.⁴³ The project made extensive use of peer supporters, who came to the group homes and taught their residents how

⁴¹ GMSA Youth Summit, Green Mountain Self Advocates <http://www.gmsavt.org/youth-summit/> (last visited May 14, 2018).

⁴² VT Leadership Series, Vermont Developmental Disabilities Council, <http://www.ddc.vermont.gov/vtleadershipseries> (last visited May 14, 2018).

⁴³ Orla Kelly, European Network on Independent Living, Peer Support for Independent Living: A Training Manual 15-18 (October 2014), http://www.enil.eu/wp-content/uploads/2012/06/Peer-Support-Training-Manual-Final_281014.pdf.

community living and independence could be achieved by people with disabilities, using their experiences as examples.⁴⁴

This was not to say that the involvement of CIL Sofia's peer supporters made deinstitutionalization easy or instantaneous. Panayotova said that the *previous* levels of social engagement and support that the young people experienced had a significant impact on how self-sufficient and independent they became. Young people who had been in "more open and social" group homes had an easier time transitioning, while those who had been in "more closed off" group homes still needed significant support several years after the move. She said that the process of teaching people how to advocate for themselves requires "showing in a very authentic way that you care about the person's needs, wants, aspirations, and desires. Showing this all the time." It requires "patience and persistence." CIL Sofia, made up of people with disabilities, is therefore able to act as "a bridge" between the community and institutionalized Bulgarians.

Policy Recommendations:

- ◆ Whenever possible, the government should directly fund peer training programs for people with disabilities. The programs should teach people with disabilities decision-making and leadership skills.
- ◆ Wherever possible, advocates should introduce people with disabilities to the idea of decision-making early. Where not possible, it may take more time to create a successful supported decision-making arrangement. However, is never too late to start making use of supported decision-making.

Recommendation 2:

Although paid long-term services and supports providers may sometimes need to act as supporters in supported decision-making, such arrangements should be limited, carefully monitored, and balanced with the use of friends and family as supporters in order to prevent conflicts of interest. Staff who provide health and support services to a person with a disability in a segregated setting (i.e. staff who work in an institutional or group home setting) should avoid becoming supported decision-making supporters.

Supported decision-making supporters are typically friends and family, who also may provide general support in the form of advice, emotional support, or at-home care. There was a lot of discussion at the summit about whether non-family services and supports providers could help people with disabilities make important decisions about everything from our health care to where we would live without having an immediate conflict of interest. There were also discussions about whether support service providers could establish a true, reciprocal friendship with a person with a disability. The term "relationships and natural supports" refers in part to friendships.

Some attendees felt that paid providers could help with decision-making. One of our summit participants argued, "Let's not discourage people becoming friends with their staff – isn't that just analogous to being friends with your coworkers? Can't this become a natural support relationship, even if it doesn't start as one?" She also noted that "There are places where there are no supports available except for friends and family, and if you want paid supports it's going to be those people getting paid to care for you." For example, in the United States, friends and family members of people with disabilities sometimes receive Medicaid funding to provide in-home services.

Other attendees, like Dohn Hoyle, Director of Public Policy at the Arc of Michigan, felt that allowing paid services and supports staff, who are paid to help the person with a disability perform activities of daily living, to help with decision-making would create an untenable conflict of interest.

44 *Id.*

One summit attendee voiced concerns about a potential conflict between the roles of the paid service provider and the supported decision-making supporter. She said that paid staff often understand their role using “a supervisory model,” in which they view themselves as responsible for the clients. She said that because of this, paid relationships have limits and boundaries that more natural relationships don’t need to have.

Sharon Lewis, Principal at Health Management Associates, asked:

“What is the right role of the professional? The idea of a facilitator or supporter, a deferential role, is different from the idea of a professional as a supervisor or ‘in charge.’ The difference from a policy perspective is if someone has a paid responsibility, that person has a legal liability – in some cases that makes them less likely to take a deferential role, allow dignity of risk, support the person as opposed to trying to make decisions for them.”

We strongly oppose the view that disability support professionals *should* have a supervisory role or that this role is a natural consequence of the paid relationship between a person and a support professional. Instead, we believe that disability service providers must honor and respect the decision-making rights and abilities of their clients. In some situations, however, enabling supporters to adopt a deferential approach to the people they support may require changes in policy, including changes in legal liability frameworks. In contexts in which paid supporters continue to view their role as supervisory, these supporters will not be appropriate decision-making supporters.

Overall, we conclude that paid providers of disability services and supports should be considered as potential supported decision-making supporters in some limited situations. Barring *all* forms of paid service providers from acting as supporters would likely be a barrier to supported decision-making for people who do not have immediate access to support from family, friends, or other natural supports such as faith communities or community centers (YMCA, youth organizations, etc.). In fact, because people who have been institutionalized for years are often socially isolated due to their unjust segregation from society, allowing only unpaid family and friends to be supporters could reduce the availability of supported decision-making as a tool for furthering deinstitutionalization and community integration.

However, if paid staff do become part of a person’s supported decision-making team or circle of support, the team should consider:

- (1) how long the service provider will act as the person’s supporter;
- (2) whether the service provider will help or hinder the person with a disability in finding more natural relationships and supports in the broader community of people without disabilities;
- (3) what kind of other services the staff person is providing and in what settings, if any;
- (4) the supporter’s approach to the support relationship and willingness to defer to the decisions of the person with a disability; and
- (5) which kinds of decisions the staff member will be supporting (for example, a staff member may only help with managing a budget but not larger decisions).

ASAN’s model supported decision-making legislation, designed for use in the United States, would allow “a person who provides independent living or home health services to the adult with a disability in a home-and community-based setting,” as defined by United States law, to become a part of a supported decision-making agreement, unless the provider works at a provider-owned or controlled residential setting “in which the adult with a disability resides and through which the adult receives care.”⁴⁵ Thus, paid supporters can be decision-making supporters if they are supporting someone in their own home, but not if they are staff at a group

⁴⁵ Autistic Self Advocacy Network, Model Legislation: An Act Relating to the Recognition of a Supported Health Care Decision Making Agreement for Adults with Disabilities (2014), <http://autisticadvocacy.org/wp-content/uploads/2014/07/ASAN-Supported-Decisionmaking-Model-Legislature.pdf>.

home or similar setting in which the person with a disability lives. ASAN made this distinction in its model legislation in order to account for conflicts of interest that may arise when a paid supporter is employed by the same provider that operates the individual's home. For example, staff at a group home may face pressure from their employer to steer clients toward decisions that benefit the group home.

Policy Recommendations:

- ◆ We agree that the concerns of many of the summit attendees about paid providers as supporters are warranted. Safeguards may ameliorate these concerns. There is a high risk of conflict of interest when the person who helps make legal and personal decisions is also the person providing support services, especially when the person providing these services works for a provider-owned or controlled residential setting. However, there are many situations, in the present-day U.S. and elsewhere, in which the only people available as supporters are disability support staff or family members being paid to provide disability support services. If we intend for supported decision-making to become a universally available, viable alternative to guardianship, paid providers and other personnel should be accepted for consideration as supporters when they are included in a manner that minimizes conflicts of interest.
- ◆ When considering the use of paid long-term services and supports staff as potential partners in a supported decision-making agreement:
 - Paid providers should, if at all possible, not be the only supporters in the person's circle of support. Their presence in the person's circle of support should be balanced by the presence of friends, health advocates, family members, and others.
 - Paid providers who are supporters should, wherever possible, help to facilitate the creation of unpaid supporters and new relationships in the life of the person with a disability that they are supporting. We encourage advocates to find ways to change law and policy, particularly reimbursement structures for services, so that they incentivize rather than de-incentivize the phaseout of paid providers as supporters.
 - Paid providers should consider time-limiting their participation as supported decision-making participants.

Recommendation 3:

We propose advocating for the establishment of service providers who are paid, on a temporary time-limited basis, specifically to help recently deinstitutionalized people (or other people with disabilities who have a limited number of friendships or relationships with family members) make decisions.

We considered many different solutions at the summit for helping people with disabilities who had few relationships and natural supports use supported decision-making, not just one. Some attendees considered advocating for the creation of a network of people who were paid *solely* to help people with disabilities make decisions. This role would be different from that of long-term support providers, who primarily help people with disabilities perform activities of daily living. Instead, this network would only be used when the person with a disability lacks friends, family members, or other individuals who could fully meet a person's decision-making support needs without conflicts of interest.

People who have been institutionalized for many decades sometimes lack strong connections with the broader community besides institutional staff. Although institutional staff may have conflicts of interest too great to help a person with a disability make their own decisions, institutionalized people *should* have the opportunity to use supported decision-making and maintain their autonomy. We cover situations in which non-institutional disability service providers *could* act as supported decision-making partners in Recommendation 2.

There are several countries that have programs that are similar (but not exactly identical) to the kind proposed in this recommendation. For instance, England and Wales of the United Kingdom have a system that uses professionals referred to as Independent Mental Capacity Advocates (IMCAs).⁴⁶ IMCAs were created by the Mental Capacity Act of 2005, which applies to England and Wales.⁴⁷ When a person with a disability in England or Wales lacks relationships and natural supports in the community, and lacks the legal capacity necessary to consent to certain major types of medical treatment, that person is appointed an IMCA.⁴⁸ The IMCA, who is trained in communicating with people who have significant communication difficulties, attempts to determine the person's preferences and to protect the person's rights.⁴⁹ While *neither the IMCA nor the person with a disability* are the final decision-maker in the contexts in which IMCAs are used (usually for medical decisions that require immediate action), the decision-maker is legally obligated to consider the information about the preferences of the person with a disability, as expressed by the IMCA.⁵⁰ The IMCA also has the right to challenge any decision made on the person's behalf that the IMCA believes goes against the person's best interests.⁵¹

A more exact parallel can be found in Sweden's legal mentorship and Personal Ombudsmen systems. In 1989, Sweden abolished plenary guardianship and replaced it with two other systems: a *legal mentor* system, and a system of *administrators*.⁵² Legal mentors are appointed by the Swedish local courts, but only with the consent of the person with a disability.⁵³ Legal mentors then can operate in a manner similar to someone holding a power of attorney, but ordinarily cannot take any non-routine action without the consent of the person whom

⁴⁶ Office of the Public Guardian, OPG606, Making decisions: the Independent Mental Capacity Advocate Service 6, (November 27, 2007), https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/365629/making-decisions-opg606-1207.pdf.

⁴⁷ *Id.*

⁴⁸ *Id.* at 11-13. People who have been detained under the Mental Health Act of 1983 cannot get an IMCA. They may be eligible to receive an Independent Mental Health Advocate (IMHA).

⁴⁹ *Id.* at 26.

⁵⁰ Medical Protection Society, Independent Mental Capacity Advocates (January 2013), <https://www.medicalprotection.org/docs/default-source/pdfs/factsheet-pdfs/mental-capacity-act-2005-series/mca-series---imca.pdf?sfvrsn=8>.

⁵¹ *Id.*

⁵² Leslie Salzman, *Rethinking Guardianship (Again)*, at 235-37. Sweden's administrators bear similarities to partial or limited guardians, although the person retains the right to vote and the administrator is (theoretically) legally required to discuss important decisions with the person with a disability.

⁵³ *Id.* at 235, 236 n. 243.

they serve.⁵⁴ The person with a disability may cancel the legal mentorship at any time.⁵⁵ Sweden's personal ombudsman system also bears a strong similarity to a system of paid supported decision-making supporters. Personal ombudsmen are a network of supporters in Sweden paid specifically to help people with psychiatric disabilities (*e.g.* depression, schizophrenia, bipolar disorder, anxiety, *etc.*) make decisions and access services in the community.⁵⁶ Personal ombudsmen do not make decisions on behalf of the person with a psychiatric disability.⁵⁷ Instead, they do whatever they can to help that person express their desires, needs, and preferences, in the context of getting that person the help they need.⁵⁸

Creating such a network would be a long-term rather than a short-term advocacy goal, as the infrastructure could potentially take years to develop. The idea also may be more feasible in countries with a well-developed long-term services and supports system, or countries with a long history of institutionalization. This is because it would be easier to identify who needs the service in such countries, as there would be a record of people with disabilities who need support to enter or remain in their homes or communities.

Policy Recommendations:

- ♦ Advocates should promote policies that would allow people with disabilities to hire paid supporters for the purpose of assisting with decision-making. We recommend that any such system be designed primarily as a time-limited measure for people with disabilities who either: (a) have been institutionalized for a long time; or (b) lack adequate relationships and natural supports in the community, such as family and friends or other potential supporters who could help with decision-making. Such a system would be an alternative to utilizing the person's present disability support providers as supporters. Such a system would have to be broadly accessible nationally, as accessible as paid substituted decision-makers and guardians are in some countries.
- ♦ While the system of paid supporters is being developed, advocates should request that policymakers implement training policies for paid supporters which ensure that they do not replicate the role of guardians. Their training should include: (1) ways to help the people with disabilities they serve develop systems of natural decision-making supports; (2) strategies for learning how people with disabilities make decisions; (3) strategies they can use to facilitate the development of decision-making and self-advocacy skills in their clients; (4) instruction on how to presume competence and avoid making assumptions about what a person with a disability wants; (5) instruction on how to avoid making decisions on behalf of the person with a disability instead of helping the person to make their own decisions; (6) training on common forms of communication used by people with communication-related disabilities (letterboards, sign language, assisted communication devices and typing devices, *etc.*); and (7) training on how to establish effective communication with people who do not speak to communicate or who communicate in ways different from that of people without disabilities.

⁵⁴ *Id.* at 236 n. 244. There *are* a couple of exceptions to the rule that the Swedish mentors cannot take any action without the consent of the person served (such as their ability to perform routine actions like paying bills or rent without consent and ability to act without consent when a person is deemed completely unable to make decisions), but this is generally true.

⁵⁵ *Id.* at 237.

⁵⁶ Socialstyrelsen, A New Profession is Born – Personligt ombud, PO, at 7, 8, 10 (2008), <http://www.personligtombud.se/publikationer/pdf/A%20New%20Profession%20is%20Born.pdf>.

⁵⁷ *Id.* at 16, 17.

⁵⁸ Socialstyrelsen at 16, 17, 26; *Innovative Policy 2015 on Independent Living: Sweden's Personal Ombudsmen*, Zero Project, <https://zeroproject.org/policy/sweden-2/> (last visited May 15, 2018).

Recommendation 4:

When a person with a disability appears to lack natural supports or relationships, those facilitating the person's move to the community should provide that person with opportunities to form reciprocal relationships. Community organizations and clubs are important resources for people with disabilities who have few natural supports due to isolation.

Some attendees discussed successfully helping people with disabilities with few natural supports build relationships by introducing them to local community organizations. For example, a person's supported decision-making circle of support could introduce them to programs at the local YMCA, and to the YMCA's members. We believe that this strategy may have some benefit for people who have limited connections to their communities, but do have *some* friends, family, or disability service providers who can act as supporters. When a person does not have existing friends or family or disability service providers who can assist them, paid disability service providers or decision-making supporters could also introduce people with disabilities to local community organizations.

Offering people with disabilities opportunities to interact with the community may increase our levels of self-determination and independence. Monique Dujue Wilson, a parent advocate and the START Parent Leadership Development Initiative Regional Coordinator for the North Essex County Council for Young Children, as well as Project Coordinator for the Statewide Parent Advocacy Network (SPAN) in New Jersey, said that supports were helping her son broaden his connections with the community:

"The community has been where all of my son's inclusive opportunities and life experiences occurred. Direct support people do continue to assist my son. They identify and support all of his preferences and choices. Over time, he has expanded his network of relationships and natural supports so that they include the community. [He now has] options that not only consist of agency, organizational support and DSP support but meaningful connections with [people in the community,] like a barber at the barbershop, someone at a favorite restaurant or store, attending community events create local networks. Although my son is seen as nonverbal and has behavior challenges that create isolation and have led to several hospitalizations, he is also very social and interested in meeting new people. Through my son's present connections and community relationships he is becoming more independent in his own decision-making and problem solving."

Relationship-building in the community *should* start at an early age if possible, and should not be neglected simply because the person has a disability. Sharon Lewis, Principal at Health Management Associates, noted that parents should ensure that their child with a disability is fully integrated within the community and can take part in community activities at an early age, by "making sure kids are being introduced to other kids at school, making sure they do chores at home, [and] making sure they do things outside of home and school... Supported decision-making can't happen without relationships."

Policy Recommendations:

- ◆ Advocates should use their organizations to create opportunities for people with disabilities to interact with community organizations, such as youth groups, associations of people with similar interests, and churches.
- ◆ People who are part of the support network of a person with a disability should help that individual interact with other people and build relationships with their community.
- ◆ Whenever possible, supporters and providers should encourage people with disabilities to direct what interactions we wish to have and with whom. This will help people with disabilities gain the lasting relationships necessary for supported decision-making.

Recommendation 5:

We recommend that people with disabilities make use of multiple supporters for the purposes of supported decision-making. Multiple supporters allow the person with a disability to use supported decision-making even if a primary supporter is not always available. Multiple supporters may also improve the quality of support, since supporters could have differing perspectives and areas of expertise.

Most summit attendees agreed that there should be multiple supporters. Bob Fleischner, Assistant Director at the Center for Public Representation, said that there should be “a median number” of around 3-5 supporters. For example, the Center for Public Representation and the service provider Nonotuck partnered to create a supported decision-making pilot project, which allowed nine people with intellectual disabilities to use supported decision-making instead of guardianship.⁵⁹ Supported decision-making in the pilot project was used most frequently for healthcare decisions, and second most frequently for financial decisions.⁶⁰ The participants in the project, both people with disabilities and supporters, found that the use of multiple supporters was beneficial.⁶¹ Sometimes, the person with a disability arranged their supporters in a hierarchical, successive fashion, which allowed whichever supporter was currently present to help the person if the person’s first choice of supporter was not available.⁶² In other cases, a group of supporters worked together to help the person understand and make decisions.⁶³ The supporters encountered few difficulties, and the people they supported were glad that they could make their own decisions but had support when they needed it.⁶⁴

Several attendees suggested that people using supported decision-making should have a group of supporters where each supporter helps the person understand and make a specific type of decision (a doctor for medical decisions, a lawyer for signing contracts, *etc.*) rather than a single supporter who helps the person understand every decision. One attendee used the metaphor: “Would you hire a lawyer to fix your car?”

Ruthie Marie Beckwith, Executive Director of TASH, highlighted the difficulty involved in creating groups of multiple supporters by describing her experience creating “microboards,” a type of circle of support:

“I worked for the microboard association for [over] ten years, and I may have supported 300-400 circles in that time, and each one is very time consuming and requires a lot of supports to set up. It really is a “one person at a time” approach, and some people’s circles need to be larger than others. States are often not happy about that, they want a simple ‘add water and stir’ process.”

She also said that at the start, there need to be at least monthly meetings of the circle of support. As a result, it can be “difficult to get people to invest” in such a process. Summit attendees did not come to concrete conclusions on how to ensure that supporters engage in the “time consuming” process of setting up supported decision-making arrangements instead of seeking a guardian.

59 Elizabeth Pell and Virginia Mulkern, *Supported Decision Making Pilot: Pilot Program Evaluation Year 2 Report, Prepared for the Center for Public Representation and Nonotuck Resource Associates, Inc.* 4 (2016) http://supporteddecisions.org/wp-content/uploads/2016/11/Evaluation-Year-2-Report_HSRI-2016_FINAL-2-1.pdf.

60 *Id.* at 13.

61 *Id.* at 19, 20.

62 *Id.* This method was described as a “successive” decision-making approach in the report, such that if the person’s preferred supporter was not available, the second most preferred person would support the beneficiary, and so on.

63 *Id.* at 13, 20.

64 *Id.* at 19, 20.

Policy Recommendations:

- ♦ Advocates should encourage the use of multiple supporters in supported decision-making wherever possible. Multiple supporters can form a “hierarchical” group of supporters, so that the person could use supported decision-making even when their primary supporter isn’t available. A person with a disability could also form a supporter group where each supporter helps the person understand a different type of decision (for example, a doctor who helps the person understand medical decisions), or form a circle of support in which the group of supporters work together to help the person make all decisions. The use of multiple supporters also makes it less likely that supporters will become too similar to guardians. With only one supporter, the supporter might influence all the decisions made by the person with a disability too extensively, becoming more like a guardian. If multiple supporters are used, no one person will advise the person with a disability on every decision they make. This makes it less likely that any one supporter will gain excessive influence over the decisions of the person with a disability.

Healthcare

Recommendation 1:

Supported decision-making in health care should include a cognitively accessible method for helping people with disabilities understand the important aspects of the decisions we are making.

Before a person can undergo any non-emergency medical treatment, they must give informed consent to the treatment. If a person with a disability does not understand what the treatment does in a general way, and the potential risks and benefits of that treatment to them, informed consent does not exist. Therefore, if supported decision-making is to be effective in the healthcare context, we recommend that it include a cognitively accessible method for explaining medical treatments to people with intellectual and developmental disabilities.

Any method used must be able to convey the pros and cons of a particular medical treatment even in a situation where the decision is **complex** and/or **time-sensitive**. For example, supporters could need to explain the risk and benefits of a particular pill that stabilizes heart rate to a woman with a disability who is pregnant and has a heart condition. Deciding whether or not to use the pill would be complex, as the pregnant woman would have to consider both the benefit of the heart rate pill and its effect on her unborn child. It would also be a time-sensitive decision, as an unstable heart rate may cause serious harm in the short term.

Supporters need not explain the exact science behind and purpose of every treatment. People without disabilities are rarely provided precise information on how each treatment they receive works. Instead, they are given general information that allows them to weigh the pros and cons of a particular medication or therapy. For instance, the hypothetical pregnant woman with a disability and a heart condition could be told that a pill she could take would keep her heart rate stable, but could potentially cause a miscarriage. The woman would also have to be informed of any other potential side effects of the pill on either her or her child. She could be offered visual supports to understand the likelihood and seriousness of good and bad results. This information alone would allow the woman to weigh her options, with the help of her supporter, and make a decision. The hypothetical woman would not necessarily need to know exactly how the pill worked, or exactly why it could potentially cause a miscarriage, to make a decision about whether she should use it.

Supporters could (and likely should) build these explanations into the supported decision-making process. Lynne O'Hara, the Executive Director of the WITH Foundation (formerly the Special Hope Foundation) at the time of the summit, presented a video at the summit, "Gabby's Story," that depicts a successful example of supported decision-making in healthcare.

In the video, a young woman, Gabby Castro, who has spina bifida, describes how she decided to receive an eye surgery despite the risks involved.⁶⁵ Castro's supporters consisted of her mother, her primary care provider, and Mark Williams, a health advocate from The Arc of San Francisco's Health and Wellness program.⁶⁶ Initially, Castro was extremely afraid of the surgery, given that she was told by her supporters that there was only a 50 percent chance that her eyes would get better instead of worse, and many risks.⁶⁷ Castro said that when she heard that, she "just shut down," because she did not want to lose her sight.⁶⁸ Gerri Collins-Bride, her primary care provider, said in the video: "The decision-making around this was to help [her] see what the benefit of- of having these procedures done, and what was the risk, and also trying to focus on, kind of the light at the end of the tunnel."⁶⁹

Mark Williams said in the video: "Talking about the risks to the surgery and the benefits--- At the beginning, she was only thinking about the dangers of it."⁷⁰ Castro followed up with: "We finally came to a decision just talking about it ... I am so happy that I did decide to have my surgery" and goes on to explain that the surgery eliminated the double vision that she had been experiencing.⁷¹ This video also highlights that all that is necessary for informed consent is a basic understanding of risk and benefit.

Policy Recommendations:

- ◆ Supporters should have a system in place for explaining the pros and cons of health care decisions to a person with a disability, and for obtaining informed consent to a treatment. The person's primary care provider must be involved in the delivery of this information.

Recommendation 2:

Several summit participants identified a lack of disability specialist care and lack of disability-friendly care as barriers to healthcare in the community. We propose that providers with a lack of disability-related medical experience be networked with individuals who have that experience.

Supported decision-making in healthcare is only useful when people with disabilities are able to find health care that meets our needs. During the summit's health care breakout discussions, many groups pointed out the lack of disability-competent primary care providers. A primary care provider may be unfamiliar in particular with the complex, intersecting health needs of a person with a developmental disability, such as an autistic person who has muscle and joint abnormalities. Lack of support for such health needs in the community is one of the many reasons people with disabilities remain in institutions to this day and is often used as an excuse to keep people with disabilities segregated.

Several participants explained that some of the most successful healthcare transitions to adulthood they had encountered occurred in rural communities in the United States. This is because, in such communities, there

⁶⁵ *Supported Decision Making: Gabby's Story*, created for the WITH Foundation, available at: <https://www.youtube.com/watch?v=UInXHR1YHMg>.

⁶⁶ *Id.*

⁶⁷ *Id.*

⁶⁸ *Id.*

⁶⁹ *Id.*

⁷⁰ *Id.*

⁷¹ *Id.*

is continuity of care between pediatricians and adult health care practitioners, who both know one another *and* have experience treating people with disabilities. The two are able to share knowledge and experience with one another. Summit attendees suggested that advocates should, in their own countries, fund programs and initiatives that allow for opportunities to network healthcare providers with different expertise.

Advocates should also consider networking healthcare professionals with disability rights advocates. For example Andrea Parra, then a Practitioner-In-Residence at the Immigrant Justice Clinic at American University, Washington College of Law, used this strategy in her reproductive rights project. Her project connected Profamilia, Colombia's major advocacy organization for reproductive health rights, to her group of disability rights advocates. Profamilia also provides a number of reproductive health services.

In the past, Profamilia had regularly performed sterilizations on people with intellectual and developmental disabilities, and advised parents of disabled children to sterilize their children. The disability rights advocates provided Profamilia with the perspectives of people with disabilities on family planning and involuntary sterilization. They showed Profamilia that sterilizing people with intellectual and developmental disabilities without our consent was wrong. The disability rights advocates and Profamilia were able to work together to advocate for the reproductive decision-making rights of people with disabilities. During her presentation, Parra said that one of the key reasons the project was successful was because she and her team took the necessary time (approximately four to five years) to introduce disability issues to Profamilia, and trained them personally on how to non-coercively serve people with developmental disabilities.

Policy Recommendations:

- ◆ In order to reduce institutionalization, people with disabilities must be able to access disability-competent health care in the community. This can be particularly difficult if a person has both developmental disabilities and complex medical conditions. Advocates should consider supporting initiatives and service delivery systems that network disability-competent health care practitioners with practitioners who lack this knowledge.

Long-Term Services and Supports

Recommendation 1:

Given that self-directed long term services and supports are a critical component of self-determination for many people with disabilities, we recommend that advocates promote the use of support coordinators.

Self-directed or consumer-directed services are services where people with disabilities possess the authority to control either the type of support services we receive, who or what provides these services, or both.⁷² People using self-directed services in the United States usually have the authority to recruit, train, hire, or fire their support staff (which the United States' Centers for Medicare and Medicaid Services (CMS), a health agency, calls "employer authority").⁷³ They sometimes have the ability to control how the funds used to pay for their support services are spent.⁷⁴

Self-direction of one's own support services is critical for the self-determination, independence, and integration into the broader community of people with disabilities. This is because many people with disabilities need support services in order to perform everyday tasks. A person who cannot direct which support services they receive and when they receive them will often have a large part of their life — where they live, what they do

⁷² *Self-Directed Services*, Centers for Medicare and Medicaid Services <https://www.medicare.gov/medicaid/ltss/self-directed/index.html> (last visited May 15, 2018).

⁷³ *Id.*

⁷⁴ *Id.*

during the day — dictated and controlled by someone else.⁷⁵ If the person can direct when and where they receive services, they can also direct how they will spend their days and live their lives. Additionally, self-directed services enhance the self-determination, independence, and the health and welfare of people with disabilities.⁷⁶ Using supported decision-making for long-term services and supports necessarily involves self-directed support services.

Many people with disabilities may require *assistance* when deciding which support professionals to hire and use, and how to fund our services and supports. In some countries at the summit, there were hundreds of different organizations and professionals providing support services to choose from. In other countries, there were only a few specific types of community-based support services available and they were not self-directed. Acquiring long term services and supports, even in countries where options are plentiful, may be difficult. In the United States, most community-based long term services and supports are funded through state Medicaid programs, which typically have complex eligibility requirements and paperwork that would be difficult for any person to navigate without assistance.⁷⁷

We therefore recommend that advocates consider promoting the use of support coordinators. Support coordinators are organizations or people who act as buyers or negotiators of long-term services and supports for people with disabilities. Their services mostly involve organizing supports for a person with a disability, such as by helping the person locate personal attendant services that they want to use, rather than providing these services directly. The ideal support coordinator has no or few conflicts of interest in their organization and respects the self-determination of the people with disabilities they serve. If public funding were used to fund support coordinators as well as providers, it could be a way of “scaling up” supported decision-making principles so that such arrangements can aid a broader group of people with disabilities.

One example of a services and supports coordinator is Shared Support Maryland. Shared Support Maryland serves over 90 people statewide in Maryland. All of its clients live in the community, and many transitioned from restrictive group homes and day programs into their own apartments. Shared Support Maryland helps its clients locate the support staff they want by screening and referring people, with the person with a disability making the final decision on who supports them in all cases.

Gail Godwin, the Executive Director of Shared Support Maryland, provided ASAN with this example of Shared Support Maryland’s services during her follow-up interview:

Jonathan⁷⁸ just graduated from high school. Jonathan works with a support team in order to make decisions. The support team gives him the time he needs to make thoughtful decisions instead of cutting him off. Jonathan wants to set aside time to exercise during his day. One of his support staff goes to a nearby college, and they were able to balance the support staffer’s class schedule with Jonathan’s desire to exercise. If Jonathan had instead been forced to pick from a limited list of supporters offered by a provider, it is possible that none

⁷⁵ Matthew P. DeCarlo, Implementation of Self-Directed Supports for Individuals with Intellectual and Developmental Disabilities: A Political Economy Analysis 17, 18, 19 (May 9, 2016) (Ph.D. dissertation, Virginia Commonwealth University) (on file at VCU Theses and Dissertations, Virginia Commonwealth University) (“Traditional service models afford the agency providing services the power to determine a participant’s daily life experience ... Although individuals with disabilities are living in the community, their lives were still to a great degree controlled by private agencies ... ”); Michelle Putnam & Lex Freiden, *Sharpening the Aim of Long-Term Services and Supports Policy*, 24 Public Policy & Aging Report 60, 61-63 (2014) (explaining that people with disabilities are often denied the right to make even the most basic choices about their lives, and indicating that self-directed long term services and supports allow them to have a greater amount of choice over their lives).

⁷⁶ Matthew P. De Carlo, Implementation of Self-Directed Supports for Individuals with Intellectual and Developmental Disabilities: A Political Economy Analysis at 51-54.

⁷⁷ See *Long Term Services and Supports*, Centers for Medicare and Medicaid Services, <https://www.medicaid.gov/medicaid/ltss/index.html> (last visited May 15, 2018); *Home and Community Based Services: Authorities*, Centers for Medicare and Medicaid Services, <https://www.medicaid.gov/medicaid/hcbs/authorities/index.html> (last visited May 15, 2018).

⁷⁸ Note: The name of the person Shared Support Maryland is supporting has been changed to protect that person’s privacy.

of the people available could meet his scheduling needs. He might have become either unable to utilize support services while he was exercising or unable to exercise.⁷⁹

Dohn Hoyle reported that a large organization for which he serves as a board chair, Community Living Services Inc., also acts as more of a support coordinator than a provider. The organization had formerly *provided* services and supports (in restrictive group homes), but had transitioned to *coordinating* supports, making it an excellent example of how an organization can transition from a quasi-paternalistic agency-directed model to one that instead supports the rights and autonomy of its clients.⁸⁰ Mr. Hoyle said that Community Living Services Inc. “does supports coordination for a great number of people and monitors contracts to make sure they get delivered. We’ve now closed 165 group homes [that CLS had previously operated], because that’s just a mini-institution. Group living was clearly not what any of them wanted.”

Policy Recommendations:

- ◆ Disability rights advocates should promote and advocate for the use of community-based service coordination agencies that help people manage the home and community-based services they receive rather than act as a one-stop shop for all services.
- ◆ If their country funds long-term services and supports systems, advocates should consider lobbying for the funding of supports coordinators as well as long-term services and supports providers.

Recommendation 2:

We recommend that advocates promote the creation of records showing: (a) what decisions a person with a disability has made in the past and (b) what activities of daily living the person has performed and in what contexts. We recommend the use of documentation mechanisms that enable the transfer of this information between long-term services and supports providers.

Background for This Recommendation:

Julia Bascom, ASAN’s Executive Director, said at the summit that we have an “ethical obligation to document” the ways in which people with disabilities communicate choices, preferences, and decisions. People with disabilities communicate our thoughts and feelings in a wide variety of different ways.⁸¹ We may communicate by typing, by pointing to letters on a letterboard, by using sign language, by using a wide variety of assistive and augmentative communication (AAC) devices, by using specific video clips or sound bites to convey information, or by indicating our intent using expressions, gestures, or emotions.⁸² ASAN’s toolkit produced for the University of California’s Office of Developmental Primary Care, “Everybody Communicates: Toolkit for Accessing Communication Assessments, Funding, and Accommodations,” describes some of these ways in detail and how people with disabilities and our families can access funding and services that help teach people with disabilities alternative forms of communication and make them more widely available.⁸³

⁷⁹ Shared Support Maryland provides a few more examples on their “Success Stories” page: <http://sharedsupportmd.org/success-stories/>

⁸⁰ *Our History*, Community Living Services Inc., <http://www.comlivserv.com/index.php/about/our-history-1> (last visited May 15, 2018).

⁸¹ Autistic Self Advocacy Network, University of California San Francisco Office of Developmental Primary Care, *Everybody Communicates: Toolkit for Accessing Communication Assessments, Funding, and Accommodations*, <http://odpc.ucsf.edu/communications-paper> (last visited May 15, 2018).

⁸² *Id.*

⁸³ *Id.*

However, without *records* of the specific ways in which a person communicates their decisions, incoming long-term services and supports staff often underestimate that person's abilities and ignore that person's communication methods. They may assume that the person is not communicating at all. This is particularly likely to happen in countries where there is an extremely high turnover of the staff who provide services and supports to people with disabilities.⁸⁴

People who lack an effective communication method--or whose communication goes unrecognized--are often stigmatized and seen as incapable of having opinions or making choices. If disability support staff underestimate a person's capacity to make decisions and communicate, that person may experience significant negative consequences. For example, if a person with a disability is incorrectly judged to be unable to communicate or make decisions about activities of daily living (ADLs),⁸⁵ they may receive unnecessary care.⁸⁶ They may even be moved into an unnecessarily restrictive setting.⁸⁷

Furthermore, many of the ways in which the ability to make decisions is traditionally assessed are flawed. For example one capacity-measuring assessment for adults at risk of guardianship, the Decision-Making Instrument for Guardianship (DIG), tests whether the person with a disability has the capacity to make decisions about *hypothetical*--not actual--problems that would occur during the course of everyday living.⁸⁸ This may cause the evaluator to significantly underestimate the person's true capacity, especially for individuals who have trouble responding to hypotheticals but may perform well in a real world situation. Many autistic people and other people with developmental disabilities fit this description. Clinicians may evaluate a person's capacity to make decisions solely by asking the person's family members, who could have conflicts of interest.⁸⁹ These assessments also assume that the person with a disability is *communicating* in a way similar to that of people without disabilities, and may vastly underestimate the decision-making ability of people who use other means of communication.

One of the solutions that summit attendees proposed to this problem was keeping a record showing what decisions the person has made in the past and in what context. The record in question must:

- be centralized and accessible, so that anyone who needs the information (including the person with a disability) can access it, provided that the person with a disability has given their consent to such access;
- be cognitively accessible to the person with a disability;
- be easily accessible and immediately available to the person's incoming support staff, with the consent of the person with a disability;
- list the specific methods that the person uses to communicate their thoughts and opinions and in what context;

⁸⁴ Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, *The Supply of Direct Support Professionals Serving Individuals with Intellectual Disabilities and Other Developmental Disabilities: Report to Congress* 15, 16 (2006), <https://aspe.hhs.gov/system/files/pdf/74651/DSPsupply.pdf> (indicating that direct support professional staff turnover is often extremely high and has a large role to play in the number of staff members available to provide care to people with disabilities).

⁸⁵ Activities of daily living (ADLs) are tasks that people with and without disabilities need to be able to do in order to live in the community. Many people with disabilities may need support services in order to perform one or more of these tasks. This terminology is mainly used in the United States. The six main ADLs are: eating, bathing, dressing, toileting, transferring (walking) and continence.

⁸⁶ See James M. Lai & Jason Karlawish, *Assessing the Capacity to Make Everyday Decisions: A Guide for Clinicians and an Agenda for Future Research*, *American Journal of Geriatric Psychiatry*, Feb. 2007, at 102, 103. This article is specifically discussing issues of assessing capacity in older adults with cognitive disabilities they developed later in life, but many of its statements would also apply to people with intellectual and developmental disabilities.

⁸⁷ *Id.*

⁸⁸ James M. Lai and Jason Karlawish, *supra* note 47, at 104.

⁸⁹ *Id.* at 105.

- include a record of every major decision (such as where to live or who to have support them) known to have been made by the person with a disability in specific detail, and the date and time of that decision;
- ensure that the person with a disability has the ability to decide which information is and is not included in the record; and
- include detailed examples showing how the person usually makes minor decisions (such as deciding what to eat for lunch, decisions on how they will spend their free time, etc.).

The documentation (and the information within) must also actually be transferred from one group of staff members or service providers to the next. If the information is not read, or it is never received by incoming support staff, it is effectively useless. One way to ensure that the information is transferred could be to require that incoming staff read the files relevant to each person that they serve as part of their staff training. Another way may be to create laws or regulations that require that long-term services and supports providers create, maintain, and transfer this information.

Before this information can be shared, consent must first be obtained from the person with a disability. The information contained in the record we recommend would at times contain protected health information, as well as sensitive personal information about the person with a disability. Before the information is transferred, the person with a disability should be asked whether or not they wish to sign paperwork that gives the person's disability service providers access to this information. This paperwork would include Health Insurance Portability and Accountability Act (HIPAA) authorization forms.

Such a system could improve the quality of care provided to a person with a disability by showing what the person is capable of doing independently, thus making it less likely that a person would receive standardized care ill-suited to meet their actual needs. The records may also reduce the likelihood of institutionalization when the person's primary support providers change (or pass away, if the person is receiving support from a family member or friend).

Such a system may not be universally feasible. Summit participants felt that, in countries that historically have not provided long-term services and supports outside institutions, it would be more practical to focus on developing community-based service models before the country develops such records.

Policy Recommendations:

- ♦ Countries with a history of funding long-term services and supports outside institutions should develop a system to record the decisions and communication methods of a person with a disability. This system will make it less likely that the communication form used by a person with a disability is ignored or forgotten, and will improve the efficiency of long-term services and supports delivery.

Recommendation 3:

Making decisions about what kind of long-term services and supports one wants, and therefore using supported decision-making for long-term services and supports, is impossible when a person has no choice but to receive these supports in segregated and institutional settings. Advocates should promote Money Follows the Person-style approaches globally, and work to eliminate regulatory or administrative barriers to community-based long-term services and supports.

Many international summit attendees noted that in their countries, long-term services and supports were provided only in institutions. Dr. Şehnaz Layikel, founder of the mental disability rights organization RUSIHAK in Turkey, described a movement from bigger institutions to smaller institutions, rather than any meaningful deinstitutionalization. RUSIHAK, founded in 2006, was the country's first-ever rights-based advocacy organization for people with mental disabilities, and remains the only organization campaigning for legal capacity reform in Turkey.⁹⁰ RUSIHAK is committed to the proper implementation of Article 12 of the CRPD in Turkey. Dr. Layikel made the following additional comments on that subject in her follow-up interview:

“We focus on the convention, especially Articles 12 and 19. And mainly on deinstitutionalization. We try to make it understandable and advocate for its use. RUSIHAK has been very successful in raising awareness of the terrible conditions inside institutions in Turkey. RUSIHAK produced and directed an extensive documentary showing what the conditions in the institutions were. ...we also do webinars, conferences, and make other efforts to raise awareness in Turkey.”

RUSIHAK has, within the limits of the current Turkish law, promoted self-determination and decision-making rights for Turkish people in institutions. It created a “client council” at one of Turkey's largest psychiatric hospitals, at which patients have been able to voice their opinions on their care and advocate for better care.⁹¹ RUSIHAK's efforts have improved the self-determination and quality of care available at psychiatric hospitals in Turkey.⁹² RUSIHAK has, in the past, created draft policies and laws on mental health which were submitted to and considered by the Turkish Ministry of Health.⁹³

Dragana Ćirić Milovanović, Director of Disability Rights International's office in Serbia and of the Mental Disability Rights Initiative (MDRI), describes a similar situation in her country. She said that “in Serbia, really the only ‘support’ is in institutions. There's no kind of systemic support structure at all.” She also said: “We have a few supported living programs and personal assistants.” More recently, Ms. Milovanović, as head of Disability Rights International's Serbian branch, helped at least four provider organizations develop supported decision-making models for their clients. MDRI-Serbia has additionally produced a number of comprehensive briefs that describe the legal capacity framework in Serbia and discuss ways that the country could utilize supported decision-making on a national scale.⁹⁴

Many summit participants were interested in instituting “Money Follows the Person” (MFP) policies in their countries. Under Money Follows the Person policies, when people with disabilities in institutions leave these settings, the money that would be used to fund their care in institutions is repurposed towards their care in the community. The United States, for instance, has a national Money Follows the Person demonstration program. This program uses Medicaid funds (which often fund long-term services and supports in institutional settings) and puts that funding toward helping people with disabilities who previously lived in institutions

⁹⁰ Nalan Erkem et. al., European Union PERSON Project, *Country Report on Legal Capacity: Turkey*, at 27 (Sep. 5, 2016), http://www.eu-person.com/publication/person-country-report-turkey/wppa_open/.

⁹¹ MMH Fellow, *Sehnaz Layikel*, *RUSIHAK mental health care in Turkey*, English, Boehringer Ingelheim, Ashoka (2012), <https://www.makingmorehealth.org/shared-value/mmh-fellows/sehnaz-layikel>; *Sehnaz Layikel*, Ashoka, <https://www.ashoka.org/en/fellow/sehnaz-layikel> (last updated 2012).

⁹² *Id.*

⁹³ *Id.*

⁹⁴ These briefs are available on MDRI-Serbia's website in English at: <https://www.mdri-s.org/publication-english/>

receive the services they need in the community.⁹⁵ It also helps the state revise policies that would prohibit the state from funding long-term services and supports in community-based settings.⁹⁶ Additionally, MFP funds transition planning and up-front expenses, as well as services and supports, that help people transition from institutions into the community.⁹⁷

Implementing MFP-style approaches may be difficult, depending on the type of aid the country provides to people with disabilities. Administrative barriers are common. Paula Méndez Azuela, Human Rights Advisor at the Mexican Supreme Court, expressed strong interest in implementing a similar program in Mexico, but noted that the government's current stipends for people with disabilities do not work in this way. The country does not provide stipends "on a person by person basis."

Administrative barriers to community-based long-term services and supports exist in the United States as well. In the United States, Medicaid funding for home and community-based long-term services and supports is primarily available through waivers, which "waive" provisions in Medicaid law that only allow Medicaid to fund long-term services and supports if these supports are provided in an institutional or nursing home setting. Long waiting lists for these waivers and limited funding ensure that only a few thousand people ever receive services in the community. Revising Medicaid law so that institutional care is no longer the default would eliminate this problem, but a revision of the law would be extremely difficult.

Policy Recommendations:

- ♦ Advocate for disability services funding for specific *people* or populations of people with disabilities rather than funding for the *settings* that some people with disabilities reside in. This is often referred to as a "Money Follows the Person" funding structure.

Conclusion

Our summit raised many questions about how best to implement and use supported decision-making. It also brought in many new ideas about how supported decision-making can help people with disabilities become full participants in our communities. We debated in which ways supported decision-making was useful given a particular country's needs, whether supported decision-making could genuinely improve the quality of life for people with disabilities, whether there was enough infrastructure in place to support the often time-consuming process of determining the wishes of someone with a communication-related disability, and whether we should address a country's other disability-related issues before implementing supported decision-making. The discussion often led us to discuss multiple elements of community integration simultaneously, rather than discussing each element as a separate issue. Samantha Crane, ASAN's Director of Legal and Public Policy, noted, "if you lose control of one aspect of your life, you lose control of all of them. They're all intertwined with one another. I hope that we can join together and take a holistic approach to these problems." ASAN hopes to do just that in its future projects.

We also agreed on the following general points about supported decision-making and deinstitutionalization:

⁹⁵ Eric D. Hargan, Report to the President and Congress The Money Follows the Person (MFP) Rebalancing Demonstration 2, 3, 4, 6, 7 (June 2017), <https://www.medicaid.gov/medicaid/ltss/downloads/money-follows-the-person/cmfp-rtc.pdf>. Beneficiaries are eligible for home and community based long term services and supports through MFP specifically for up to a year after the transition. However, the services provided are services the beneficiaries would remain eligible for independent of their status as MFP participants. MFP's purpose is to transition beneficiaries from receiving these services in institutional settings to receiving them in the community.

⁹⁶ *Money Follows the Person*, Center for Medicare and Medicaid Services, <https://www.medicaid.gov/medicaid/ltss/money-follows-the-person/index.html> (last visited May 15, 2018).

⁹⁷ *Id.*

- Supported decision-making and person-centered planning arrangements tailored to a person's individual needs are always more effective than generic, one-size-fits-all approaches. "One decision at a time" may be best for people with disabilities who take a great deal of time to make each decision. This process is time-consuming but necessary if we are to truly get people out into the community. People who successfully moved from an institution into the community almost always did so due to an intensive planning process that took time and effort. This process should itself be government-funded.
- There should be more than one supporter, and more than one way to obtain a supporter. Sometimes, paid supporters might be necessary when a person leaving an institution has been isolated from their community for years. Supporters ideally should have different expertise from one another and should cooperate as a group. Supporters should never behave like guardians.
- Advocates should promote the funding of support coordinators as well as support providers. Support coordination is a promising practice that allows persons with disabilities to plan our own supports. By its very nature it also acts as a deinstitutionalization aid, as funding for long-term services and supports could then be divorced from specific service providers.
- Community engagement and natural supports are crucial, both from peers with disabilities and from the community. Advocates should put more emphasis on helping those without natural supports develop them.
- Cultural context is important for successful deinstitutionalization. Interactions with our international attendees revealed that every element of community integration we examined at the summit had to be placed in its cultural context to be useful in a particular country. Supported decision-making is built on the premise of independence and autonomy, the meaning of which may vary depending on the country. To be universal, supported decision-making must be presented as being about the ability to direct one's own choices and one's own life as well as being about independence.
- There should be a system that documents the way in which people with disabilities communicate our decisions and preferences. Without these records, support staff and other supporters may misinterpret us or fail to recognize that we are making choices.
- We should work with non-disability-rights focused parts of our communities and network those knowledgeable in disability rights with those who know little about it (*i.e.*, connecting affordable housing organizations with disability rights organizations, or connecting clinicians with experience treating people with developmental disabilities to rural doctors). This will spread knowledge of supported decision-making to a broader array of people.

All summit participants also agreed on one other thing: in all countries and in all contexts there must be a "cultural shift" in the way that we think about people with disabilities. Many summit attendees expressed disappointment that, in 2016, all across the globe, people with disabilities were not considered full citizens, lived in settings that isolated us from society, and could not make our own choices. As Paula Méndez Azuela said, "We need to change attitudes--- In the government, among families, among society as a whole."

What we need is a different culture for supported decision-making than we have had for guardianship. The summit revealed the high risk that supported decision-making, if treated like a service rather than a right, will be perverted towards provider needs the way guardianship has been. Supported decision-making can be both a natural part of life and a legally recognized arrangement that people with disabilities can use to make decisions. **It starts with us.**