

Universal Themes



“I would like to see our children with this disability have the same chance to be like the rest of the ‘normal world.’”–Survey Comment

What improvements could have impact across areas?

There were issues that crossed all topical areas in the summit and thus can be considered universal themes. As will be seen in the following discussion of how these issues came up in each area, they are highly interrelated and relevant to quality of life. It can be concluded that considering these issues and making improvements whenever possible could have broad impact.

Transportation

- **Housing Arrangements:** Transportation was brought up frequently as a critical issue relevant to housing. Participants expressed needs for more transportation options and more expansive systems of transportation. It was noted that location of housing needed to consider closeness to accessible transportation, and distance from grocery stores, shopping centers, food banks, and shelters. Transportation was also a factor in making community activities accessible.
- **Advocacy:** Lack of accessible transportation was noted as a physical barrier to people with disabilities, increasing the negative impact of a disability and preventing or limiting participation in all dimensions of community living.
- **Relationships:** Access to transportation was noted as critical to preventing social isolation. It was noted as necessary for accessing information and supports for developing healthy relationships, as well as for participating in social activities. Independent access to transportation was noted as a factor to facilitate freedom of choice and privacy in relationships that people without disabilities take for granted.
- **Economic Wellbeing:** Individual access to reliable and consistent transportation was noted as crucial to economic wellbeing, particularly in adolescence and continuing across the lifespan. It was noted as essential for the ability to successfully hold down a job, and to participate in volunteer and leisure activities. One survey respondent noted that the ability to be punctual is often a factor in whether or not an employer will choose to hire the person with a disability or another applicant for a job.
- **Health:** Reliable transportation was noted as a necessity for getting to and from medical appointments and wellness activities within time constraints. For more rural communities, it was noted that reliable and affordable transportation extended to travelling to more urban communities to access necessary services.

Inclusion

Something mentioned periodically by people in the summit and in survey comments was that not every person with a disability wants the same things or has the same capacity. This particularly came up in talking about issues relevant to inclusion. It is worth reminding readers of this report that the population of people with disabilities is highly diverse. Inclusion is about removing societal or systematic barriers that single out and exclude people with disabilities. What a person might choose is dictated by unique personal goals, values, and desires, as well as strengths and limitations.

- **Housing Arrangements:** Inclusion was expressed as a need for more housing options that are fully integrated with other people in the community, and to be included in community activities. It was noted that all people should have the option to spend time with their peers across the lifespan – with other children, adolescents, adults, and seniors. Considerations mentioned for location of housing included proximity to schools, spaces for meeting, and inclusion in emergency preparedness.
- **Advocacy:** Inclusion was largely addressed in the context of being involved in the decisions that impact one's own life, to be invited to the table for policy development, and to be considered for government, community, and cultural leadership roles.
- **Relationships:** Inclusion was addressed in the context of human rights in relationships. Participants noted fears and stigmas as barriers to accessing the same social activities as other people. It was noted that more natural supports from peers might better facilitate social inclusion.
- **Economic Wellbeing:** Inclusion was addressed in terms of being able to participate with other people in activities and opportunities related to improving access to employment. This included expectations for education and employment, and participation in job/career exploration, internships, and volunteer opportunities. It also included access to the same technology resources as peers.
- **Health:** Inclusion was addressed in the context of wellness, such as inclusion in sports, clubs, and drama activities. It was also addressed in the context of the respect that is afforded to other people to be informed and to be included in decisions about medications, approaches to healing (e.g., holistic, alternative, traditional), and personal health behaviors.

Advocacy

Advocacy was a topic of the summit with focused attention on its own merits. Those results were covered earlier in this report. However, advocacy was also brought up under other topics in the context of strategies. Generally, advocacy as a strategy was relevant to both self-advocates and other advocates.

- **Housing Arrangements:** Advocacy was noted as a strategy to increase housing opportunities for people with disabilities so that they have choices like other people about where they live and with whom.
- **Relationships:** Advocacy was noted as a strategy to ensure people with disabilities have a voice. Awareness for parents could enable them to advocate for the rights of their children with disabilities to participate in summer camps, both day camps and overnight camps. Another specific strategy was supporting self-advocates to educate the public about people with disabilities, to dispel the myths and stereotypes that are barriers to their participation in the social fabric of the community.
- **Economic Wellbeing:** Advocacy was noted as a strategy to increase the services necessary to facilitate economic wellbeing across the lifespan, to inform the public and employers about the value and contributions of people with disabilities, and to develop partnerships in the community to increase opportunities for employment of people with disabilities.
- **Health:** Advocacy was noted as a strategy to help address the long list of issues related to improving the quality of healthcare and access to healthcare. It was noted as a specific strategy to help reduce overuse of medication in foster care. Helping people understand healthcare, their needs and options, along with self-advocacy training was a specific strategy to enable people to make choices about their own bodies. Patient advocacy was also mentioned in the context of a team approach to making health and healthcare decisions.

Equality

- **Housing Arrangements:** Equality was brought up in the context of being considered equally valued in interdependent relationships among fellow residents in neighborhoods. It was also addressed in having individual and family housing options equal to peers who are not dealing with disabilities.
- **Advocacy:** Participants expressed a need to advocate for people with disabilities to have equality under the law with people who do not have disabilities, with equal access to due process.
- **Relationships:** Equality was framed as an issue of human rights in the context of relationships. Participants expressed a need for people with disabilities to receive the same respect and dignity afforded to other people, including the right to explore their own values and beliefs, and to be supported in making their own choices in friendships, romantic relationships, and marriage.

An issue that came up in relationships, and also in the next two topical areas was the right afforded to people in U.S. culture to take risks and to make mistakes, and consequently to learn from their own successes and failures. Participants voiced this as something that is taken for granted for everyone else, but often denied to people with disabilities

- **Economic Wellbeing:** Equality was mostly an issue of access to the same educational and experiential opportunities designed to prepare people for economic security. It included giving families an equal voice in setting goals and making plans for the future economic security of their children.
- **Health:** Equality was an issue of both rights and access in the context of health. Participants did not want life and health denied to people because they have disabilities. They wanted to see equal access to treatment, preventive services, health education, and wellness activities. This included equal access to faith-based and alternative medicine approaches.

Accessibility

- **Housing Arrangements:** Accessibility was brought up frequently in the context of housing. Participants asked for both more accessible homes and more ability to make homes accessible. Universal Design was brought up as a specific strategy for the former, while it was noted the latter would need more landlords willing to allow modifications, as well as more resources to make modifications. Accessibility was also discussed in the context of a need for increased participation in the community, making more places and activities accessible to people with disabilities.
- **Advocacy:** It was noted that utilizing advocacy to increase public awareness about people with disabilities could help encourage increased accessibility across the community.
- **Relationships:** In the context of relationships, accessibility was largely addressed in terms of making existing curriculum and information resources accessible to students with disabilities, so they could participate in the same classes and use the same resources as their peers. This included health and sex education in schools and using technology-based social resources.
- **Economic Wellbeing:** Accessibility was largely addressed in terms of making existing activities in schools aimed at future employment accessible for students with disabilities. For adults, it was making employee assistance programs and financial planning resources accessible to people with disabilities.
- **Health:** In the context of healthcare, it was noted medical and service facilities needed to be more accessible. It was also noted medical information needed to be more accessible so people with disabilities could make informed decisions. Examples were information about medications, contraceptives, and conditions related to aging. Similarly in the context of wellness it was noted that health clubs and churches needed to be more accessible, as well as wellness information on topics such as diet and nutrition.

Choice

- **Housing Arrangements:** People mentioned needs for more diverse options for housing, including choices of where to live, who to live with, and routines. It was noted that personal perspectives based on individual values, goals, family, and culture should be respected, and that there should be flexibility in funding to accommodate reasonable choices.
- **Advocacy:** In discussions around advocacy, choice was an issue of freedom – the freedom to make choices, to express desires and opinions, and to have them respected whether or not others agreed with them. A specific issue mentioned was the freedom to choose how to eat, particularly a healthier diet, often denied to people in assisted living.
- **Relationships:** Choice was about the freedom to choose relationships, particularly romantic relationships, based on one’s own values and desires, not controlled by the opposing values and desires of others or restricted by regulations. It was also an issue in social activities, choosing where to go to meet people. It was acknowledged that choice and privacy had to be balanced with risk and safety, but people wanted to see more freedom to make choices in relationships like what is afforded to peers without disabilities, including the opportunity to learn from bad choices.
- **Economic Wellbeing:** In discussing economic wellbeing, choice was largely an issue relevant to developing a career. This included access to resources for early preparation. It was noted that the system should support career development based on individual capacity and choice, allowing more time for training or education as appropriate. It was also noted that a choice to stay in one’s own home and age in place might well be a factor in economic wellbeing.
- **Health:** Choice was an issue integral to every aspect of health – being able to choose providers and approaches to health and healing. Spiritual and cultural approaches were mentioned, in addition to alternative medicines and therapies, prevention services, and wellness goals and activities. Access to understandable and transparent information, and flexibility in funding were essential for the ability to make choices.

Flexibility

- **Housing Arrangements:** Flexibility in regulations and licensing was noted as essential to having real choices in housing, to include people in the community, accommodate personal preferences, and to respect cultural values.
- **Advocacy:** The concept “dignity of risk” was noted as a general advocacy issue for quality of life, the flexibility to allow for reasonable risks.
- **Relationships:** In relationships, flexibility was noted in the context of the supports provided to people with disabilities, responding to the diversity of

individual needs and priorities, and recognizing that needs and priorities change over the course of a person's life.

- **Economic Wellbeing:** Flexibility was discussed both in terms of system supports and from the perspective of employers. This included flexibility in supporting different types of work that might not fit the usual mold, as well as flexible workplace policies to accommodate differences. One specific example for flexibility in the system was to allow people to keep benefits when work is temporary in nature, such as seasonal work.
- **Health:** In healthcare, it was noted there needed to be flexibility to provide care on an individualized basis, considering a person's values and beliefs as well as strengths and limitations. This included making adaptations and spending more time with people, as well as more flexibility in how a person's healthcare is funded. It included flexibility in funding to allow for diverse approaches, including alternative medicine.

Safety

- **Housing Arrangements:** Safety was a major topic of discussion in housing, particularly in consideration of where housing is located. Safety and stability were often mentioned together. It was acknowledged this might not mean the same thing to every individual or be the same for every stage of life. Safety was discussed in a community context, such as finding ways for community members to work together on making neighborhoods safe for all residents.
- **Advocacy:** It was noted in discussions of advocacy that people are safer when they are known. It was mentioned that people need safe places to learn about advocacy, and safe avenues for speaking up.
- **Relationships:** Safety was a big issue in discussions about relationships. It was noted as critical for people to be safe from abuse and exploitation. However, the "dignity of risk" was a particularly salient issue, calling for a balance among safety, choice, risk, and privacy in relationships. Safety was brought up frequently in the context of training/education for people with disabilities. "Safe spaces" were mentioned for learning, asking questions, and for socializing with others.
- **Economic Wellbeing:** It was noted a person needs economic stability to be safe. It was connected with safety in housing and relationships.
- **Health:** It was noted that sometimes people make choices in health and wellbeing that conflict with safety, and there is a need for better guidance for families and care providers to navigate this situation.

Public Awareness

Public awareness crossed all topical boundaries as a need for promoting general acceptance and respect for people with disabilities. It was mentioned frequently in the context of reducing stigmas, fears, prejudices, stereotypes, and myths. It was also noted for avoiding apathy and antipathy.

- **Housing Arrangements:** Public awareness was mentioned in terms of improving attitudes toward people with disabilities living in the community.
- **Advocacy:** Public awareness is a core purpose of advocacy. More specific strategies to promote public awareness included using publicity, social media, and cultural champions.
- **Relationships:** Public awareness was relevant to relationships in promoting the acceptance of people with disabilities in social arenas.
- **Economic Wellbeing:** The need to educate the public was brought up by a number of people in discussions of economic wellbeing, particularly regarding the potential of people with disabilities to work and contribute to their communities.
- **Health:** In discussions of health, public awareness about people with disabilities was a means to increase awareness among the people who provide a variety of services in the community for everyone.