

“The Best Outcome We’ve Had”: Key Themes From A Self-Advocate Summit On Community Living

STATEMENT OF PURPOSE

This report describes and examines themes discussed during a self-advocate summit on community living for people with intellectual and developmental disabilities, or I/DD. The Community Living Summit, a two-day moderated discussion, was hosted by the Autistic Self Advocacy Network (ASAN) and funded by the University of California-San Francisco’s Community Living Policy Center.

The purpose of the summit was:

- for autistic self-advocates ourselves to develop a definition of “community living,”
- to determine what supports, ideas, relationships, and systems are necessary for successful community living, and
- to provide recommendations on how researchers and policymakers could foster true community living among autistic people and other people with I/DD.

We invited 10 autistic self-advocates to our summit, and interviewed or utilized the blog posts of an additional 4 autistic self-advocates. The primary themes of the discussion included self-determination, autonomy, housing, employment and economic opportunity, accessibility, policy barriers, and avenues for future research on disability and community living.

This report will demonstrate how each of these themes relate to community living and will describe what autistic self-advocates felt to be the most important aspects of each of these themes. We hope that this report will therefore guide policymakers and service providers as they attempt to establish best practices for providing supports and services in the community to autistic people and other people with I/DD.

INTRODUCTION

Since its founding in 2006, the Autistic Self Advocacy Network (ASAN) has advocated for a world where autistic people and others with intellectual and developmental disabilities (I/DD) have the same rights, freedoms, and opportunities as all other people (Autistic Self Advocacy Network, 2019). Among these important rights and freedoms is the right to live in the broader community of people without disabilities.

The right to live in the community affects all our other rights. An autistic person living in an institution will have trouble voting, getting a job, following their dreams and interests, and accessing public services and businesses.

To exercise those rights, people with disabilities need access to supports geared toward our individual needs. Unfortunately, disabled people often face significant barriers to community inclusion, including harmful attitudes, laws, and institutional policies.

When people with disabilities are excluded from conversations about community living, the meaning of community living becomes distorted and misrepresented, leading to re-segregation.

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A Brief History of Community Living

Although people with disabilities have fought for our right to live, work, and play in the broader community since the very beginning of the disability rights movement, the push towards community integration in the United States first gained ground during the deinstitutionalization movement of the 1960s and 1970s (National Council on Disability, 2018, pp. 39-45). Media exposure of the horrific conditions in institutions like Willowbrook and the Pennhurst State School (Pennhurst Memorial and Preservation Alliance, 2015) and the tireless advocacy of people with disabilities ourselves (National Council on Independent Living, 2019) led to a nationwide reevaluation of the laws and policies which kept people with disabilities in institutions (National Council on Disability, 2018, pp. 44-45).

At around the same time the Independent Living Movement was born. A central tenet of this movement is that people with disabilities are “the best experts” on our own needs. Movement leaders proclaimed that segregating people with disabilities from the community and denying us needed supports and services violates our civil rights. The founders of the early disability rights movements had high support needs, and many were fighting against being placed in institutions (McDonald & Oxford, 2005; Elliot, 1995). They based their advocacy on the belief that everyone, regardless of disability or support needs, can live in the community (McDonald & Oxford, 2005; Elliot, 1995).

The Americans with Disabilities Act (ADA) (1990), guarantees people with disabilities the right to be free from discrimination. The right to community living for people with I/DD was enforced more fully after the case *Olmstead v. L.C.* (1999), in which the Supreme Court ruled segregating people with disabilities in institutions violated Title II of the ADA.

Recent federal agency rules and regulations have also made it more likely that people with disabilities can receive necessary supports and services in the community instead of in institutions. In 2014 the Centers for Medicare and Medicaid Services released their final regulations for home- and community-based services (HCBS) (Home and Community Based Services Final Rule, 2014).¹ This regulation included rules that the location or “setting” in which services are provided must follow to be eligible for Medicaid funds earmarked for HCBS (Centers for Medicare and Medicaid Services [CMS], 2014). These rules include the requirement that the setting be integrated into the broader community and optimize the personal agency and autonomy of the person receiving services (CMS, 2014). This requirement is known as the “HCBS Settings Rule.” ASAN participated in the conversations that led to the development of the HCBS Settings Rule through its “Keeping the Promise” report (Autistic Self Advocacy Network, 2011). ASAN continues to argue fervently for strong enforcement of the HCBS Settings Rule to ensure that people with I/DD receive the high-quality services that we deserve.

An Unfulfilled Promise

These changes in laws, attitudes, and policies regarding people with I/DD have helped many of us become part of the community at large. Nonetheless, many barriers to our civil rights still exist. Even now, most conversations about community living and housing for people with disabilities happen without us.

For example, in the last several years, segregated institution-like neighborhoods or gated communities created just for people with disabilities, where we would have very little control over our own lives, have nonetheless referred to themselves as “community living.” Similar disability-specific “farmsteads” have formed in rural areas. These segregated settings are planned and run without the input of the people who live in them and frequently force people with disabilities to do jobs we do not want in the name of “therapy.” They are in fact quite similar to nineteenth-century institutions, which forced their inhabitants to perform agricultural labor to make ends meet. These facilities were created without the input of people with disabilities ourselves. They do not represent real community living for people with disabilities.

¹ Home- and community-based services (HCBS) are a form of long-term services and supports (LTSS) that are funded by Medicaid. Medicaid is the primary funder of most long term services and supports. (footnote 1 continued) These services can include long-term physical and behavioral health care, long term occupational and speech/language therapy provided in the home or other community based settings, prevocational or supported employment services, and any other service that a person with a disability might need to lead a fully independent life in the community. Since HCBS services must be provided in the community instead of in an institution, CMS needed to determine what settings counted as being “in the community.” This was the purpose of the HCBS Settings Rule.

About The Summit

Along with researchers at the Community Living Policy Center (CLPC), ASAN determined that autistic self-advocates ourselves must craft our own definition of community living and provide practical guidance to researchers and policy-makers. ASAN convened a two-day invitational summit, bringing together policy and advocacy experts with disabilities.

Over two days in May 2018, summit attendees were asked to talk about what community living meant to them, with a focus on formal and informal supports, accessibility, autonomy and self-determination, community inclusion, and the intersections between disability and other marginalizing experiences. We also held one-on-one interviews with three other autistic policy and advocacy experts and drew from the writings of invitees who could not attend the summit in person. Following the summit and interviews, we derived a list of themes, suggestions, and considerations for policy-makers to help us live and stay in our communities.

About Our Attendees and Interviewees

Ten autistic self-advocates attended our summit, not including the ASAN staff members who were present. Our attendees had a variety of different support needs, means of communication, co-occurring disabilities, ethnicities, gender identities, and lived experiences. Several of our summit attendees had intellectual disabilities.

Our attendees were:

- **Cal Montgomery**, an activist, writer, and member of ADAPT. Cal Montgomery's essays on disability are potent examinations of what it means to be disabled and have been featured in ASAN's anthologies.
- **Benjamin McGann**, a member of the "Arlington Five," (Crane, 2016) gifted athlete, autistic self-advocate, and aspiring college student. Mr. McGann has many interests, including history and museums.
- **DJ Savarese**, a recent college graduate, Open Society Foundation/Human Rights Initiative Youth Exchange Fellow, and co-producer of the documentary film *Deej*, which won a 2017 Peabody Award and has the tagline "Inclusion shouldn't be a lottery."
- **Ivanova Smith**, of Self Advocates In Leadership (SAIL), a statewide legislative advocacy organization for people with I/DD in the state of Washington.
- **Nicole LeBlanc**, a Self Advocacy Resource and Technical Assistance Center (SARTAC) Fellow at the National Disability Rights Network (NDRN) and a Dr. Ruth Sullivan Policy Fellow at the Autism Society. She is creating a toolkit that will have information on the basics of disability employment policy and on competitive integrated employment in it.
- **Brent White**, Director and designer of Ala Costa Adult Transition Program (ACAT), which serves students with I/DD from the Berkeley Unified School District and the North Region Special Education Local Plan Area (SELPA).
- **Dr. Scott Michael Robertson**, a co-founder of ASAN in 2006 and current Policy Advisor at the U.S. Department of Labor's Office of Disability Employment Policy (ODEP). He leads ODEP's activities focusing on autism and neurodiversity in the workplace.
- **Finn Gardiner**, Research Associate at the Lurie Institute for Disability Policy, The Heller School for Social Policy and Management, Brandeis University, and ASAN Policy Fellow. At the time of the summit, he was the ASAN Regional Policy Analyst for Boston.
- **Greg Robinson**, a graduate student working at Drexel University's Career Services Department. He supports the school in its mission to improve the neurodiversity of its student body and the success of its students.

This paper includes remarks from four additional autistic self-advocates, who were not able to attend the summit in person. The self-advocates in question were:

- **Ari Ne’eman**, co-founder of the Autistic Self Advocacy Network and ASAN Executive Director from 2006-2016. He currently runs MySupport, a service which connects people with disabilities and families with workers who share our values.
- **Mel Baggs**, self-advocate, activist, and writer. They are a recipient of developmental disability services and have asked us to use their posts on community living and the developmental disability services system.
- **Dora Raymaker**, a research assistant professor at Portland State University’s Regional Research Institute of Human Services, co-director of the Academic Autism Spectrum Partnership in Research and Education (AASPIRE), associate editor of *Autism in Adulthood*, and author of stories with neurodiverse protagonists, including *Hoshi and the Red City Circuit*.
- **Jillian Parramore**, an autistic self-advocate, previous participant in our Autistic Campus Inclusion leadership training, and activist.

ASAN staff members both acted as facilitators during the meeting and provided their own opinions as autistic self-advocates. ASAN staff members who participated in the meeting were:

- **Julia Bascom**, Executive Director
- **Samantha Crane**, Legal Director and Director of Public Policy
- **Reid Caplan**, Associate Director of Advocacy and Development
- **Kelly Israel**, Policy Analyst

Dr. Steve Kaye, Director of the Community Living Policy Center, also participated in our summit.

About this Thematic Analysis

ASAN conducted a thematic analysis on the statements made by our summit attendees, and the other self-advocates we interviewed, in order to determine what people with disabilities need in order to live in our communities. Thematic analysis is a form of qualitative research that aims to “identify patterns of meaning across a dataset that provide an answer to the research question being addressed” (University of Auckland School of Psychology, 2019).

We identified twelve themes in all, which we grouped under five overarching categories: self-determination, accessibility and support systems, equal opportunity and participation, belonging, and policy barriers.

Under self-determination, we included the themes autonomy, the presumption of competence, and risk-taking. The accessibility and support systems category included themes on different kinds of accessibility aids people with disabilities use, as well as the support systems we need to help build our lives in the community.

Equal opportunity and participation included community inclusion, economic participation and employment, and housing. We included relationships, privacy and safety, and the intersections between disability and other forms of marginalization within the belonging category.

Summit attendees also discussed policy barriers to community living that people with disabilities encounter. They also discussed with ways to dismantle those barriers. Each section additionally includes first-hand narratives from our attendees.

Usage of We, Us, and Ours In The Thematic Analysis

Throughout the thematic analysis, ASAN uses the terms ‘we,’ ‘us,’ and ‘ours’ to refer to the broader community of people with developmental disabilities. This is because the purpose of the summit was for autistic self-advocates ourselves to define community living. Although the views expressed herein are solely the views of those who participated in the summit, they are consistent with those that ASAN has encountered among self-advocates overall.

SELF-DETERMINATION: AUTONOMY, PRESUMING COMPETENCE, AND RISK-TAKING

Self-determination is the ability of people with disabilities to make our own decisions, direct the course of our own lives, understand our own needs, and learn through trial and error. Self-determination allows us to engage with the community on our terms. Three primary themes regarding self-determination arose during the summit: autonomy, the presumption of competence, and risk-taking.

Autonomy

“If you get support, you’re being controlled, and we need to be able to talk about breaking these things apart.” —Cal Montgomery

Summit attendees agreed that self-determined community living requires *autonomy*, or the freedom to direct the course of one’s life. First and foremost, autonomy is *never* dependent on someone’s abilities or level of support needs. All people with disabilities are capable of exercising any degree of autonomy and have the unequivocal right to do so.

Non-disabled people’s autonomy is frequently treated as a given, while disabled people’s autonomy is frequently denied or restricted. People with disabilities should be able to receive support while maintaining our autonomy. Autonomy can take different shapes, including directing one’s support system personally or delegating responsibility to others.

Autonomy and Interdependence

The autistic self-advocates we interviewed believed that independence means being **in charge of one’s own life while accessing the support we need in our daily lives**. Summit attendees noted that many developmental disability service providers, in contrast, saw “independence” as the ability to do the same things as non-disabled people without help. DJ Savarese described the combination of being in control and receiving support from others as “interdependence.”

Autonomy is not the same thing as making superficial choices. Cal Montgomery said he was wary of the word “choice,” primarily because he has seen service providers offer clients superficial choices and call them “autonomy.” For example, providers may allow a client to choose to wear a red or blue shirt. Access to these limited choices is not representative of the ability to determine the course of one’s life. Instead of “choice,” Montgomery suggested using the term “liberty.”

Reducing us to lists of deficits can harm our autonomy. Brent White added that “self-determination cannot exist within a medicalized system.” The “medicalized system” he was referring to was the medical model of disability, which treats disability as a deficit or disease. The medical model focuses on “fixing” disability, or on making a person with a disability indistinguishable from a person without one. Often, therefore, the medical model zeroes in on eliminating whatever society thinks is “wrong” with disabled people, instead of giving us the support we need in society. Without this support, we may lose some of our autonomy. We are not laundry lists of deficits, but human beings.

Autonomy includes the right to make all kinds of decisions, even ones that our supporters or service providers may disagree with. For example, Cal Montgomery said that people should be able to engage in personal, political, or social protest, and to receive the supports we need to protest, regardless of whether or not our supporters agree with us.

Ivanova Smith said that “our personal freedoms need to be respected. You can’t have a place where they say you can’t smoke in your home. What if you’re a person who likes to smoke?” She added, “I create my own rules and my own structures,” and noted that “if you’re living with other people, you shouldn’t have to follow all the other people’s rules and do everything together.”²

Autonomy involves self-expression, too. Brent White discussed a client who, with supports, “was able to tell her grandparents she wanted a Mohawk.” He described this client’s ability to express and ultimately act on this desire as “the best outcome we’ve had.”

Autonomous community participation is spontaneous. We should be able to decide when and how we want to engage with the community, because this is part of what having autonomy means. Sam Crane called this ability “spontaneous

² In Smith’s example, smokers should have the right to live in spaces that allow them to smoke if their housemates agree to it. However, not everyone can deal with cigarette smoke. Community living should include the right to choose your own housemates, which we discuss in more detail later in this report.

community participation.” Summit attendees believed that being required to adhere to a strict schedule by service providers prevents people with disabilities from exercising our autonomy.

Some attendees discussed the “burrito test” (Hingsburger, 2013) and the “IHOP test” for spontaneous community participation. These tests ask whether people can go to the kitchen to heat up a frozen burrito at 3:00 AM, or go to a restaurant or a café late at night. Most summit attendees felt that a person who couldn’t do either of these things was living in an institution, even if they did not live in a large congregate setting.

Autonomy also includes the right not to participate. For instance, a person should not be forced to go out bowling just because their support provider is taking its other clients out bowling. Ivanova Smith said, “Also, if you wanted to stay home and you [didn’t] want to go out to a community event that day, you should be able to stay in your PJs and have a lazy day.” Instead, the person should feel free to choose the extent of their interaction with people who live nearby.

Having to share support workers and supports reduces autonomy. Support workers should not be assigned to multiple people in the same location, or at the same time. Summit attendees noted that when support workers have to work with several different people at the same time, they are faced with competing priorities from all their clients. The focus shifts from providing individual disabled people with what we need to ensuring compromise among all the clients. Ivanova Smith said, speaking of how her own situation prevented the need for such a compromise, “If I want to go to the movie, my support person will take me to the movie. I don’t have to worry that I don’t get to go to the movie because my support person has to take another person to the doctor.”

Ensuring that each client works with one staff member at a given time will help everyone have their needs met.

Autonomy and Institutional Settings

“And no you can’t build a magical institution that isn’t an institution because you waved your hands and cast a spell that called it an ‘intentional community.’”—Mel Baggs

Granting people with disabilities autonomy and paying attention to power dynamics between us and our supporters helps protect us from segregated, isolated, or exploitative living arrangements.

Far too often, however, settings marketed as “community-based” may actually replicate institutional models. These new institutions may be rebranded as group homes, “intentional communities,” or farmsteads. Regardless of the name, these settings have strict rules, wield control through rigid power hierarchies, and prioritize the agency’s values over those of their clients - all hallmarks of institutional settings.

Controlling, congregate care models are never community living. Community living means that every person with a disability will live a life different from that of every other person with a disability, unique to them and their circumstances and desires. We cannot find true freedom in the confines of spreadsheets and tallies, or in behavior charts and overly bureaucratic, rote documentation that fails to acknowledge that people with disabilities are complex individuals.

Summit attendees believed that service providers should instead serve people with disabilities according to our specific, individualized, and, most importantly, our self-reported needs. Cal Montgomery said that even if someone wants their life to be highly regimented, it is better to simply “hire support workers and train them to get you to go to bed at 8:35 every night” rather than to “fund institutional centers” that will impose such regimentation on others as well. Service providers must stop assuming they know what a person with a disability needs better than the person does. In other words, they must stop relying on the medical deficit model of disability and start relying on their clients’ wishes. Doing otherwise merely perpetuates the institutional model in new forms.

“[A]n institution is not created by the shape of the building. It’s created by who holds the power, and what kind of power they hold.”—Mel Baggs

Allowing disabled people to have autonomy over our services and supports saves lives. In her post “The agency matters to the agency more than you will ever matter to the agency,” Mel Baggs described an encounter with staff at a hospital who tried to persuade them to refuse a feeding tube because they would “need 24/7 care from [their] local DD (developmental disability) agency while in the hospital,” and attempted to discharge them despite their having aspiration pneumonia.

The DD agency, too, was complicit; when Baggs returned from the hospital, a caseworker told them, “You shouldn’t have done that. Do you understand you are jeopardizing our agency’s good relations with the hospital?” (Baggs, 2018 May 5). Systemic reform requires shifting agencies’ priorities from their organizational needs to those of the people they serve every day. Baggs’ Designated Power of Attorney had to organize a social media campaign to contact the hospital’s staff to ensure that Baggs received the care they deserved. Baggs did receive their tube, but the hospital--and the DD agency--should have respected their wishes in the first place.

Presumption of competence

Recognizing our right to autonomy and self-determination includes respecting our insights into our own lives, including our support needs. Far too often, however, people with disabilities are treated as though we cannot make decisions about our own lives, or that we lack expertise on disability, policy, or our own lives.

Presuming competence includes the acknowledgement that adults with disabilities are still adults. Summit attendees believed that **infantilization** was a barrier to equitable community participation. Applying concepts like “mental age” to limit our decisions is ableist and hurtful, and doesn’t help us get the support we need. We are not children because we have support needs. Infantilization is endemic among social-service providers, even outside disability-specific programs. For example, some programs for homeless people—typically based on the Continuum of Care model—make clients’ care contingent on their compliance with specific programs or sets of rules (Hennigan, 2016; Latimer & Ly, 2015). While these programs are not disability-specific, the same kind of paternalism informs their design and administration. However, programs directed towards specifically people with disabilities are particularly infantilizing.

Some disability support services programs presume incompetence and attempt to control what their clients learn and do, even when they’re designed to teach independent-living skills to people with disabilities. For example, some support programs have required adults with disabilities to learn specific tasks, like cooking and cleaning. The providers see this as making the person more “independent,” even if the person has no desire to learn the task in question and can meet their needs some other way.

Coercive independent living skills training is particularly troubling when the tasks in question are actually difficult, painful, or impossible to accomplish without sacrificing the ability to work toward clients’ other goals. Ivanova Smith encountered some disability services programs that forced people to learn how to cook despite her difficulties following recipes or dealing with sensory stimuli, and shamed her if she was not interested in learning to cook.

Julia Bascom agreed, saying, “I could probably learn to do more things by myself if I didn’t have a job, and could spend all day making a sandwich instead. I’ve decided that this job is important to me and what I want to spend my time on.” One attendee said, “I feel like depriving people of their autonomy does not create responsibility.” Another added, “Those types of programs force you to learn independence skills, but shame you if you’re not compliant.”

Presumptions of incompetence affect people across a range of support needs. While people with cognitive disabilities and high support needs often bear the brunt of this form of stereotyping, it isn’t limited to this population. Finn Gardiner, who was frequently referred to as “high-functioning” by service providers, said that his family, teachers, and therapists still had low expectations of him. He ended up internalizing a mentality that emphasized his weaknesses and diminished his strengths. Greg Robinson found that the presumption of incompetence harmed his ability to make decisions that worked for him. Robinson argued strenuously with his high-school guidance counselor to allow him to attend the most academically rigorous university that accepted him. He suspected that if he were not disabled, he would have encountered less resistance.

Presuming that a person is incompetent can affect close personal relationships, too. Attendees agreed that people with disabilities should be able to receive support and maintain our relationships simultaneously. Jillian Parramore said that she should be able to “call [a support worker] and talk about my breakup with their actually knowing that I have sex.” One summit attendee said that they were worried about losing custody of their daughter if they were seen self-injuring.

Disabled people are experts on our own lives and the policies that affect us. The presumption of incompetence isn’t limited to service providers’ attitudes toward how and when people with disabilities should learn activities of daily living

or receive support. Ivanova Smith, who is an experienced legislative advocate, has had her expertise discounted multiple times because of her disabilities. She also expressed frustration at bureaucrats and other non-disabled disability professionals who dominate policy discussions: “[Disabled people] were not at the table at those discussions and work groups,” and the only way disabled people could participate was if non-disabled advocates mentioned self-advocates’ priorities for them.

Risk-taking

“Who here in this room has made a bad decision, and who made a bad decision who shaped who you are today? How many of you lost all your rights as soon as you made a bad decision?” —Brent White

People with disabilities have the right to take risks and make mistakes. For example, Ivanova Smith mentioned that people with disabilities should have the right to perform riskier actions, such as going to a bar late at night, without being stopped by our service providers — and should have the absolute right to support at those times if support is needed.

Unfortunately, well-meaning supporters think that they must protect us by preventing us from failing or making mistakes, even though adverse experiences can help us find out which strategies do and don’t work. Learning by trial and error is a form of self-determination. DJ Savarese referred to it as “the right to take risks and make errors.”

Cal Montgomery said: “I think it’s about control of risk. There are risks I choose to take. I could go hang out in a park for 12 days and that’s risky. But I have the right to choose to do it ... I [also] have a right to be in a situation where [I can choose not to take risks others think I should take]. Within reason, obviously. ... But somebody else doesn’t decide what risks I take. I have the right to take reasonable protections from risk I don’t want to take and I have the right to take risks that I do want to take.”

ACCESSIBILITY AND SUPPORT SYSTEMS

Accessibility removes barriers to participation for people with disabilities by adapting our environments to our needs. **Formal and informal supporters** perform a similar role for us by connecting us to services and resources that we may not be able to access without help. Accessibility and support systems can facilitate the self-determination and community participation of people with disabilities by allowing us to focus on what we **can** do, rather than what we **can’t**.

Accessibility: Physical, cognitive, and communicative

Attendees used an expansive definition of accessibility. Three forms of accessibility that were mentioned repeatedly were physical access, cognitive accessibility, and accessible technology.

Physical access is probably the first thing people think of when they consider accessibility: the ability to enter a physical space, like a store, classroom, or government office, without encountering barriers that make your entry difficult or impossible. Examples of accessible spaces include buildings with wheelchair lifts, elevators, ramps, and clearly marked entrances and exits. Physical accessibility goes beyond mobility aids like wheelchairs, canes, and walkers.

Cognitive accessibility involves making an environment or information easier to process mentally. This may include decision-making aids (such as maps on an app that show different routes a person could take to get somewhere), translations of complex documents into cleaner, simpler language (such as translation of documents into Easy Read format), presenting information multiple times and in multiple formats, and the reduction of the number of steps someone must perform to complete a task.

Accessible technologies are tools that people with disabilities use to navigate our physical, cognitive, or social environment. These technologies may include Braille, text-to-speech devices, cueing and prompting applications, and wheelchairs.

Services, spaces, and events should, however, include accessible features for people with more than one kind of disability. Many of us have multiple disabilities, and may need all three forms of accessibility, or more than one, in order to participate. Some attendees encountered accessibility barriers even in places that were supposedly for people

with disabilities. For example, Brent White noted that a local Center for Independent Living (CIL) - which exists to help people with disabilities be more independent - “held their gala on a site that’s not accessible.” He added that the CIL “believe[s] in Title III [of the Americans with Disabilities Act] for wheelchair users, but they don’t believe in it if you want CART.”

Summit attendees discussed all three forms of accessibility simultaneously and applied them to various specific circumstances. Three of the specific circumstances discussed most frequently were **accessibility and forms of transportation**, **accessibility and communication**, and **accessibility and executive functioning**.

Accessibility and Forms of Transportation

Summit attendees felt that accessible transportation was a vital component of community living. Transportation involves both **physical accessibility** and **cognitive accessibility**.

Physical Access to Transportation

Having access to good transportation helps us integrate into the broader community and avoid isolation. Ivanova Smith said that she would prefer to live in a rural area, but the lack of public transit available outside major cities made it impossible for her, especially since she does not drive.

Cognitive Access to Transportation

Sometimes the most cognitively accessible forms of transportation, like rideshares, are more expensive than cheaper mass-transit options. Finn Gardiner said that he often had to decide whether he wanted to save money by taking public transit and put up with constant transfers, noise, and erratic stops, or spend the extra money and go straight to his destination with a rideshare app. As an autistic person, the transfers and erratic stops were difficult to manage due to his executive functioning-related difficulties with switching between tasks, and the noise was louder and more difficult to handle given his sensory sensitivity.

Accessibility and Communication

Summit attendees felt that access to communication was vital for community living. Without access to communication (which is both a means to express oneself and to understand what is being said), people with disabilities cannot communicate our needs, wants, and desires. Access to communication involves both **accessible technologies** and **cognitive accessibility**.

Accessible Technologies and Communication

Accessible technologies include communication supports for people with disabilities. Ben McGann, who uses alternative and augmentative communication (AAC), said that non-speaking people should have communication support so they could advocate for themselves. Dora Raymaker emphasized the value of AAC in their professional and personal life. Raymaker wrote an AAC application, used the AAC app Proloquo to present at academic conferences, and use a mobile app to display a customized message during meltdowns.

Communication supports should let us say what we want to say. Cal Montgomery said that when he was living in a nursing home, he “asked the speech therapist for help with this [text-to-speech] device to learn to use it. She said, ‘OK, I need to take it from you so I can figure it out and teach you how to use it.’ She brought it back. There were 66 phrases about going into the bathroom programmed into it and nothing else.”

This is not real access to communication. AAC users should be able to access open-ended communication supports, not a pre-programmed list of phrases that others think we may want to say.

Cognitive Accessibility and Communication

Communication access includes cognitive accessibility. There are many cognitive disabilities that affect people's ability to process written material. Service providers' documents should be written in a clear and simple style, adhering, for example, to plain language or Easy Read standards. This practice can lead to "curb cut effects" that benefit other populations, such as those who are not fluent in English (Blackwell, 2017). Readability checkers built into Microsoft Word and various online services can help writers make documents easier to read.

Adding images can help, too. Ivanova Smith, who has extensive experience creating cognitively accessible documents, said, "I put visuals in. I know that a lot of people don't do that. But it's actually really helpful for people who can't read or have limited reading. ... some people try to criticize them saying, 'Oh, well, that's really kiddie.' [Saying] that ... visuals are childish [...] encourages shaming people for needing visuals. I have a friend who's the co-chair [of a group Smith is involved with]. He [can't] read. He loves my agendas because [they're] accessible for him."

Cognitive access isn't limited to written materials. In her interview, Jillian Parramore suggested that everyday tools like cooking appliances should be cognitively accessible, too; for example, if someone has difficulty remembering whether appliances are on after they have finished cooking, stoves and other appliances with built-in timers help save energy, time, money, and lives.

Cal Montgomery also suggested using or creating "cognitive interpretation and translation services" to make legal or policy jargon easier for people with cognitive disabilities to understand. Scott Robertson suggested enshrining cognitive-accessibility criteria into law to ensure compliance.

Accessibility and Executive Functioning

Some people with disabilities have difficulties with executive functioning (EF), or the ability to plan, prioritize and organize tasks.

Executive Functioning and Assistive Technology

Assistive technology can help us with executive functioning (EF) tasks. For example, Kelly Israel said that she struggled with prioritizing; she said that she "couldn't tell the difference between a life-threatening emergency and a mild accident." She suggested creating an app to help people rank priorities.

Some of us have a hard time initiating tasks without guidance or reminders and may benefit from apps that help us by prompting and cueing. Prompting and cueing supports can include mobile apps with reminder systems, as well as services that connect people with coaches who guide them through tasks and remind them. Cal Montgomery and Greg Robinson shared ideas for creating apps that combined multiple kinds of prompts and a chat function for people who need to talk to others. Scott Robertson suggested that the technology behind Aira, a tool that blind people use to help interpret visual information, could be used to support people with EF disabilities by providing auditory cues. Brent White added that voice-activated assistants like Alexa, Siri, and Cortana could be programmed to guide people through tasks. Robinson also suggested that support apps could be used to provide mutual aid or peer-to-peer support among disabled people.

No one form of prompting and cueing will work for all people who need EF support; some attendees said they need live people to physically prompt them or talk them through tasks, rather than computerized prompts or remote cueing.

Accessible Technology

Summit attendees made several additional points about accessible technology more broadly.

Accessible technology must be affordable. Ivanova Smith said, "[Accessible technology] is great stuff, but I feel like the only people who get to access it are really rich people." Accessibility tools must be available to low- and middle-income people, including those who cannot use Medicaid or other coverage to pay for those tools. Training to use these technologies must also be affordable. People who are unfamiliar with a tool may balk at using it without guidance.

Trial and Error and Assistive Technology

The right to trial and error also applies to supports, including assistive technology. Reid Caplan noted that some people assume that, when a particular assistive technology fails to help someone perform a task, that person will never be able to perform that task. People should be able to try different methods to communicate, plan, and organize without being penalized for trying several options before making a decision.

Caplan also suggested that research on disabled people's experiments with different assistive technologies may help us find solutions that work consistently. Brent White added, "My participants are intellectually disabled. Nobody asks intellectually disabled people what they want to see happen. [It] might not be what they actually want [because] nobody has even asked them."

Support needs and systems

Accessible spaces, technology, communication, and transportation must exist in conjunction with high-quality support. While accessible objects and spaces help us navigate the community, we often also need supports from other people to be fully included. Summit attendees had a variety of different things to say about support needs and support systems.

Community living should be conceptualized as a form of interdependence—the recognition that no single human being, disabled or not, can manage their life on their own—rather than independence. Cal Montgomery mentioned the tensions between the way activists in the Independent Living (IL) movement and other disability-rights movements viewed the relationship between independence and support. He noted that the IL movement "define[s] independence as doing it without control [by others]. In the DD system, and both the educational and the adult system, independence means doing it without help." He also noted that the IL movement "has done great work on the civil rights model that we can learn from. The self-advocacy movement has done amazing work on mutual accommodation, and learning how to support one another, as opposed to depending on outsiders to come in and support."

People's support needs should not be defined solely by our functioning label or our performance on intelligence or cognitive tests. Support needs are extremely individualized and cannot be reduced to IQ scores or scales of adaptive functioning. For example, some people with an intellectual disability diagnosis may have a difficult time at school, but have fewer struggles with daily-living tasks. In contrast, some autistic people with average or above average IQs are unable to access needed services due to their test scores, despite needing considerable support in their day-to-day lives.

Ivanova Smith, who does have an intellectual disability, added that IQ cutoffs may result in service denials for people with intellectual disabilities: "...even I am denied formal services. I actually tried to apply for DDA—the Developmental Disability Administration—and they rejected me." Because she has struggled to access formal services, Smith relies primarily on her husband to help with daily-living tasks.

People and agencies supporting disabled people should maintain high standards by prioritizing our needs, lives, and access. Some agencies cut corners by maintaining dangerous staff-to-client ratios, avoiding clear communication between leadership, staff, and clients, and treating clients in a perfunctory way. Unfortunately, low standards aren't merely annoying; they can be life-threatening. Mel Baggs wrote, in their blog post "Agencies Can Set the Bar Really Low": "Part of the medical neglect I experienced from this same agency involved having my staff hours cut in half for a while and becoming dehydrated enough I almost passed out [...]. I kept saying I needed more help the worse my health got as a result of this, and they kept pushing me further and further to perform beyond my limits" (2018, May 5).

Support agencies should also avoid placing agency rules over the needs of people with disabilities. Focusing on rules over principles can have dangerous, and potentially deadly, consequences. Someone may need a support worker to guide or prompt them while they perform a household task, but their support worker's agency may ban staff from doing anything but actively performing the task *for* the disabled person. The opposite could also be true: the support worker could be prohibited from performing the task on the person's behalf.

Agencies that emphasize rules over individualized supports often have a "menu" of services a support worker is allowed to do. Jillian Parramore said that she could only have her in-home supportive service workers help her with errands,

groceries, and medical appointments; she couldn't use them to go to work or spend time with friends. While defining the scope of a supporter's job is helpful, there must also be enough flexibility to allow people with disabilities to receive individualized supports.

We previously mentioned Mel Baggs' encounter with agency workers refusing to offer help that was technically off the "menu" when they needed life-saving medical care. Focusing on the agency's needs, rather than the client's, might have killed Baggs had others not intervened. In contrast, another agency Baggs worked with allowed staff to be flexible. Baggs wrote, in "Agencies can set the bar really low": "There was a week when my staff person was out sick and I was unable to get medication, food, and water. [...] The head of the agency came into the room. [...] He asked me what had been happening. I told him, and he personally drove me home. He cleaned my apartment. He cooked for me. He got my meds. He got me water. When people are allowed to act on their conscience, they will do things like this if they see someone in trouble."

Service agencies should improve working conditions for their staff. Jillian Parramore said that support workers needed better training and higher pay to ensure their investment in the crucial work of helping disabled people live in the community. Support staff who receive a living wage and respectful treatment on the job are better equipped to help people with extensive support needs.

Unfortunately, many support workers are paid at or below the minimum wage, have restricted hours, receive little to no training on their clients' disabilities, and are exploited at work (Oh, 2017; Barbarotta, 2010; PHI). Poor working conditions increase turnover rates, which threaten our wellbeing (Oh, 2017; Barbarotta, 2010; PHI). Summit attendees said that good support workers often find other jobs and are replaced by someone who does not know the client well, may not have the same level of expertise as their predecessor, and needs to be retrained to meet their client's specific needs. This cycle may repeat itself multiple times, leading to serious disruptions in support. Policymakers, agencies, and funders should set higher wage floors for direct care workers to boost hiring and retention.

Under current systems, it is often difficult to get formal supports without qualifying for programs that are often means-tested or that have overly strict criteria for being considered "officially disabled." Summit attendees recommended that the government pursue policies that decouple paid supports from the requirement to be in poverty, or overly strict disability-determination guidelines.

Self-directed supports can help promote autonomy and safety. Shifting from an agency-centric model to one focused on self-direction helps people with disabilities exercise more autonomy over our services. It can also help keep us safe. Under a self-directed model, clients work with designated supporters whom they can report or fire if they feel they are being mistreated.

People with disabilities who rely on informal supports should be able to find backup support if something happens to our usual supporters. Attendees who were primarily dependent on informal supports felt a real fear that they would be less able to participate in the community in a fulfilling way if they somehow lost access to those supports. One summit attendee said, "I live with a roommate who is my direct support person, who is not paid by Medicaid. If he gets married or moves or something, at some point in my life, I don't know if I can keep my job. I don't know what happens to me, and that's an awful way to live." Deaths, breakups, divorces, accidents, and illnesses can happen at any time, and it's important to ensure that there are contingency plans in place to help anticipate the loss of informal supports.

Not everyone has access to informal supports. Having alternative support plans is also beneficial for disabled people who cannot rely on our families as a primary source of support. Family members can have their own support needs that prevent them from providing care. They could also be dead, abusive, or otherwise unavailable to help. One summit attendee said, "Not everybody has excellent parents who are wonderful advocates. My parents were abusive. They were anti-LGBTQ."

Even when family members are available to act as support, they can sometimes make it difficult for people to exercise their autonomy. Jillian Parramore said, "when [my support person] is a family member, it messes up the dynamic. When I tell them to do something, they don't see me as the boss; they see me as the person they've always cared for."

EQUAL OPPORTUNITY AND PARTICIPATION

People with disabilities have the right to engage actively with the community. Accessibility tools and spaces, supporters, and self-determination can help us get there, but we still need the opportunity to be fully included in education, employment, housing, and other aspects of community living. The subjects attendees discussed at the summit which relate to the theme of equal opportunity and participation include **community inclusion, economic participation and employment, and housing.**

Community inclusion

Our engagement with the community requires that we be fully included within it. We want to be participants, not spectators. Segregated settings are not “community.” Summit attendees criticized the tendency of segregated congregate programs to co-opt the language of self-advocates. For example, self-advocates use “in the community” to refer to the cities, towns, and neighborhoods in which people without disabilities live. We refer to “inclusion” as the ability to access any part of the community we choose, including the supports we need to do so.

Segregating people with disabilities from the general community does not make us safer. In fact, segregation is always a threat to the safety of people with disabilities. Segregated settings, because they are more isolated, may increase the likelihood that a person with a disability will face abuse and neglect. Additionally, Finn Gardiner and Ivanova Smith encountered bullying and harassment in segregated settings in the past, including a special-education classroom and a segregated workplace. Smith was repeatedly harassed and called names in a segregated workplace. Gardiner said that he was “bullied just as badly in middle school by students with disabilities, just as much as the kids in the mainstream classes did.” For more information on both bullying and abuse and neglect, read the “Abuse and Neglect” subsection of the “Privacy and Safety” section of this report.

Organizations and policymakers must make good-faith efforts to integrate people with disabilities. As noted above, summit attendees reported that institutional settings sometimes misuse the words “community” and “inclusion.” Another common misinterpretation of the word “inclusion” involves forced normalization. Some developmental disability service providers assume that being included in the community means being the same as people without disabilities, rather than having the same opportunities. Julia Bascom said, “[W]hen people talk about inclusion, they’re talking about one of two ideas. [...R]ights and access and opportunities, or [...] forced normalization. [T]hose are different concepts and if we can name that, that tension goes away.”

Inclusion requires educating non-disabled people about disability and how they can help make us feel welcome at work, school, and within the community in general. Sometimes people have unaddressed stereotypes about people with disabilities, leading to bullying, ostracism, and harassment. When Ivanova Smith attended mainstream classes, she said, “they [non-disabled students] hated my guts. They didn’t want me there, and would tell the teachers all the time, ‘Why is the retard there?’ They would say it to my face.” Smith had the right to be included in mainstream classes **and** to be free from harassment and bullying.

Economic participation and employment

People with disabilities deserve support in finding jobs that work well for us. Attendees emphasized the importance of well-paying jobs that match our skills, abilities, and interests. Under- and unemployment, subminimum wage, and other inequities disproportionately affect people with disabilities (International Labour Organization, 2014; National Disability Rights Network [NDRN], 2012; NDRN, 2011). Only 34% of working-age adults with disabilities are employed; in contrast, 74% of working-age adults without disabilities have jobs (International Labour Organization, 2014; NDRN, 2012; NDRN, 2011).

Even if people with disabilities are employed, we still encounter significant disparities. Some people with disabilities work in dead-end jobs that often pay subminimum wages (International Labour Organization, 2014; NDRN, 2012; NDRN, 2011). Ivanova Smith encountered this firsthand when she received a job through Vocational Rehabilitation (VR) that required her to clean cafeterias on a military base, despite her request to be assigned to an office job. Smith encoun-

tered verbal abuse, sensory overload, and inaccessible working conditions. When she complained to her VR coordinator, she was told, “you just don’t know what work is like. You’ve been too cozy in that community college.”

Agencies must use thoughtful strategies to help match people with disabilities with prospective employers. Nicole LeBlanc suggested that VR agencies and other organizations provide a comprehensive array of services, including counseling, job coaching, and customized employment. She also suggested that job-development organizations capitalize on positive traits of disabilities and play to potential employees’ strengths.

Skill-building isn’t limited to traditional education and employment. Scott Robertson mentioned that apprenticeship may work for people who don’t want student debt or a traditional four-year university degree. The Department of Labor (DOL) lists a number of apprenticeship programs for people with disabilities (Office of Disability Employment Policy; U.S. Department of Labor, 2018). In 2018, DOL awarded a \$1.9 million contract to Social Policy Research Associates in Oakland, California, to create a pilot apprenticeship program for people with disabilities (Office of Disability Employment Policy, 2018). Though this program is currently at a single site, the research and narratives that arise from it will help policymakers identify what people with disabilities need, and how we benefit, from apprenticeship programs.

Economic participation includes access to benefits and programs. Employment is only one component of economic opportunity for people with disabilities. Full access to the economy also includes: (1) having access to government benefits like SSI, SSDI, TANF, and other cash supports; (2) being able to manage our own money or find support with money management; and (3) being able to make our own purchases or delegate those purchases to people we trust. Robertson summed this up succinctly, saying, “Most things in the community cost money, so we need the economic opportunity to be able to access them.”

Economic inclusion includes access to health care. For instance, LeBlanc discussed her desire for expanded access to medical services not typically covered under Medicaid or other plans, including massages, cranial-sacral therapy, and dental care. While disabled people with high or moderate incomes may be able to afford dental care or alternative treatments, these opportunities are largely closed to low-income people with disabilities.

Access to Housing

People with disabilities should be able to live in accessible, affordable housing that meets our needs and doesn’t segregate us. Accessible housing should be affordable and should take into account our diverse sensory, cognitive, spatial, and social needs.

Unfortunately, accessible, affordable housing is often difficult to come by. Summit attendees said that cheaper housing may be in lower-demand rural or suburban areas with few or no public transportation options. Developers may not build in accessible features by default. The housing stock in a given location may be old and difficult to retrofit for accessibility. Local policies may make it nearly impossible to build new accessible units because of size, density, or other restrictions. Some people with disabilities may live in inaccessible houses or apartments, congregate sites like institutions and group homes, homeless shelters, or on the streets because finding an affordable home can be so difficult. Strict rules associated with institutions and shelters, inaccessibility, and the threat of homelessness are all barriers to our community integration.

Summit attendees urged agencies to let people with disabilities direct the process of finding our own housing. Sometimes agencies will assume that disabled people need to be placed in disability-specific housing, and will steer people toward housing that may not actually fit our access needs. Someone may need to be near major shopping or transit hubs and may prioritize this access over access to housing that is labeled “accessible.” Not everyone has the same needs for architectural accessibility features. Moreover, it may be possible to retrofit inaccessible but well-located housing to be more accessible.

Self-direction also helps us prioritize which access needs are most important to us. Nicole LeBlanc encountered an agency that didn’t take her sensory needs into account and placed her in a high-rise apartment building full of loud people. LeBlanc is a light sleeper and needs to have outside noise blocked out from within her apartment. This was impossible in the apartment where she was placed, and as a result she was constantly awakened and had to file multiple noise

complaints. Sensory and cognitive access needs are just as important as physical ones and should be taken seriously by agencies that help us find housing.

Summit attendees also believed strongly that people with disabilities should be able to choose the people we live with and invite into our homes. Our comfort with the people we live with can make or break a housing situation. Congregate housing situations like nursing homes often randomly choose room assignments, which proves problematic if the people they put together do not get along. Often, agencies will place people in congregate housing because they believe these settings are more manageable or inexpensive. They will then assign people to live together based on agencies' own inflexible policies or on whatever is most convenient to the agency. Self-direction in choosing a housing setting can help us live with the people we want to live with.

Housing for autistic people should adhere to the principles of universal design and easily accessible to people with mental disabilities. During the summit, Cal Montgomery raised the subject of visitability, a principle focused primarily with the construction of a space and its accessibility to wheelchair users. For wheelchair users, basic visitability primarily includes an entrance with no steps, ensuring that doors are wide enough to accommodate wheelchairs, and a bathroom on the main floor. Montgomery suggested that there should be widespread standards for people with mental disabilities as well. Montgomery's suggestion is similar to the idea of universal design, which holds that housing and other spaces should be designed so that they are usable by the broadest possible range of people. People with developmental disabilities may also have co-occurring physical or sensory disabilities. Housing designed to be accessible for people with developmental, intellectual, or other cognitive disabilities must also take into account other access needs.

Accessible housing should be individualized. One-size-fits-all housing is characteristic of institutions, not community living. Accessible housing features should be geared toward the specific people using each unit, rather than the other way around. Sam Crane said, "I think we can all agree that we're not trying to make [segregated] housing just for us. I would really not want it if someone were to look at all of the things that we said [and responded with,] 'We're going to construct 20 units in this specific place and it's going to have sensory-friendly buildings and it's going to have to be secured ... and it's going to have a shuttle that will take you whenever you want.'"

Homeownership can increase access to accessible features. For some disabled people, buying our own houses or condos is a step toward individualizing our access needs, since we would be able to make our own decisions about alterations without going through a landlord. Ivanova Smith said that "if you have control, you have full control. You can alter it the way you need it to be altered. When I lived in an apartment, I couldn't put the rails in the bathroom to help me get out of the bathtub. But now I own my own home. It took me a long time to be able to do that. I can alter it to make it more accessible. You can't do that if you have a landlord."

Unfortunately, homeownership is out of the financial reach of many disabled people; even if we could afford a mortgage, income and asset limits for Medicaid or Social Security benefits or low-paying jobs make it difficult or impossible for us to save up for a down payment or qualify for a home loan. Paying for the necessary modifications may also be too expensive.

Affordability is a form of accessibility. A housing unit may meet all the spatial, cognitive, and sensory accessibility criteria we need, but if we can't afford to live there, it might as well not exist for us. Many people with disabilities have fixed incomes, and these financial limitations place barriers on the kinds of housing that we can reasonably afford.

A lack of affordable housing options for people with disabilities can force us into homeless shelters, nursing homes, group homes, or onto the street. Autistic adults are also at a disproportionate risk of becoming homeless compared to the general population; a recent study indicated that autistic traits are represented at a higher rate among homeless people than in the general population (Churchard, Ryder, Greenhill, & Mandy, 2018). While the study took place in the United Kingdom, there may still be similarities between the experiences of British and American autistic people. During the summit, Scott Robertson also mentioned the high rates of homelessness among people with disabilities in general, indicating that the problem extends beyond the autistic community.

The comparative ease of using Medicaid funds to cover institutional services instead of community-based supports can also make it difficult to find affordable community-based housing. Although Medicaid can pay for institutional placement, it cannot be used to pay rent in the community.

Flexible funding options and more diversified supports will help people with disabilities have housing options geared toward our own needs. Ari Ne’eman said, “People with intensive needs are expected to go into a group home, but that deprives them of choice. One of the biggest issues is the lack of funding streams for individualized supports. I think people end up in congregate settings because they lack the resources to pay for housing. [There are a] broad range of possible options, but we don’t really afford people significant [enough] resources to [make] meaningful choices. Financing streams that are flexible and can meet different needs. We need to move away from the combination of service provision and landlord that we’re doing for disabled people.”

Affordability concerns may lead to tough choices between accessibility and safety. Jillian Parramore said, “I have a hard time with stairs and my house is three stories, but this was the only option that checked all of my super-important boxes. It’s built on a very steep hill, so if I used a wheelchair I’d be screwed. My community is gated, which is great, but it is because the area I live in isn’t very safe.” She later added, “I definitely cannot go out after dark; it is not that kind of neighborhood. Last week an armed robber shot up the grocery store in front of my house.”

However, there is a pervasive misconception that lower-income communities are “less safe” than higher-income communities. Affordable housing is often located in areas that have a higher proportion of Black and Latino residents than average, which some people with disabilities or our families may view as “less safe” due to racial bias (Tegeler, Korman, Reece, & Haberle, 2011). Our attendees thought that policymakers should work to create affordable housing units in more areas, and proactively address systemic inequities, rather than exclude or stigmatize any particular locations.

BELONGING

People with disabilities don’t just need to access the community. We also need to *belong* to it. We need to form and maintain relationships with people who aren’t paid to spend time with us, have our safety and privacy protected, and receive services that take into account the diversity of our experiences. We determined that discussions of **relationships, privacy and safety**, and **intersectionality** at the summit related to the broader theme of belonging.

Relationships

“To me, one of the most important things about community is the access to the reciprocal, voluntary, chosen relationships that you want. And that means being able to go to [the] places where [there are] people that are interested in what you’re interested in... .” —Cal Montgomery

It’s important for disabled people to have healthy, sustaining relationships with people other than paid support staff and family caregivers. We all deserve to find, strengthen, and maintain relationships with our families (including pets), spouses and partners, friends, and colleagues. Unfortunately, when disabled people are isolated from the rest of the community and lack adequate supports, it is more difficult for us to engage in those relationships. DJ Savarese said that good supports “don’t disrupt my natural, unpaid relationships,” and Cal Montgomery added that good supporters should go further and help people make friendships with people who aren’t staff or family members.

We have the right to be parents and receive support to take care of our children. Parents with disabilities should be able to access help without losing parental rights. One of our summit attendees, who is a parent, said,

“It would be nice if I could get support with that [parenting]. Luckily, I’ve had some natural supports that have been helping me. My husband [had to be] in the delivery room the whole time because I did not want someone to come in and take my child. Because I know that happens to disabled people a lot. So I had to do a lot of preplanning and take extra classes just so that wouldn’t happen to me. But not everybody has those resources or those natural supports to be able to do that. [...] We need to allow for people to start and support their own families.”

In 2012, the National Council on Disability published a report, *Rocking the Cradle*, making the case for the rights of parents with disabilities and recommending that states pass laws protecting them from discrimination in family court (pp. 15-37). *Rocking the Cradle* also recommends that CMS expand its definition of activities of daily living (ADLs) to include parenting, as parenting is indeed a critical daily task and people with disabilities are currently unable to include parenting support as one of their government-funded Personal Assistant Services (PAS) (National Council on Disability,

pp. 195-250). Doing so would help parents with disabilities care for our children and supports our right to be parents. Research and advocacy programs like *Through the Looking Glass* (2019) and the National Research Center for Parents with Disabilities (2019) also provide data and personal narratives on the experiences of parents with disabilities and the importance of supporting our right to be parents.

Access to supports can affect our relationships with our families, friends, and partners. People ineligible to receive government-subsidized supports often have to rely on support from family, spouses or partners, and friends. As noted in the “Support Needs and Systems” section, not all people with disabilities have family on whom they can depend for support. When we do have these natural supports, however, it may complicate our relationships with the individuals we are receiving support from. Ivanova Smith relies on her husband to provide support that others receive through Medicaid. She said, “Medicaid has a monopoly on long-term support services. I really wish that my private insurance from my husband’s work would pay for long-term support services for me, so that it’s not always on my husband and that he gets a break and is allowed to be my husband. I’m glad he’s my natural support, but he shouldn’t have to do it all by himself.” Smith was also worried that her daughter would feel pressured to become a natural support for her in the future; her priority was to preserve the mother/daughter relationship instead of reversing roles.

Relationships aren’t just human ones. Summit attendees—Cal Montgomery in particular—noted that autistic people and others with disabilities struggle with access to the social environment, but pets and emotional support animals can provide us that well-needed companionship and comfort. The Fair Housing Act (FHA) allows dogs, cats, and other pets to be treated as emotional support animals (ESAs) and be exempt from landlords’ pet bans or fees. However, Montgomery noted that having a pet declared an ESA requires that the owner see a mental-health professional to provide verification, which may be difficult depending on our access to health coverage (Humane Society of the United States, 2018). Even if our health plans give us access to multiple providers, a potential client will have to interview multiple people to find one who works well with them. An owner must also know the FHA provisions in the first place to ask a provider for a letter verifying the need for an ESA (Humane Society of the United States, 2018). Increasing access to animal-friendly housing makes it easier for people with disabilities to maintain our relationships with support animals without the red tape, interviews, and legal battles associated with the official ESA process.

Privacy and Safety

Integrating people with disabilities in the community also includes ensuring that we’re safe and have a right to privacy. Being part of the community means that we can live, work, and play without worrying constantly about being threatened, assaulted, or exploited by other community members. If we don’t feel safe in the community, then it’s unlikely that we’ll feel as though we belong within it.

Privacy

Our privacy matters. We should be able to feel comfortable in our spaces by having some of that space to ourselves. The right to privacy is connected to presuming competence and respecting autonomy: we should be able to control our own space and who enters it.

We should be able to avoid being monitored by others. Ivanova Smith said, “I feel it’s important to have some place ... to go that your roommates and care provider don’t know about. You don’t want them telling everybody else your business.” Sometimes safety and privacy intersect with spatial access needs, too. Sam Crane, for example, lives with another person with a disability. To ensure that both of them have privacy when going in and out of their house, they have divided the house into separate units and use separate entrances.

The right to privacy should be independent of concerns related to abuse and neglect. If a support agency does witness abuse or neglect taking place, that agency should not use our right to privacy as an excuse for not reporting the abuse. However, the agency should not report what they see as abuse over the objection of the person with a disability (unless they are required to by law), nor should they take steps to monitor the person with a disability that invade that person’s privacy solely to prevent theoretical abuse (such as cameras in the home or regular unexpected visits). This is a difficult balance to strike. Policymakers, self-advocates, and service providers nonetheless absolutely must devise reporting

mechanisms that allow disabled people to maintain our privacy while also making it easier to get help if we're being abused or exploited.

Technology should be used to protect our privacy, not threaten it. People with disabilities have a wide variety of emerging technologies available to us that help us communicate, manage our health, and navigate our environment, including remote-monitoring software that allows health-care providers to keep track of their patients' health outside their offices (Center for Connected Health Policy, 2018). Some examples of remote monitoring include wireless-enabled glucose meters for people with diabetes or hypoglycemia,, and other internet-enabled durable medical equipment (Center for Connected Health Policy, 2018). Finn Gardiner mentioned that he uses a PAP machine that sends sleep data to his pulmonologist. Cal Montgomery added that some AAC devices also record everything users type, presumably for speech therapists to help people "communicate better." Unfortunately, this can be a gross invasion of privacy, especially if someone uses an AAC device to talk about intimate relationships or other topics they don't feel comfortable sharing with their speech therapist.

Internet-enabled assistive technology and telehealth are two-edged swords. Telehealth (sometimes called "telemedicine") is a broad term for health-care services delivered remotely to patients, including online medical records, videoconferencing, and remote monitoring (American Medical Association). On the one hand, remote monitoring and remote visiting may be helpful to track patients' health. For example, remote communication and monitoring can help patients who cannot easily visit their clinicians' offices regularly. On the other hand, these technologies can restrict the autonomy, safety, and community integration of disabled people. An attendee mentioned that some agencies that use Electronic Visit Verification (EVV) require support staff to check in as soon as they start work, and disallow staff from leaving the premises, preventing clients from planning outings with their supporters. Attendees urged policymakers to ensure that users can decide exactly who can view their private data. They also agreed that providers should not use these tools to track people with disabilities without significant oversight. Summit attendees recommended that public and private health-care administrators create clear guidelines for the use of remote technologies for tracking and surveillance of patients from vulnerable populations.

Safety

Our definitions of safety vary from mainstream perceptions of safety (Autistic Self Advocacy Network, 2017). Some "solutions" supposedly intended to protect us are actually **unsafe**, including the police, institutionalization, and legal guardianship of adults with disabilities.

The Police and Safety

Encounters with the police are not intrinsically safe. Members of vulnerable populations, like Black people, the Latinx community, and people with disabilities, risk being harmed by the police rather than being helped. In 2011, a young Black autistic man, Neli Latson, was arrested for sitting outside a public library and attempting to prevent a police officer from attacking him (Cevik, 2014).

When "protection" and "safety" result in death or long-term injury, we must reconsider what protection and safety means for people who are multiply marginalized. Living near the police is not necessarily safe, especially for people who are at a high risk of being racially profiled. The association between safety and the presence of police officers arises from classist, racist, ableist assumptions that everyone can live in expensive gated communities or receive protection from the police. Sam Crane said, "[Service providers will] assume certain neighborhoods are safe neighborhoods. A neighborhood where everyone calls the cops on someone who's doing something different is not a safe neighborhood."

It can be better to know that the people in your community have your back than it is for the police to be nearby. Ivanova Smith called this the "community involvement test." A person who cannot explain their disability to the police may especially benefit from active community support. Ben McGann, for example, is black, autistic, and non-speaking; he said he feared being stopped by the police because he cannot explain to them that he is autistic. When he was going through a non-speaking period, Cal Montgomery had police "come at [him] with guns for trying to go on a subway with a wheelchair, which is not actually a crime."

Attendees were also concerned about police autism registries and other mechanisms that agencies use to supposedly protect disabled people, including live GPS trackers for police officers to identify all autistic people on a local registry (Greenberg, 2017). Julia Bascom said, “There’s one tech emerging where not only is there a registry, but it’s a live GPS, so it’s tracking you so every cop in the area knows you’re there.” In a joint research project involving the University of Massachusetts Medical School, the Human Services Research Institute, and ASAN on autism registries, respondents to a survey said they were less likely to feel comfortable with the police accessing personally identifiable information about them than other classes of individuals, such as doctors (Bonardi and Gardiner, 2016).

Abuse, Neglect, and Safety

Protecting us from abuse doesn’t mean that we have to lose our autonomy. Like the police, congregate living sites and guardianship are not intrinsically safe for us. They can actually introduce *new* dangers.

Cal Montgomery said, “Group homes may force you to be out doing things you may consider [...] risky to yourself or your sensory environment. It’s a risk to your disability accessibility.” They may require people to share rooms with people that they don’t know or trust.

Reporting abuse should not come with an implicit or explicit threat to have people with disabilities placed under guardianship. Julia Bascom mentioned that in many cases, disability agencies recommend placing disabled people under guardianship after an incident of physical or sexual assault. Guardianship severely limits the level of control disabled people have over our lives.

Allowing another person to have control over our lives may actually make it **easier** for unscrupulous people to exploit us. Isolating and restricting people with disabilities creates a higher risk of abuse and neglect than allowing us more autonomy (Autistic Self Advocacy Network, Research on Autism and Safety, 2017). Non-disabled people are unlikely to worry about being placed under guardianship or losing their right to live autonomously because they are the victims of abuse. The same should apply to people with disabilities. Nicole LeBlanc criticized the idea that guardianship automatically ensures that people with disabilities will be safe from “stranger danger” and similar threats; indeed, the opposite was true for her.

Supported decision-making is an alternative to guardianship that lets disabled people decide what we want to do while still getting help. People who use supported decision-making enlist the aid of family, friends, and other supporters to help them identify their needs and connect them to services. Cal Montgomery suggested microboards as a form of supported decision-making. Montgomery described microboards as “a network of people who care about [a disabled person]. Friendships. Family relationships. Those who are trusted. Together they figure out what the person wants. And then they go out and find money to do it.” Julia Bascom added that adopting microboards or other forms of supported decision-making should take into account other life circumstances: “And if I don’t have a lot of natural supports, or a family who can step in to do that, or if I’m a mother who cares really deeply about my adult son with a disability, but I have five other kids, and I’m working two jobs, and English isn’t my first language, and no one wants to help... How can [these individuals] use [these] concepts?” Montgomery suggested that policymakers and supportive services should look at support systems that work well for people who have more resources and replicate them for those who have fewer resources.

Agencies should be vigilant about identifying abuse, health problems, and exploitation, but should use caution in how they respond to these forms of maltreatment. Julia Bascom pointed out that agencies may not report clear-cut cases of abuse by their staff, while they disallow clients from staying out late because they may theoretically be mugged. Attendees noted that different kinds of maltreatment need tailored responses, too; internet scams and stolen credit cards are unlikely to require the intervention of Adult Protective Services, unlike a sexually abusive caregiver or a violent spouse.

The same thoughtful approach should apply to reporting health problems. For example, Cal Montgomery mentioned that many universities will call 911 on any student having a seizure, regardless of the severity. The university requires that everyone call 911 in these cases, even though there is no explicit legal requirement to do so. The university’s one-size-fits-all approach to calling 911 wastes time, money, and other resources.

Reports about agency staff should be investigated thoroughly to ensure that abusive staff are dismissed. An independent ombudsman program can help ensure objectivity in abuse investigations. For example, Ivanova Smith mentioned Washington State’s Developmental Disability Ombuds office, a private, independent agency that oversees state developmental disability services and handles clients’ complaints (Office of Developmental Disability Ombudsman, 2017).

Providers should also be careful to distinguish premeditated abuse from meltdowns, difficulties with motor skills, and other actions that are not intended to hurt others. A client’s meltdown that results in a staff member being hit does not automatically constitute abuse. During meltdowns, autistic people and other people with disabilities have less motor control than we would otherwise. Motor disabilities like cerebral palsy affect how people enter others’ personal space. Cerebral palsy can make it more difficult for people to drive their wheelchairs, causing them to bump into people by accident when they are trying to approach them to have a conversation. Cal Montgomery said, “We have a hard time [...] distinguishing [from abusers] people who are not in control of their bodies at a given moment or who are really provoked in subtle ways that other people don’t recognize. They’re actually being threatened.”

Intersectionality

Summit attendees emphasized that **disability does not exist in a vacuum. The effects of systemic ableism intersect with other forms of marginalization and oppression, like racism, misogyny, classism, homophobia, and transphobia.** Culture, race, class, disability, gender, sexuality, language, education, family, and other characteristics all play roles in our lives, and thoughtful policy and practice should take those roles into account. It’s important for disability advocacy groups and service providers to place the voices of disabled people who experience multiple forms of marginalization at the forefront—hiring us, including us in stakeholder meetings, speaking to us as consultants—to ensure that they can best support us.

Supporters’ perceptions of, and attitudes about, power intersect with different kinds of marginalization. Policymakers and program coordinators should pay attention to class-, race-, or gender-based power differentials between paid staff and disabled clients. Racist and classist attitudes about employment affect the way some agencies and staff see our needs in the workplace. Finn Gardiner said that his African American heritage made him acutely sensitive to the racist implications of shunting people with disabilities into low-skilled agricultural work, saying that “people like my grandparents and great-grandparents on my father’s side were working on farms in the Carolinas.” He also likened residential programs that combine jobs and housing to the social dynamics of antebellum slavery.

Power differentials are multidimensional, too. For instance, a white middle class staff person could be serving a working-class disabled person of color. The power differential in this situation would compound upon itself. To address the power imbalance, Cal Montgomery suggested providing support to staff members themselves. Montgomery said, “I think we need to be providing supports to support workers in thinking about these ethical issues. It’s not generally a field that people go into who have had a lot of ethics [training].” Julia Bascom agreed, adding that some people think of power imbalances as mere personality conflicts rather than the civil rights issues they are. Power dynamics can also be more complex and difficult to address.

Relationships that involve multiple interlocking forms of oppression or cultural considerations aren’t limited to those between paid support staff and clients. In some cultures, families take a more active role in decision-making for all of their adult children without considering them less autonomous. Similarly, as described in the “Support Needs and Systems” section, if an LGBTQ person lives with homophobic or transphobic relatives who refuse to support them, they will not have the same natural familial supports that others have. Socioeconomic status can also affect the availability of family support; some disabled people’s relatives cannot afford to become unpaid caregivers without risking their jobs.

“And there’s always people with physical and intellectual disabilities. They have both. So why don’t they get to sit at the table, too?” — Ivanova Smith

People can have more than one disability, and cross-disability advocacy involves being aware of what various disability communities need. Disability advocacy groups have developed different vocabulary, strategies, and community norms. When people have multiple disabilities, it can sometimes be difficult to navigate those intersections.

For example, many autistic advocates prefer identity-first language (autistic people) versus person-first language (people with autism), as do many Deaf and hard-of-hearing people. People with intellectual disabilities often prefer person-first language. Ivanova Smith said, “In the [intellectual disability] self-advocacy movement, a lot of people want to use people-first language, but then they get ostracized from people that demand we only use identity-first language. You know, you’re just fighting over words.”

Smith also noted:

“I understand that a lot of people hate person-first language, but if you look at the history of the self-advocacy movement, there’s a reason why [previously institutionalized people prefer person-first language.] And [using identity-first language] ... it’s kind of triggering because a lot of people in the self-advocacy movement, especially the older people, were institutionalized, and they feel the reason they were institutionalized is because of that label, [disabled]. And so that’s why they say people first, because they want to just remind people, ‘I’m a person.’”

Similar tensions can exist among other disability advocacy groups if people don’t understand the views of people with other disabilities. For example, a group focused on physical disability may not be as welcoming to people with other disabilities. Far too often, people will say things like “My mind is fine,” or “At least I can walk.” These are divisive, ableist stereotypes.

POLICY BARRIERS AND REFORMS

Ensuring that service providers foster inclusion, increase accessibility, keep people with disabilities out of institutions, and respect our autonomy requires wide-ranging, systemic change. Unfortunately, there are a number of legal and regulatory barriers that restrict disabled people’s full and equal participation in the community. These policy barriers can relate to: **publicly funded supports such as Medicaid and Social Security, obtaining high-quality support services, employment, enforcement, and affordable housing.**

Publicly Funded Supports: Medicaid and Social Security

Public programs like Medicaid and Social Security form the bedrock of service provision for many people with disabilities. Medicaid is typically the primary payer for home- and community-based services (Reeves and Musumeci, 2015). Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) give people with disabilities income they need to survive. Eligibility for Medicaid and Social Security also guarantees access to other services and supports. Unfortunately, applying for and receiving these benefits is a difficult, time-consuming process.

Medicaid: Eligibility and Service Provision

“They have told me over and over again, ‘We’re not opening this gate for you.’” —Ivanova Smith

Many disabled people rely on Medicaid to receive services and supports that allow us to live in the community. Unfortunately, Medicaid isn’t open to all of us. Beneficiaries must have low incomes to access Medicaid-funded services, and additionally beneficiaries must meet their state’s eligibility criteria (such as a particular type or degree of disability a person must have in order to receive specific classes of Medicaid-funded services). While some states like New York (New York State Department of Health, 2018) Texas (Texas Health and Human Services) and Massachusetts (Kaiser Family Foundation, 2015) have a Medicaid buy-in program for people who qualify for its services but have incomes above the state cutoff, this is not universal (National Disability Navigator Resource Collaborative, 2014). Disabled people who cannot use Medicaid must rely on informal supports, which may be less reliable in the long run. Ivanova Smith said, “Medicaid has a monopoly on long-term support services,” and that “insurance companies should have to pay for long-term support services to DD people, too, because [...] I don’t really want the government telling me how much I can make.”

These restrictions are especially burdensome in states that refused the Affordable Care Act (ACA)’s Medicaid expansion. In states like Texas, Georgia, Florida, and North Carolina, adults under 65 who are ineligible for Medicaid, Medicare, ACA subsidies, or employer-sponsored insurance are often uninsured, especially if they do not have dependent children; these people are said to be in the “coverage gap” (Garfield, Damico, & Orgera, 2018). One in five adults in the coverage

gap report having fair to poor health, indicating possible disability (Garfield, Damico, & Orgera, 2018). There is also a racial dimension to the coverage gap; low-income white people under 65 are more likely to be insured than are members of other racial or ethnic groups (Garfield, Damico, and Orgera, 2018).

Other attendees worried that the Trump administration would follow through with threats to allow states to impose work requirements on Medicaid beneficiaries. When a program has a work requirement, people have to find jobs or do volunteer work in exchange for receiving benefits. Not long after the summit, Legal Aid of Arkansas, the National Health Law Program, and the Southern Poverty Law Center sued the U.S. Department of Health and Human Services for allowing Arkansas to implement its proposed work requirement (Southern Poverty Law Center, 2018; Tracer and Tozzi, 2018).

Difficulties with accessing services through Medicaid aren't limited to eligibility. Even when people with disabilities are eligible for Medicaid, we may not be able to access necessary supports because of strict rules on what it covers. Though many people with disabilities use laptops, tablets, and smartphones to communicate, plan, and schedule, some states' Medicaid programs will not cover these devices because they are not dedicated support devices. New York State's Medicaid program, for instance, bans coverage of non-dedicated speech devices (New York State Department of Health, 2012). This means that Medicaid will pay for more expensive text-to-speech devices like Dynavox PCs (Tobii Dynavox) and tablets that can only access AAC software, while refusing to cover a stock iPad or another tablet.

Social Security: Eligibility gatekeeping

Medicaid is not the only government program that has erected barriers to receiving support. The Social Security Administration uses burdensome criteria to determine whether an applicant is eligible to receive disability benefits. This standard typically requires that a potential claimant have a medical condition that prevents them from working for over a year, or a terminal illness (U.S. Social Security Administration, 2018). Sometimes agencies' disability-determination procedures may be unrelated to the actual reason the person requires services; when Finn Gardiner applied for SSI benefits in his 20s, his claim was rejected based on the results of an IQ test the SSA ordered when his application had nothing to do with IQ.

Being wrongly determined "not disabled" by agencies is a barrier to accessing services. Cal Montgomery mentioned that people who are not determined disabled may be forced to participate in work requirements. Another summit attendee said they were "dumped off of SSI" because they were determined to be "not disabled." One way to increase the availability of supports is to implement a determination system that uses the ADA's broader guidelines of what constitutes a disability (42 U.S. Code § 12101).

Social Security rules can also affect supporters. Adults with disabilities who use Social Security benefits based on a parent's work credits are not allowed to legally marry without losing access to benefits unless their spouse is another Social Security beneficiary who meets highly specific criteria (Ervin, 2016; Bush, 2005). This can make community living more difficult for a disabled person whose spouse is an informal supporter; civil marriage has automatic legal benefits that other adult relationships do not.

Quality and Provision of Support Services

While public funding sources do exist for some home- and community-based services, there is still room for improvement. People with I/DD often receive services through a waiver--the Home- and Community-Based Services waiver. The waiver allows for home and community-based (HCBS) services to be delivered to a person at home, rather than in an institution (Home and Community Based Services Final Rule, 2014). Often, people with disabilities nonetheless live in congregate sites because it is comparatively easier to fund these services, or because the State has been slow to bring its HCBS settings into full compliance with the HCBS Settings Rule. The State may also be funding services using HCBS waiver funds that *are* delivered in congregate sites, due to a limited or overly rigid interpretation of the HCBS Settings Rule (i.e. adhering to the specific requirements of the Rule in practice, but not in spirit). Additionally, long waiting lists for services, enrollment caps, and limits on the number of hours of services or type of services a beneficiary can get can also make it harder for people with disabilities to access Medicaid-funded HCBS services.

Policy Enforcement

Laws and regulations may state our rights in theory, but enforcement makes them real to us in practice. Laws that would benefit from more stringent enforcement include the Americans with Disabilities Act, the Fair Housing Act, the Individuals with Disabilities Education Act, and other federal and state statutes. They also include Supreme Court rulings, like *Olmstead v. L.C.*, which ruled that the Americans with Disabilities Act applied to the provision of long term services and supports by state Medicaid agencies. Enforcement is especially important in an era in which state and federal officials have tried to erode protections for people with disabilities.

Policymakers should also be aware of organizations trying to use the Settings Rule to create congregate living settings that are institutions in all but name. Scott Robertson noted that the Medicaid HCBS Settings Rule was created in part to prevent segregated gated communities from declaring themselves “community-based.” Cal Montgomery agreed, adding that some service providers were closing institutions and building scattered-site cottages on the same land, which Robertson likened to “shuffling chairs on the *Titanic*.” Enforcing the Settings Rule more vigorously will help prevent unscrupulous agencies from creating neo-institutions that masquerade as community-based care.

Housing

Federal, state, and local policies regarding the housing supply make it more difficult for people with disabilities to find housing that is accessible and affordable. These policy barriers include zoning laws, strict means-tested criteria for Section 8 benefits, and the comparatively limited scope of the Fair Housing Act.

Zoning laws make it more difficult for cities and towns to allow the creation of accessible housing units. Sam Crane mentioned that if there is more than one kitchen and entrance in a single house, some regional governments require zoning approval to ensure that the unit is still considered a single-family home. Zoning laws can affect access to services in other ways, too. In crowded housing markets like San Francisco, some enterprising landlords illegally turn single-family homes into apartments by converting garages, basements, or bedrooms into apartment units (City and County of San Francisco, 2018; Semuels, 2016).

The strict means testing used in the Section 8 voucher program is also a barrier for people whose income may be just above the threshold, but isn't high enough to afford average rents in their areas. Policies addressing housing access must ensure that units are accessible and affordable for people with disabilities regardless of our income; ensuring accessibility must not be associated with a concomitant poverty trap like those of Section 8 and Medicaid.

Federal laws should also be reformed to provide us with more accessible housing options. Certain protections for disabled people under the Fair Housing Act (FHA) are less extensive than those of the ADA (Diaz, 2014). The FHA covers private accommodations, while the ADA focuses on public accommodations like restaurants and hotels (Diaz, 2014). The ADA requires that older buildings be retrofitted for accessibility, while the FHA does not, making it more difficult for people to find accessible housing in areas where most available housing is older (Diaz, 2014).

The FHA is also a “reactive” statute; unlike the ADA, the FHA does not require landlords to modify their property for accessibility until a disabled resident brings forth a complaint (Diaz, 2014). Scott Robertson noted that disabled people can receive some accommodations via the FHA, but that reporting those needs is highly dependent on executive functioning, and that it is easier to get accommodations at a hotel under Title III of the ADA than it can be to get accommodations at home. Robertson also added that landlords are less well-trained on disability compared to accessibility coordinators on sites governed by the ADA.

One step toward improving housing accessibility could involve incorporating some of the ADA's stipulations into a future congressional reauthorization of the FHA. Robertson encouraged collaboration with the Department of Housing and Urban Development (HUD) and the Administration on Community Living (ACL) to strengthen federal housing policy for people with disabilities. He urged that disability advocates push state policymakers to “embed our values into policy” by delineating our housing rights. Robertson added that policymakers and researchers could define priorities

from state data on community living and housing, like the data collected by Pennsylvania’s Bureau of Autism Services. Ari Ne’eman additionally urged that policymakers use “more aggressive enforcement of the Fair Housing Act regarding landlords and tenants with disabilities,” primarily by pushing the Department of Justice and attorneys to compel landlords to adhere to the law.

CONCLUSION

Throughout the summit, our interviews, and the preparation of this report, we shared conceptual definitions of what community living looks like to us. Our discussions were as complex as the concept of community living itself, and ranged from what real community-based housing looks like, to apps that remind us when to eat, to ways policymakers and researchers can facilitate true inclusion. We may have disagreed about specific methods, but we agreed on a set of underlying principles: self-determination is vital, community living is about more than just the location of your home, living in the community is about living in freedom, and more needs to be done to make community living accessible and affordable to us.

Underlying these theoretical discussions are real concerns that people encounter throughout their everyday lives: being paid a living wage for our work, spending time with the people we love, raising a family, trying new things, and having a safe, comfortable, and accessible home. Most of these things are treated as a given for people without disabilities. Belonging, fair treatment, justice, and inclusion should be a given for people with disabilities, too.

Ultimately, community living policy is about recognizing the humanity of disabled people. *We have the right to community living because we are people.* We hope that this report will help guide policymakers, researchers, advocates, and service providers and serve as a foundation for the difficult task of shaping and reforming programs and policies that affirm that essential truth.

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