2017

Joint Needs Assessment Report

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Summary

This report highlights the life areas of need for Kentuckians with developmental/intellectual disabilities. It also presents the areas of need by stakeholder groups—individuals with disabilities, family members, service providers. Self-advocates identified the following life areas relatively high in terms of need- self-advocacy, community supports, employment, and education. Family members identified following life areas relatively high in terms of need -- self-advocacy, housing, employment, and education. Service providers identified the following life areas relatively high in terms of need -- self-advocacy, transportation, employment, and childcare. Following are some of the issues identified within each high need life area.

Area of Need	Issues
Self- Advocacy	◆ Need for transportation to attend advocacy meetings and information, support, or resources about self-advocacy and advocacy groups ◆ Scarcity of advocacy groups in their area ◆ Complexity of paperwork and programming ◆ Lack of leadership, mentors, and disability pride
Education and Early Intervention	◆ Need for awareness and knowledge of services and technology to assist students with different challenges ◆ Struggles with interventions or the need for proper supports ◆ Need for activities for students with working parents and the importance of providing accommodations early in students' lives ◆ Students faced issues of inclusion in the school and integration into general education classrooms ◆ Issues of school/parent communication and the need for parent training in disability resources and services ◆ Need for increased teacher training in teaching students with disabilities
Childcare	◆ Lack of available childcare providers in general ◆ Lack of personnel trained about special needs ◆ Lack of affordable childcare ◆ Need for childcare before and after school, during the summer, and other times when school is out

Employment	◆ Lack transportation resources to get to work
	◆ Low expectations and lack of acceptance
	◆ Need for support services
	◆ Challenges with social security and SSI rules
	◆ Lack of knowledge about employment
	◆ Employers were either unwilling to employ people with disabilities or lacked awareness of the value people with disabilities bring to the workforce
	◆ Lack of jobs for people with disabilities in their area
	◆ Need for more resources for employment and greater coordination of those resources
Housing	◆ Insufficient appropriate housing, making it effectively unavailable to many
	◆ When housing is available, families often find it unaffordable, inaccessible and unsafe
	◆ Need for education about what to expect in various housing models as well as about existing resources that assist with housing
Transportation	◆ Lack of access to quality transportation that is safe, reliable, and accessible.
	◆ Public transportation, where available, is insufficient in coverage, scope and consistency
	◆ Rural counties have few transportation options or none at all
	◆ When transportation services are available, it is expensive
Community Supports	◆ More funding for Supports for Community Living/Michelle P Waiver slots
	◆ Direct support staff pay is too low, cannot find qualified persons for the position.
	◆ Need of individualized supports
	◆ Need to develop a network of natural supports (outside of paid supports)

Introduction

In late summer 2017, the Commonwealth Council for Developmental Disabilities, Kentucky Protection and Advocacy, and the Human Development Institute (HDI) (University of Kentucky) developed a needs assessment to identify areas of high need for people with disabilities in Kentucky in an effort to assist the above agencies in planning. The survey asked demographic information (including race/ethnicity, gender, county, and type of respondent). Respondents were asked to rate ten areas of life needs on a Likert scale. Table 1 displays the areas of need that were included in the needs assessment. The Likert scale ranged from 1 to 5, with 1-being very low need, 2- low need, 3-moderate need, 4- high need, and 5- very high need. The survey included open-ended questions to gather information on specific issues that individuals faced within a particular area of need. The target audience for the survey included individuals with developmental disabilities, families/caregivers, service providers, and administrators. The survey was available in English and Spanish. The online survey was hosted on Qualtrics, an online survey platform, by the evaluation unit, HDI. The survey link was distributed electronically through various listservs. The survey link was activated in mid-July 2017 and was open until October 31st, 2017.
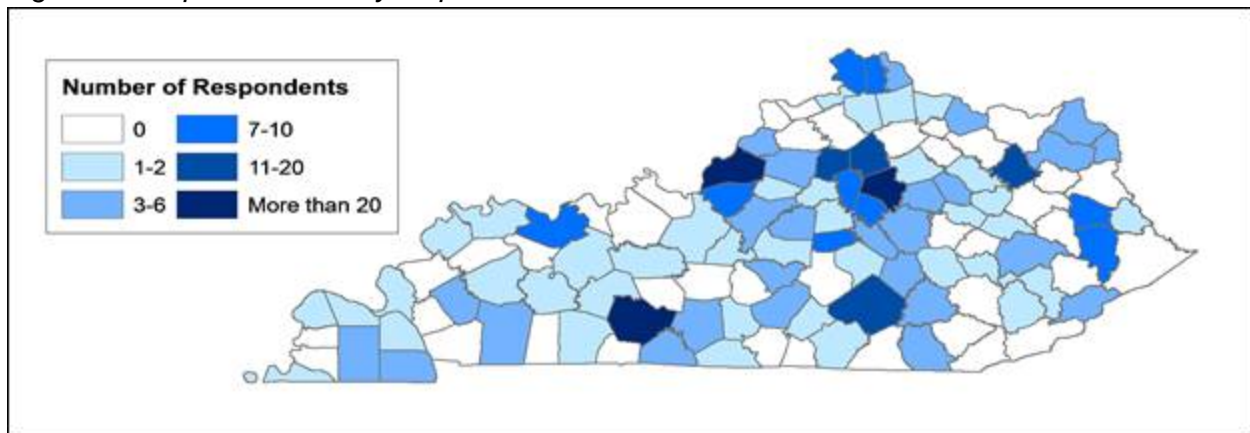
Table 1. Areas of Need Included in the Needs Assessment Survey

Area of Need	Description
Self- Advocacy	Activities that help people with developmental disabilities have as much control as possible over their lives, and to speak on their own behalf
Education and Early Intervention	Activities that support full access to an appropriate education, and to be included in all parts of school life
Childcare	Activities that support children and families in school, before-school, after-school and out-of-school in their communities
Employment	Activities that support paid employment, including supported employment or self-employment
Healthcare	Activities that help people receive coordinated health, dental, mental health, and preventive services in their communities
Health and Wellness	Activities that promote health and wellness in one's community
Housing	Activities that support access to housing in one's community, including help related to renting, owning or modifying an apartment or home
Transportation	Activities that support people having transportation where and when they want to go in their community
Recreation	Activities that support inclusive recreational, leisure and social community events
Community Supports	Activities that enable people to live work and enjoy live in the community

Respondent Demographics

A total of 467 individuals completed the survey. Of the 467 individuals, 76 completed the paper survey. Individuals from 80 counties completed the survey. Figure 1 highlights the respondents' counties. Thirty one percent of the responses came from four counties—Franklin, Warren, Fayette, and Jefferson. Most of the respondents were female (83%). Only 17% of the respondents identified as male. A little more than half of the respondents (54%) reported to be between 40-59 years of age. Twenty-nine percent reported to be between 18-39 years of age and 16% between 60-80 years of age. Ninety-one percent of the respondents identified as White Non-Hispanic, 5% as Black or African American.

Figure 1. Respondent County Map

Respondents were asked to identify by role—service provider, family member/caregiver, individual with a disability, and other. Respondents could choose more than one role. More than half of the respondents (58%) chose the 'service provider' or 'other' option, 37% chose the 'family member or caregiver' option, and finally only 5% of the respondents identified as an individual with a disability. It should be noted that 31 individuals chose more than one stakeholder group. Twenty-seven individuals identified both as family member and a service provider. Seven individuals identified both as an individual with a disability and a service provider. Since each stakeholder group (service provider, family members, self-advocates) provides a unique perspective, the need assessment findings were broken down by stakeholder group. For the individuals who identified in more than one stakeholder group, their voice as family member or a self-advocate was given priority. For example, if an individual identified as both a family member and a service provider, then their response was counted under the family group. This allowed for the non-duplicated comparisons across the three stakeholder groups. The results of the self-advocate stakeholder group should be cautiously interpreted because of the relative low number of respondents. The findings are organized in 3 sections—Section A. Self-advocates; Section B. Family members, and Section C. Service Providers.

Section A. Self-Advocates

Twenty-four individuals with disabilities responded to the Joint Needs Assessment. One respondent did not complete the entire survey. Table 2 displays the results of the needs assessment. Of the 10 life areas, four life areas had overall means above 4.25—self-advocacy, community supports, employment, and education. It should be noted that for self-advocacy not only was the overall mean high but also the variance was low. This indicates there was a high agreement among the respondents that self-advocacy was an area of high need. This section also presents the thematic analysis of the comments provided by the respondents under each life area. This thematic analysis provides further insights of the perceived need within each life area.

Table 2. Overall Means: Self Advocates

Life area*	N	Minimum	Maximum	Mean
Self-Advocacy	23	3	5	**4.52**
Community Supports	21	3	5	**4.43**
Employment	17	3	5	**4.29**
Education/ Early Intervention	22	2	5	**4.27**
HealthCare	21	2	5	4.19
Childcare	21	1	5	4.14
Housing	21	3	5	4.10
Transportation	21	2	5	4.10
Recreation	21	2	5	4.00
Health and Wellness	21	2	5	3.90

*1- Very low need, 2- Low need, 3- Moderate need, 4- High need, 5- Very high need

Self-Advocacy

Self-advocacy was rated 4.52 (overall mean on a 5-point scale) by individuals with disabilities. Several individuals mentioned the need for transportation to and information, support, or resources about self-advocacy and advocacy groups. Other concerns involved a scarcity of advocacy groups in their area; the complexity of paperwork and programming; and a lack of leadership, mentors, and disability pride.

Self-Advocacy	Comments
Information	"Advocates, parents and providers need current information regarding issues important to them individually and as a community." "Knowledge of the laws and the things they are truly able to help or do for them self. The knowledge of support groups that hold self-advocacy meetings so you can learn how to exercise self-advocacy."

	• "Lack of leadership skills, lack of leadership mentors, [and] lack of disability pride."
Transportation and Support	• "Transportation to different local meetings and events to help promote and assist in developing self-advocacy. Support and assistance from caregivers, family, [and] house personnel supporting in several ways to help the advocates in support, encouragement, understanding of the importance, and transportation to the local meetings to allow meeting with other advocates to participate in events and to learn ways to be a self-advocate!"
Scarcity	• "There are not enough support and advocacy groups available." • "Not enough self-advocacy resources in rural areas."
Other	• "Complex paperwork and programming."

Education and Early Intervention

Education and early intervention was rated 4.27 (overall mean on a 5-point scale) by individuals with disabilities. Several individuals mentioned the need for awareness and knowledge of services and technology to assist students with different challenges, and some mentioned struggles with interventions or the need for proper supports. Other concerns included the need for activities for students with working parents and the importance of providing accommodations early in students' lives.

Education and Early Intervention	Comments
Intervention Services	• "Individual who is medically complex, because the medical issue is not visible, has difficulty getting access to assistance. The medical issue is debilitating, but not obvious when looking at them. The individual with IEP is still in school. Franklin County is difficult to work with. If the school doesn't like your child, good luck getting services you need. You'll get what they offer or nothing at all. Intervention services in this county are a real joke." • "The school system does not understand interventions, especially behavioral. The IEP system is majorly flawed, not integrated with pre-intervention services at all. And, that's when you can finally get permission to proceed with an IEP. Check how many IEPs FCPS [Franklin County Public Schools] has allowed in five years."
Awareness	• "The number one issue I think is to educate teachers and counselors, but mostly fellow students to learn about those of us with different challenges and that wheelchairs and other technology is our normal and is nothing to be afraid of or uncomfortable with." • "Community groups and partners need more encouragement and awareness of available services and waiver options within the state." • "Not enough sympathy and empathy. Accessing services, diagnosing, and to make it less complicated to get the services they need."

	• "That the parents do not keep them from a typical education afraid for the for all children and teachers and others in our school systems learn not to be afraid or to be so rude and un-understanding, well to learn to be understanding of people with different challenges."
Early Intervention	• "But not 'interventions' like ABA which are abusive!" • "The earlier that individuals can have access to appropriate accommodations the easier it is to address many of these other needs."
Other	• "Activities for those with working parents."

Childcare

Childcare was rated 4.14 (overall mean on a 5-point scale) by self-advocates. Several self-advocates said there were few or no childcare providers for children with disabilities in their area. Some individuals indicated that providers needed training about how to support individuals with disabilities. Other needs included having inclusive childcare facilities and flexible childcare schedules.

Childcare	Comments
Scarcity	• "There are none, or very minimal options. Childcare centers could be incentivized by the state/funding to offer services for children with disabilities." • "There are none in rural areas." • "Very few resources available in our area."
Training	• "Again, as in the school system, EDUCATION! Teaching teachers, other parents and the fellow students the understanding of those that have disabilities and challenges." • "Childcare providers have no training in de-escalation, trauma-informed care or dealing with difficult students. They are woefully under staffed and untrained." • "Providers, training for how to interact with children with special care." • "Support systems run by autistic people or at least which understand autism."
Other	• "Times services are being provided verses needs." • "Social inclusion is a foundation for other kinds of inclusion."

Healthcare

Healthcare was rated 4.19 (overall mean on a 5-point scale) by individuals with disabilities. Several individuals mentioned that healthcare providers did not want to work with people with disabilities and that medical professionals needed more education and awareness about disabilities. Other concerns involved lack of specialized care, lack of coordinated care between specialists, and the need for support when making decisions related to health.

Healthcare	Comments
Awareness/ Education	• "Medical actual care is usually really good, but as you would call it, the bedside manner, the personal touch, is just not there, more

	than even than young children, our nurses, CNAs, other assistants, respiratory therapy, even our doctors just are so uncomfortable, they assume that we are unable to communicate just because we are also in a wheelchair. To learn we are intelligent, to understand we have feelings, to know we have our own thoughts and opinions. To learn to look at me and talk to me, not whomever else from my family is in the room with me. EDUCATION is so needed, so very important in all of these categories." • "Not enough people advocating in the medical field." • "Lack of providers with disability knowledge, awareness."
Scarcity	• "Many providers do not want to work with individuals with disabilities or are frustrated or refuse to complete the required paperwork associated/required by regulations." • "We need doctors that want to treat patients with ID like the Lee Clinic or Cincinnati Med center." • "Lack of specialized care in our area."
Other	• "If you are an individual with multiple issues, concerning multiple specialists, healthcare is a nightmare. They do not talk to one another to coordinate care." • "Coverage with for specific illness, dentures, and eyeglasses." • "Although parents should take their children to these doctors, the schools should maybe have health fairs to teach the importance, but as young adults start making their own decisions or living on their own, they really need the help to stay on top of their medical care and healthy eating." • "Autistic people usually can't afford health insurance."

Health and Wellness

Health and wellness was rated 3.90 (overall mean on a 5-point scale) by self-advocates. Needs listed included education about proper diet, fitness, and self-care; programs and resources to encourage health, wellness, and prevention; and one person cited a need for dentures to be able to eat properly.

Health and Wellness	Comments
Education	• "Proper diet, to be taught that and helped by caregivers everywhere to be able to attain the healthy meal for our lunches and supper. Really to have caregivers, in particular waivers, assist in proper groceries being bought by advising us at the store, to help us make the best decisions." • "Lack of awareness, education, and funding."
Programs	• "Not enough programs that encourage health and wellbeing and fitness." • "Huge health disparities in our state; disability does not equal unhealthy; we need to educate practitioners about providing accessible health and wellness resources and programming for everyone, with a focus on people with disabilities, to help avoid the

	onset of conditions that can be more disabling than the person's disability!"
Other	• "Not having dentures to chew food properly." • "Number one to just eat and be healthy, to care for them self."

Employment

Employment was rated 4.29 (overall mean on a 5-point scale) by individuals with disabilities. Individuals mentioned that there were few opportunities for employment and that transportation to work was an issue. Other concerns included low expectations, lack of acceptance, the need for support services, challenges with social security and SSI rules, and a lack of knowledge about employment.

Employment	Comments
Scarcity	• "Very hard to find jobs, hard to find things to do." • "Opportunities." • "Only a few jobs that would even consider employing them. No support services even after they are hired. Transportation to/from work is a joke as well." • "Unemployment is very high in our area. Huge lay off for miners which has affected other business in a very negative manner. Therefore, no one is hiring. People leaving the area to find employment to support their families."
Transportation	• "Being realized and accepted, for the public as well as fellow workers to be educated in abilities, and knowledge that a person with developmental disability may still have, for a really good employer to find that little job that someone may do, that usually isn't really paid attention to. Transportation costs are also a real issue for the specialized transportation." • "Transportation. Mock interviews."
Other	• "Not enough employers willing to hire persons with developmental disabilities. Social Security and SSI rules." • "Support paid employment, including supported employment or self-employment seems to be one of the most important topics that these organizations should hold activities to teach the importance of and how to go about it and the benefits of." • "Agency designated to offer the assistance refuses to provide help outside the agency. Only provides for people within agency." • "People with disabilities face low expectations of employers, providers, family and friends. Employment should be expected, strived for, and modeled from the earliest ages. We must improve employment outcomes for people with disabilities in Kentucky. We are a much-needed element of the workforce."

Housing

Housing was rated 4.10 by (overall mean on a 5-point scale) self-advocates. Several mentioned accessibility, affordability, and scarcity of available housing as the major difficulties to gaining housing. Other concerns included regulations and requirements acting as a deterrent to residential providers, the cost of repairs to ADA-approved housing, lack of available information about housing, and a long waitlist for public housing.

Housing	Comments
Affordability	"Accessibility and reasonable costs." "Lack of accessible, affordable housing that promotes full inclusion into one's community." "Autistic people usually can't afford housing (nor anyone else honestly)."
Scarcity	"Again, limited options for residential providers. Lack of funding for residential providers with the increase in regulation and requirements deters possible providers from offering residential." "Very limited houses available for individuals with disabilities." "Limited apartments and housing that are ADA approval. Very costly to make the repairs." "Very limited public housing. Always a huge waiting list for those that are available."
Other	"Housing, Transportation." "To teach this knowledge but even more to have this information available if someone called and needed guidance, help or advice."

Transportation

Transportation, was rated 4.10 (overall mean on a 5-point scale) by individuals with disabilities. Individuals mentioned affordability, accessibility, and scarcity of options as the main challenges to transportation access. Other needs mentioned included more advocacy for diverse transportation options, advocacy to communicate the needs of the disability community to public transportation systems, and assistive technology that helps people with disabilities to drive.

Transportation	Comments
Affordability	"The costs I think is most important; for someone to work, and possibly also a day program, you had going to a couple of Special Olympics practices a week, and a game and then to church, that's a lot of bus rides and the costs add up." "Not accessible, affordable, [and] limited hours of service. Rates vary across the state."
Scarcity	"Limited public transportation." "No taxi or bus service in our area. Only transportation available is LKLP."
Other	"We just need these organizations to lead the desire, the need for transportation, someone bigger than just the advocates to help express this importance and support the need."

	• "Just not enough options. People dismiss the fact that many with disabilities can be independent drivers of motor vehicles when the proper assistive technology is utilized." • "If you can't get somewhere, you can't be included. How might we educate public transportation systems to understand the needs of the disability community?"

Recreation

Recreation was rated 4.00 (overall mean on a 5-point scale) by self-advocates. All but one respondent pointed out that options for recreation were limited. Cost and transportation were also cited, and accessibility was mentioned as well.

Recreation	Comments
Scarcity	• "Limited activities through the year; Special Olympics is a fabulous opportunity but some of the events are only available for a brief time. It would be nice if regular little leagues or public programs had the accessibility for a wheelchair to participate sometimes." • "There are only limited amounts."
Affordability	• "Limited options for low-cost (since people with disabilities are on fixed incomes) activities, methods to get to those activities, etc." • "Income and having funds to participate in recreation is a concern. Limited recreational activities in rural areas." • "Recreational activities in the community are very expensive and transportation is not always available."
Other	• "Feeling empowered to choose your recreation is key for quality of life."

Community Supports

Community supports were rated 4.43 (overall mean on a 5-point scale) by individuals with disabilities. Individuals mentioned accessibility, inclusion, and limited resources as issues in this area. The need for disability awareness and individualized supports were also mentioned.

Community Supports	Comments
Scarcity	• "Transportation, housing, and supports after caregivers died." • "Community supports are on the up and rising but there are still not enough." • "Resources are limited in rural area."
Accessibility	• "There are just two main issues I think that are so important: accessibility and education within our communities!" • "Again, just support to share the knowledge of no fear, inclusive to everyone on both sides of the table, to all be ok together and that everywhere should be accessible."
Other	• "Community Supports provided by agencies are wonderful. Making progress each day in this area. Churches are a great resource our individuals we support. Local government is very cooperative. Networking with different agencies has proven successful." • "We must maintain individualized community supports to continue to build strong communities."

	• "How might we identify and address the practical day to day barriers to inclusion."

Other Concerns

Self-advocates listed other thoughts about the problems or needs faced by people with developmental disabilities. Education about disabilities for the general public was mentioned twice. Other comments addressed the need for more advocates, the need for more support and friendship, the importance of voting and having transportation to the polls or assistance with absentee ballots, and the need for more mental health treatment and better crisis stabilization.

Other Concerns	Comments
Accessibility	• "The same answers seem to keep coming up, and education about those of us with different challenges and needs and in appearances to let everyone all feel comfortable in our communities together and to get the same medical care with the same care. But one thing that can begin the understanding between us all, is the accessibility issue, that businesses, churches, doctor's offices and other medical facilities, even personal homes would all be so welcoming if they could just allow everyone even if the guest is in a wheelchair, or a scooter or walker. That assistance, be it through braille or other specialized communication should be at least known about and as available as possible."
Education/ Awareness	• "Education for the general public on inclusion and programs available for people with developmental disabilities." • "Prejudiced against.... not enough people advocating."
Other	• "We need to keep them involved together; friendship [and] support are important to them at any age." • "The knowledge is so needed to people with disabilities and their parents and guardians and counselors that they all need to be registered voters and assistance to get to the polls or help with absentee ballots, but we all need to vote." • "More mental health treatment and better crisis stabilization." • "Way too many to write here."

Section B: Family Members/Caregivers

169 family members/caregivers responded to the survey Table 3 displays the results of the needs assessment. Of the 10 life areas, four life areas had overall means above 4.15—self-advocacy, housing, employment, and education. This section also presents the thematic analysis of the comments provided by the respondents under each life area. This thematic analysis provides further insights of the perceived need within each life area.

Table 3. Overall Means: Family Members/Caregivers

Life area	N	Minimum	Maximum	Mean
Self-Advocacy	169	1	5	**4.28**
Education/ Early Intervention	157	1	5	**4.27**
Employment	128	2	5	**4.20**
Housing	152	1	5	**4.17**
Community Supports	150	2	5	4.13
Childcare	154	1	5	4.10
Transportation	151	2	5	4.05
Recreation	151	2	5	4.01
HealthCare	152	1	5	3.97
Health & Wellness	151	1	5	3.87

*1- Very low need, 2- Low need, 3- Moderate need, 4- High need, 5- Very high need

Self-Advocacy

Self-advocacy was rated 4.28 (overall mean on a 5-point scale) by family members. The most common issue cited was lack of understanding and training on self-advocacy. Other themes included was the lack of true participation in events and feeling disconnected from the legislative process.

Self-Advocacy	Comments
Training on Self Advocacy	● "Individuals need support, training, and people who are willing to listen." ● "Services teaching how to self-advocate." ● "Self-Advocacy starting in IEP process with more intention, training, and coaching."
Lack of participation	● "I think many of them want to self-advocate but feel like no one will listen to them due to their disability. " ● "True participation in meetings. Many that I attend, family members speak for the individual or speak over the

	individual. Also an issue when a guardian disagrees with a choice the individual makes."
Removed from the legislative process	● "Disconnect from the participant and the people who can make a change." ● "They do not have the interest or ear of state legislators."

Education and Early Intervention

Education and early intervention was rated 4.27 (overall mean on a 5-point scale) by families. A lack of services, programs and resources for people with disabilities was the most common reported issue. Insufficient funding for programs aiding people with disabilities was reported as well. Students faced issues of inclusion in the school and integration into general education classrooms. Issues of school/parent communication and the need for parent training in disability resources and services were often mentioned. The need for increased teacher training in teaching students with disabilities was also another common theme.

Education and Early Intervention	Comments:
Lack of resources	● "In Bourbon County there is nothing for children with developmental delays/autism just School therapies." ● "Lack of funds, lack of activities, lack of providers, lack of classes, and definitely more involvement with families and local resources."
Inclusion	● "Lack of inclusion in non-academic activities of a typical school experience: recreation, clubs, attendance at school events, extracurricular. All these activities that make school pleasurable for so many students are often severely lacking in students with moderate to severe disabilities." ● "Example: my son wanted to be on the swim team when we lived in Fayette County. He was denied due to not being fast enough. He will never be fast. But he would have loved being part of the team."
Need for training	● "Teacher training for all teachers (both general education and special education and paraprofessionals) is still a huge issue. Many of the teachers don't actually know how to effectively teach a person with a developmental disability (how to make accommodations and modifications)." ● "General education teachers need assistance in upper elementary and beyond to know how to educate these children." ● "Families are not aware of what is available until it's too late."

Childcare

Childcare was rated 4.10 (overall mean on a 5-point scale) by family members. Most families found that there were too few or no services in their area that were equipped and willing to provide childcare for children with disabilities. When there were services that would provide childcare, families found the cost of childcare was often prohibitive or the staff lacked adequate training to provide care for children with disabilities.

Childcare	Comments:
Insufficient or no childcare	● "East, KY has little to no childcare support. " ● "There's a lack of childcare for children with Special Needs, and places won't accept kids with challenges." ● "There are not any places here for special needs child care. Many kids get kicked out of day care because the staff don't know how to meet their needs."
Ill-equipped or unwilling	● "There are not as many childcare facilities that will or are equipped to take care of children with varying disabilities. " ● "No one wants to take a child with disabilities of any magnitudes. Private care is the only choice leaving parents unavailable to work or have any normalcy in a career."
Unaffordable	● "Affordable and accessible options are very hard to find. " ● "The costs and the lack of support."

Healthcare

Healthcare was rated 3.97 (overall mean on a 5-point scale) by family members. The rollback or de-funding of Medicare and other healthcare initiatives was noted most commonly as an issue. Respondents also noted that healthcare accessibility for people with disabilities was a barrier. Families note that coordination of care was an issue because people saw multiple providers in a plethora of different settings. They also felt healthcare provider training to serve patients with disabilities was inadequate.

Healthcare	Comments:
Loss of healthcare, resources	● "We are afraid of losing health care. Preexisting conditions, life time caps, cost associated with additional expenses" ● "Not having insurance, No social security or medical insurance" ● "Funding for Medicaid waivers very critical."
Inaccessible healthcare	● "Most healthcare professionals have little training in how to assess and treat a person with a developmental disability, particularly if the person with the disability has poor communication skills. People end up getting poor care because of this." ● "In our rural county I have PCP care, but drive at least 45 mins for other health services to find providers equipped to deal with the

	sensory needs."
Coordination of care	● "There is not a "one stop shop" facility to meet healthcare needs in rural areas" ● "It is difficult to coordinate all their disability specialist. Especially when they go to one place for this and another for something else." ● "There is rarely coordination of services and it becomes very time consuming and overwhelming. Sometimes impossible to do at the time care is needed."

Health and Wellness

Health and Wellness was rated 3.87 (overall mean on a 5-point scale) by family members. The primary concern for families in Health and Wellness was the absence of or limited access to community health facilities (parks, recreational centers, etc.). These facilities were either not designed to be accessible to people with disabilities or were not present in their locale. Another issue facing families was the need for trained assistant's help to fully access exercise equipment and programs. Many other families cited the need for health education about healthy lifestyles, medications and exercise.

Health and Wellness	Comments:
Absence of or limited access to health facilities	● "No gyms in rural areas. No walking trails, bike paths in rural counties." ● "Not any activities like this here. My son needs an exercise program desperately but there is nothing for special needs people." ● "Most parks, trails, locations are NOT accessible to those in wheel chairs."
Assistance	● "Access is needed to be able to join a gym or other activities that promote physical fitness. Also access to a nutritionist if needed is difficult. " ● "Lack of people trained to assist with challenging behaviors."
Health Education	● "This needs to be a daily regimen whether eating right or getting enough exercise. Schools, community and in the home need to be teaching the importance of long-term benefits of health and wellness."

Employment

Employment was rated 4.20 (overall mean on a 5-point scale) by family members. The most common employment issue reported by families was that employers were either unwilling to employ people with disabilities or lacked awareness of the value people with disabilities bring to the workforce. Families also reported that jobs for people with disabilities were not available in their area. A need for more resources for employment and greater coordination of those resources was also voiced.

Employment	Comments:
Lack of awareness or unwilling	● "Employment is very difficult, we need businesses that are willing to work with supported employment centers." ● "I think our community is very low on awareness. They do not have an understanding of how employment for them and their families work." ● "Lack of employers willing to hire the disabled; lack of support/scaffolding once the person has gotten the job; lack of 'safe' environments (many of our developmentally disabled are the perfect "victims" and can easily be taken advantage of)." ● "Employers are not willing to create modified jobs for people with disabilities."
Jobs unavailable	● "There are very few opportunities here. " ● "Not enough jobs." ● "Employment is almost impossible."
Need for more resources on employment	● "I can't find info. Ever." ● "More opportunities and awareness of opportunities." ● "Rural area...lack of resources."

Housing

Housing was rated 4.17 (overall mean on a 5-point scale) by family members. The prime issue facing families was that there was insufficient appropriate housing, making it effectively unavailable to many. When housing was available, families often found it unaffordable, inaccessible and unsafe. Families also saw a need for education about what to expect in various housing models as well as about existing resources that assist with housing.

Housing	Comments:
Insufficient, unavailable housing	● "There are insufficient opportunities for people with disabilities to secure accessible housing." ● "Individuals with disabilities need appropriate housing with supportive services. There is a shortage or long waiting list for these housing options." ● "There is little to no access to funding that will help new persons get access to housing. If it is available, it is buried so deep in the system, no one can find it."
Unaffordable	● "There is a complete lack of low-cost housing in SAFE neighborhoods." ● "Access, affordability, being in safe parts of town and supports to be able to successfully live alone."
Education about housing	● "I don't know of any resource in our community that addresses this issue." ● "Educate families and people in Michelle P Waiver that there are ways to figure this out than thinking have to have SCL waiver to

	move out.”

Transportation

Transportation was rated 4.05 by family members. The main transportation issue reported by families was that transportation was effectively unavailable, especially in rural areas. When public transportation was available it was reported to be insufficient and too infrequent. Many families found transportation services inconvenient, frustrating, and difficult as they provided poor service and required extensive pre-planning and long wait times.

Transportation	Comments:
Transportation unavailable	● “There is little or no transportation services available unless you have a "medical" need.” ● “None! No TARC routes. TARC 3 will not transport to day programs in Bullitt County. As a case manager I have several clients who live in Bullitt County. Their parents are disable and not capable of doing all of the transportation needs. If your living arrangements include someone who also lives in the same place with a car registered in their name, Federated will not provide transportation. I feel this is unfair especially after the individual reaches over the age of 18. If they want to go someone on the weekends, unless they have natural supports it isn't going to happen.” ● “We have a severe lack of transportation options available, especially in rural areas which comprises the majority of the state.”
Public transportation insufficient	● “Buses in Lexington run too infrequently and I understand Wheels must be scheduled in advance, so you arrive at work 30 minutes before you have to, leave 30 minutes after you're done. Lots of waiting around for people with disabilities.” ● “Transportation is available, but must wait or be bussed for long periods of time. Need more options.”
Transportation inconvenient	● “Transportation is often unreliable and drivers/attendants are often untrained to deal with persons with disabilities.” ● “Transportation is limited to 7a-4p and not provided on weekends/or at night which really limits peoples mobility. Also, it is only allowed for medical reasons so this makes it difficult. Folks have limited financial resources so often public transportation is out of their financial means.”

Recreation

Recreation was rated 4.01 (overall mean on a 5-point scale) by family members. Families' central issue was a lack of accessible recreation spaces and events. When recreation was accessible, families often did not find it to be inclusive. In addition, transportation to recreational spaces and events presented a significant barrier.

Recreation	Comments:
Lack of accessible recreation	"There are lots of activities that don't make accommodations for those with disabilities." "Accessible venues- lack of support staff when needed." "NEED REGULARLY SCHEDULED ACTIVITIES FOR THE DD OTHER THAN ONCE OR TWICE A YEAR AND WHICH ARE OUTSIDE DAY TRAINING SERVICES."
Inclusion	"Lexington Parks & Rec does a great job, but there are no inclusive recreational opportunities I'm aware of." "Need for inclusive recreation in rural communities." "We expect the community to just embrace our loved ones but the community on a whole has to learn about this population."
Transportation	"The greatest challenge is time and transportation."

Community Supports

Community supports were rated 4.13 (overall mean on a 5-point scale) by family members. Family members' prime issue in the area of community supports was the waiver process, its prohibitively long wait list, and lack of choice. Families also had issues with the lack of trained staff to act as supports.

Community Supports	Comments:
Waiver process, wait-list	"The waiting list is too long for Michelle P and SCL." "The waiting lists for Supports for Community Living Waiver and Michelle P. Waiver are unreal. People are being led to believe their loved one might get assistance in 3 of 4 years, when the reality is that people are waiting 10 years or more (my loved one has waited 18 YEARS & still waiting) for assistance through Home-and-Community-Based Medicaid Waiver programs."
Lack of trained supports	"There are not enough staff that are trained to assist." "Lack of competent caregivers especially in rural communities." "Better training and pay for people who support others in areas of recreation, independent living and employment. Also needed; more education on how to create natural support networks."

Other Concerns

Family members expressed frustration about insufficient resources and funding, as well as the possibility that funding would be cut. Issues concerning the lack of qualified support staff and caregivers were reported. Family members also saw the need for increased education about and awareness of people with disabilities.

Other concerns	Comments
Insufficient Resources and possible cuts	● "When goods and services are needed and even Medicaid approved still have to be approved by several other people to receive any goods needed. " ● "The loss of Medicaid." ● "Concern about continuing support by the government and the restrictions that such support may place on them."
Lack of qualified support staff and caregivers	● "Lack of trained support staff. DSP's must be paid adequately to reduce turnover rates" ● "Caretakers need respite but need quality employees they can trust to take person with disability out into the community."

Section C: Service Providers

265 family members/caregivers responded to the survey. Table 3 displays the results of the needs assessment. Of the 10 life areas, four life areas had overall means above 4.00—self-advocacy, transportation, employment, and childcare. This section also presents the thematic analysis of the comments provided by the respondents under each life area. This thematic analysis provides further insights into the perceived needs within each life area.

Table 4. Overall Means: Service Providers

Life Area	N	Minimum	Maximum	Mean
Transportation	249	1	5	**4.20**
Self-Advocacy	265	1	5	**4.11**
Childcare	252	1	5	**4.06**
Employment	202	2	5	**4.01**
Education/ Early Intervention	259	2	5	3.98
HealthCare	250	1	5	3.94
Housing	250	1	5	3.91
Community Supports	246	2	5	3.85
Health and Wellness	250	1	5	3.80
Recreation	247	1	5	3.79

*1- Very low need, 2- Low need, 3- Moderate need, 4- High need, 5- Very high need

Self-Advocacy

Self-advocacy was rated 4.11 (overall mean on a 5-point scale) by service providers. The need for more information about how to self-advocate was mentioned more than any other theme. The need for support, a lack of available opportunities for self-advocacy, and issues with guardians or family were also mentioned frequently.

Theme	Comments
Need Information (32 responses)	• "Individuals do not know how to advocate for themselves or what resources to access." • "There are NOT enough resources, opportunities, placements, education, trainings, etc. for people with disabilities to be able to be independent and be self-advocates." • "Individuals with disabilities have difficulty advocating for themselves to ensure their needs are met. Often times they are not aware of what resources are available, know how to access them, and have difficulty communicating with others to advocate for themselves."
Need Support (17 responses)	• "Issues with having opportunities to advocate and having the support needed to appropriately advocate for themselves."

	• "There is just so little support outside home or staff that support them. It is a population that is still overlooked. Persons with disabilities rights still have to be brought to the forefront of some government officials for them to fully understand." • "There are a lot of people with disabilities yet very few advocates. Some concerted effort to engage and encourage self-advocacy is needed."
Scarcity (16 responses)	• "There are no self-advocacy groups in Lincoln, Mercer or Boyle County." • "Limited access to forums of advocacy, knowing where to go and who to talk to, feeling unheard when issues are expressed." • "Not enough programs for individuals with autism or their family members."
Guardian (11 responses)	• "Some parents/guardians think they know what is best for that person and limited what the person can express or be involved in/speak up for themselves." • "They don't know how to take up for their selves. It's hard for families of them to let go of charge." • "Adults with guardians are often unheard because the guardian trumps the individual's decision with what they think it best. Good intentions do not always promote growth and development. Life is a journey, and everyone should be allowed to experience the positives and negatives that shape who we are and who we become."
Other	• "Communication issues limiting their ability to express for themselves their needs and wants. Advocates attempt to fill these roles, but advocates have limitations in their ability. We need earlier intervention and education in alternative means of communicating from an early age, so individuals may learn an effective system to communicate with others around them." • "Shift in mentality of all. Valuing self-advocacy and seeing its need. Both with the individual and the community."

Education and Early Intervention

Education and early intervention, which includes activities that support full access to an appropriate education and being included in all parts of school life, was rated 3.98 (overall mean on a 5-point scale) by service providers. A need for additional supports and resources for students was the most common issue reported. Additionally, service providers cited issues of access to services within the school and access to appropriate education. Many respondents talked about the lack of inclusion for students with disabilities. Service providers also often mentioned improving upon and emphasizing early intervention programs.

Theme	Comments
Additional Supports and Resources (26 responses)	• "Not enough supports in the school system and not enough help with supervision outside of school." • "More services need to be available in schools for individuals with disabilities and while some programs may already be available there could be more variety in what is offered to fully meet

	individual's educational needs. There also seems to be a lack of early intervention programs and more need to be developed in schools and communities." ● "I feel that KY has excellent early intervention, but I think the schools should provide teachers with more education and tools to work with."
Access to services and education (23 responses)	● "Students with disabilities need to be treated the same and have access to the same things non-disabled students do." ● "They do not receive education that is of equal value to their non-disabled counterparts. Also, they need to be made more aware of their disability at a younger age." ● "Access to service providers. No providers in our area and very difficult to get providers to come here." ● "Schools have budget cuts and inadequate training for teachers and staff who work with children and persons with disabilities. The school systems refuse to allow behavior specialists and case managers in the school to assist students. School systems are equipped to provide individualized instruction for students because they have to conform to the educational standards for the regular classroom."
Inclusion (13 responses)	● "Involving people with disabilities in regular classrooms instead of being isolated to their own classroom." ● "Most children with severe autism are put in a corner and given a piece of paper and left there for most of the day. These children need a lot of activity of keeping their mind as well as their body busy. Should not have a normal classroom setup but a more stimulation classroom." ● "Being outcast as different from 'normal' children is still the biggest issue."
Early Intervention (11 responses)	● "Early intervention is critical to improving long term outcomes for children and their families. Early childhood service providers need programs to build their capacity for serving these children." ● "Limited resources to support First Steps and State Funded Preschool Programs. Universal preschool could remove many barriers in accessing services." ● "Receiving timely identification and the subsequent implementation of services. The large number of school districts (independent and public) with a variety of policies on implementation is a challenge."

Childcare

Childcare was rated 4.06 (overall mean on a 5-point scale) by service providers. Both a lack of available childcare providers in general and a lack of personnel trained about special needs were the most common themes related to childcare. Many respondents also mentioned affordability and the need for childcare before and after school, during the summer, and other times when school is out.

Theme	Comments
Scarcity (27 responses)	• "In rural communities especially, there is limited access to qualified before- and after-school care, or to care during breaks from school." • "No appropriate childcare available for kids with disabilities." • "Lack of childcare or childcare that dismiss students due to behavior (main reason) but other reasons as well." • "There are no special needs day cares in our area. Childcare centers cannot afford to have one on one folks for children with special needs at their business. There are no other places that offer those services either. It is hard for families with children with special needs to find anyone to watch their children."
Need Training on Special Needs (21 responses)	• "No enough providers trained in this area." • "Lack of trained staff." • "Not enough childcare providers are versed in the needs of individuals with intellectual disabilities." • "Facilities [that] provide childcare do not have staff who are trained to work with children with disabilities."
Affordability (14 responses)	• "Low-cost childcare options are limited." • "Affordable, high quality care with appropriate services." • "Many families have problems with childcare especially immediately after school. After-school programs too expensive for many families." • "1. Transportation to and from childcare. 2. Affordability in obtaining childcare."
Need Care Outside of School Hours (12 responses)	• "Finding places that will accept school-age children in the after-school programs and during the summer." • "Many parents have to work and do not get off work before school is out." • "More places that integrate persons with disabilities after school." • "Many families have problems with childcare especially immediately after school. After school programs too expensive for many families."
Other	• "In my experience most, parents in these situations will have one or two-family members who they trust to cope with and care for their children. This is due to their vulnerability and their behaviors many times. We have no qualified sitter service or childcare providers in our area with a daycare setting for special needs individuals. Many of our disabled are also medically fragile, so parents often spend seven days a week providing care, unless they are being provided Respite through a Medicaid waiver." • "There is not childcare for special needs children. Daycares will not take children with behavior issues, with Autism and medically fragile children. There is one program in Paducah, Kentucky that takes medically fragile children. Most parents cannot work or have to quit their jobs to care for their children." • "Access—transportation, financial, medical, insurance, support."

Healthcare

Healthcare, which includes activities that help people receive coordinated health, dental, mental health, and preventive services in their communities, was rated 3.94 (overall mean on a 5-point scale) by service providers. Barriers to accessing healthcare was the most common issue referenced. Limitations in the healthcare obtainable through Medicare/Medicaid including quality of care and scarcity of care were also a common issues. Many service providers talked about issues relating to communication with and attitudes of healthcare providers. Service providers, especially in rural areas, reported that transportation to healthcare was an issue.

Theme	Comments
Barriers to Accessing Healthcare (35 responses)	"[We need the] same health care available to others of same age." "Need more help in the area of the mental health aspect. " Having more certified people to work with people who have dual diagnoses. " "Having access to all health needs in a timely manner and not based on type of insurance coverage."
Limited Care from Medicare/Medicaid (33 responses)	"Finding doctors who are well versed in dual diagnoses and understand the health issues of various disorders AND who accept Medicaid." "Finding good doctors work with individuals with disabilities and who will listen to the individual and/or their caretakers." "Combination of limited service coverage by Medicaid such as dental care and eye care and limited funds." "As far as using Medicaid, you cannot get dentures, if teeth need to be pulled. Also, you are able to get an eye exam, but not corrective lenses."
Healthcare Communication and Attitudes (23 responses)	"Health care providers are dismissive of and don't want to work with persons with intellectual disabilities. " "Limited medical professionals that will communicate with the person to understand the true need. " "A lot of the local Drs. do not understand how to communicate with or understand the people we work with."
Transportation (12 responses)	"In rural communities especially, there is limited access to healthcare for persons with disabilities, including transportation to and from healthcare facilities. " "There are places for healthcare. Our local pediatrician's office is fantastic. However, there are not any specialists for children in our area. Parents have to drive at least 30 minutes to an hour or more to access those specialists for their children."

Health and Wellness

Health and wellness was rated 3.80 (overall mean on a 5-point scale) by service providers. Equal access to facilities or activities, a lack of opportunities or programs, and a need for programming that promotes health and wellness were all frequently mentioned themes. Respondents also commented on the need for nutrition education and the affordability of activities that promote health and wellness, such as gym memberships.

Theme	Comments
Access (13 responses)	• "Lack of access and education to the basic services, including prevention, are challenging for many. I thought we had learned that prevention is much more cost effective and improves the quality of life." • "Communities have gotten better about offering activities for special needs, but it can always be improved. They need access to activities, exercises, nutrition." • "Clients have been asked not to return to Silver Sneaker's classes. Staffing is an issue when it comes to gyms, etc." • "Kentucky has very poor education of appropriate nutrition and fitness. Many of the people with disabilities do not have options to access more nutritional food and exercise options due to staffing levels."
Scarcity (11 responses)	• "There are not that many options in this field to reach out to those with disabilities on how to take care and maintain health and wellness." • "Most have poor health and are overweight with numerous physical ailments. Many are on a waiting list to receive services, so they sit at home and do-nothing day in and day out." • "Wellness is key! It is harder for individuals with disabilities to engage in fulfilling activities that promote wellbeing—lack of resources and facilities that meet their needs."
Programs Are Needed (9 responses)	• "There is a park system and they have made some strides by installing an accessible playground. It would be good to have classes that are modified to meet the needs of those with disabilities. For instance, there is someone completely deaf that takes a Zumba class and she has to watch somebody else to do the moves. Also, it would be good if water aerobics for those with disabilities was available." • "Health and wellness groups and activities are needed." • "Special Olympics is great, but having activities that are designed for all individuals to participate. Ideas can include yoga, dance class, cooking and eating healthy foods. Have ongoing classes."
Nutrition (9 responses)	• "Understanding how diet and exercise affect their health and wellness. Many believe that health and wellness are only a concern when the doctor prescribes a medication." • "Ongoing nutrition and health counseling." • "Information to make better nutritional choices."
Affordability (9 responses)	• "Lack of physical exercise, inability to pay for any type of gym memberships."

	• "Kentucky as a whole needs to have more low-cost opportunities for health and wellness activities. We have a very sedentary society and often parents find themselves using electronics and screen time to appease children, particularly those with behavioral challenges. This can lead to a devastating cycle of inactivity, poor eating habits, and health problems." • "Can't afford the healthy foods. Organic, natural, fresh, etc. Medications are so insurance-controlled that the physicians can't treat the patients. The mental health treatment is a mess." • "1. Safer access to local parks and fitness facilities for persons with a wheelchair, walker or unsteady balance. 2. Free or sliding fee scale for membership or day visits to fitness facilities for low income and/or persons with disabilities."
Other	• "Support to understand reasons for the need for our body to move, the physical and mental health reasons." • "Transportation, lack of motivation." • "Health and wellness should be regular and not intermittent." • "Promotion is the key question here. There is [an inherent] difficulty in work with a population that often struggles with long term thing and promoting healthy life styles. Also promoting anything often requires resources and or funding which do not currently exist in any significant degree."

Employment

Employment was rated 4.01 (overall mean on a 5-point scale) by service providers. Barriers to accessing employment services through the Office of Vocational Rehabilitation (OVR), Supported Employment Agencies (SE), or other programs was the most common issue referenced. Service providers also often cited the need for greater awareness and education of employers about hiring people with disabilities. Many service providers also mentioned issues relating to the awareness of the physical-mental benefits of work and retaining financial disability benefits while working.

Theme	Comments
Barriers to Accessing Employment Services (33 responses)	● "There are very few providers in our area that offer this service." ● "The process of going through Voc Rehab to get to supported employment is so long that the people often lose hope." ● "More supported employment agencies and specialists that help persons with disabilities find jobs they love and that have competitive salaries and natural supports." ● "No OVR services in Monroe County and no service providers in Monroe."

Employer Education / Awareness (29 responses)	● "More employers need to be aware of how individuals with disabilities contribute to the workforce and organization. There are positive effects from the individual up to the community." ● "Getting employers and the employees that are willing to be that natural support to someone that has behaviors or developmental disability that is will to assist when needed." ● "Employers who are willing to craft jobs for folks with disabilities; staff to assist." ● "Many places won't even consider hiring an individual with disabilities. They think it will require too much work on the part of the employer. Education is needed, both for employers and for individuals with disabilities (to give them the skills and training needed to become gainfully employed)."
Awareness of work and benefits (12 responses)	● "Expectation of employment first. Information on work and benefits." ● "Knowledge about working while receiving government benefits." ● "Integration into community workforce, not volunteering but paid employment, contributions made as citizens such as paying taxes and having advocacy groups in the community to raise awareness."
Early Employment Training, Expectation (11 responses)	● "More education on how to obtain the services following school." ● "More or better personal finance education for a middle school or early high school level student. More home economic education in the middle or high school level."

Housing

Housing was rated 3.91(overall mean on a 5-point scale) by service providers. The most common issue reported was a lack of access to adequate housing because it was not accessible or did not exist in that area. Where there were housing options available, service providers said they were too costly. Service providers talked about the need for support services to facilitate housing searches, maintenance and assistance.

Theme	Comments
Access (37 responses)	● "This is going to be an ongoing area of need. Making homes accessible, ensuring neighborhoods are accessible in terms of walkability and/or the availability of accessible transportation are important priorities." ● "Huge need for more residential settings for persons with disabilities. There is a huge waiting list because there are not enough residential providers." ● ""Lack of adequate and available housing faces most areas. There are not enough rental units available for those who need."

	● "Lack of housing that is accessible for the individual person."
Cost (14 responses)	● "Home modifications are very costly and there are few resources available to help people on fixed incomes afford to have modifications completed. " ● "Financial support." ● "The cost of living. Unless you are on section 8 and have some type of job. Then is harder for our individuals to get their own place."
Support Services (8 responses)	● "Are the rates of reimbursement for this service sufficient for providing the level of care the individuals need and deserve." ● "Individuals need more assistance with obtaining and maintaining housing, education and responsibility of cleaning." ● "We see more and more SCL providers added to a growing moratorium list. Staffing in homes provided by SCL providers is minimum and underpaid. Also, the homes often have structural problems that remain unresolved. In fact, many are to be considered substandard living arrangements. Yet, we expect the intellectually disabled to enjoy living in them and to not really notice that they aren't living like their neighbors."

Transportation

Transportation was rated 4.20 (overall mean on a 5-point scale) by service providers. The most common issue cited was a lack of access to quality transportation that was safe, reliable, and accessible. Where public transportation was available service providers service providers often reported that it was insufficient in coverage, scope and consistency. Many service providers also reported that rural counties had few transportation options or none at all. When transportation services were available many service providers cited the cost as an issue.

Theme	Comments
Lack of Access to Quality Transportation (43 responses)	● "Transportation services are not available when and where they are needed." ● "There is very little in the way of transportation for individuals who are wanting to participate in activities on their own, and without a paid staff. Programs like Community Access are greatly limited in their success, because the assumption that the individual will develop natural supports for the transportation needs is simply not true. Many individuals miss out on activities simply because they cannot find way to get only a few miles." ● "The current transportation companies, like Federated, are terrible and do not provide safe transportation."

Theme	Comments
	● "The hoops that people with disabilities have to jump through to get transportation services such as TACK are ridiculous. Medicaid will not pay for this if there are vehicles in the home, but people work and can't utilize that car every time a person needs to go to the ADT, to work, to the doctor etc."
Insufficient Public Transportation (29 responses)	● "Limited hours available for public transportation (end early no weekends) strict guidelines on use of transportation for families when there is a car registered at the address. " ● "There is not sufficient public transportation in this area. Sandy Valley Transportation is available but has to be approved by Medicaid and a 72-hour notice is given. If SVT is not available, then the individual has to pay for a taxi which is very expensive and on a fixed income does not help." ● "We are at the further end of Jefferson Co. and public transportation doesn't come out this far." ● "Unpredictable para transit. Available but not always convenient, we are lucky Lexington has it."
Rural Transportation Difficulties (12 responses)	● "Living in a rural county, it's hard to find transportation. Let alone transportation for someone with a disability. This limits community involvement, employment opportunities and independence." ● "In rural area transportation is limited. People with disabilities are endured by not experiencing out of home activities. " ● "There is no public transportation. People with Medicaid can ride free to medical appointments but those without Medicaid are out of luck."
Cost of transportation (11 responses)	● "If living on your own and paying for transportation to activities can be expensive. If you do not live on a bus line or have someone willing to pick you up, Cabs or Uber can deter individuals from doing the activities in the community." ● "There is really no affordable transportation for people on a fixed income with disabilities in this area."

Recreation

Recreation was rated 3.79(overall mean on a 5-point scale) by service providers. The most common issue reported was a lack of access to recreation opportunities because they did not exist, were not accessible or were otherwise out of reach. When there were recreational events, service providers said they fell short of being truly inclusive. Some service providers talked about the need for support service staff in order to make recreation feasible.

Theme	Comments
Access (34 responses)	● "Not many activities planned that they have access to." ● "There are virtually no recreational facilities available in this area, especially those that would accommodate persons with

Theme	Comments
	disabilities." ● "Very few programs that are universal in design include people with disabilities." ● "Change in people's attitude that all people like to be involved in recreational activities of some kind. There is a lack of recreation activity in general. In many areas across our state, there just isn't much to do for anyone."
Inclusion (14 responses)	● "Most leisure/recreational activities that are offered are not inclusive, but rather encourage people with disabilities to engage and interact with other people with disabilities. True inclusion is not often understood by the community members or sometimes even guardians." ● "The key word here is 'inclusive.' There are many opportunities for socialization, but they may not be integrated with individuals who do not have disabilities. Example: Special Olympics is a great opportunity for exercise and socialization, but the individuals competing are mostly interacting with peers who also have disabilities."
Support Service Staff (8 responses)	● "Having available staff. CA services are sometimes used for this, but it is limited due to the fade out required." ● "I do not see that many people with disabilities participate in recreation outside of school, once again because of transportation and also because they need someone to guide them, such as a Community Living Services."

Community Supports

Community supports, were rated 3.85 (overall mean on a 5-point scale) by service providers. The most common issue reported was a need for more resources and more community supports. Service providers also talked about a need to raise awareness and understanding about people with disabilities in their communities. Improving the quality of community supports was often mentioned in terms of hiring, remuneration, and best practices. Service providers also mentioned the need for more focus on generating natural supports.

Theme	Comments
Limited Resources, Services (31 responses)	● "If they do not have a Medicaid waiver the options are extremely limited/nonexistent." ● "The limited funding available to support these activities. We could use additional funding to help organize and provide more opportunities." ● "Issues start with the fact that are little community supports for people with disabilities in our community." ● "Creation of another waiver or opening of slots for those sitting on the MP waiver wait list."

Awareness, Understanding (10 responses)	● "There remains great stigma related to persons with disabilities. The general population seems to 'steer clear' of those with disabilities, further isolating them within the community. Because those with intellectual/developmental disabilities often have unique behaviors, congenital deformities, and/or unique ways of communicating, others are very hesitant to interact with them." ● "People who have experiences with individuals with disabilities are comfortable offering assistance if needed in the community. People who have not known someone with a disability are not as likely to develop relationships with someone who has a disability. This is where the community support piece is tricky. In many settings our society is not particularly welcoming to people we do not know. Repeatedly seeing and having even the smallest of interactions can help begin to break down the walls between people whether of disability or not."
Better Supports (10 responses)	● "Agencies that support waiver services have limited staff available for community supports. Their budgets do not support travel, the staff pay is too low, cannot find qualified persons for the position." ● "Finding consistent people who are willing to take on the responsibility of Community Supports. There is no chance for advancement to consider it a career, no benefits, and the person has to be able to handle another person's behaviors, social abilities, etc. also at times to deal with the family if the person with disabilities. A lot to ask for people trying to make a living." ●
Natural Supports (7 responses)	● "Greater identification of natural supports and nurturing those relationships; more Waiver staff who provider quality Community Access supports that truly help." ● "There needs to be a network developed that is outside of paid supports to foster relationships that garner natural supports to help persons with disabilities have inclusion and feel like they are part of the community they live in every day."

Other Comments

Service providers added other thoughts about the problems or needs faced by people with disabilities. The most common issue reported was a need for more funding for programs. Service providers also talked about a need to raise awareness and understanding about people with disabilities in their communities. Many service providers talked about the importance of early intervention programs and the need to invest more in their success. Service providers also mentioned the need to find a solution to the caps on waiver programs and waitlists that result.

Theme	Comments
Funding (14 responses)	● "In our current economic situation many programs that have helped our individuals to become more independent and to have more of a role in our communities are facing financial cuts, which will set back our progress by years. We as a society need to focus energy on protecting the programs which have helped so many of our disabled individuals to enjoy their lives more freely. We still have areas needing improvement in education, medical care, and other areas. Cutbacks in funding will leave us with serious setbacks for our friends and families with disabilities." ● "More funding for SCL/MPW slots. Rate increases for current SCL services in order to provide better pay for direct support staff to decrease turnover rates." ● "The funding received for providing services to individuals with developmental disabilities is not sufficient to hire and retain quality DSP's or operate programs needed to better these individuals lives."
Awareness, Understanding (10 responses)	● "Education and support to the community at large concerning the enrichment of diversity and strengths evolves when accepting everyone for who they are no matter their differences." ● "General public needs constant education to understand how to deal with people with disabilities and know that they CAN do anything if given the proper access and support."
Early Intervention (11 responses)	● "Focus on children and developmental delays to make a lifetime of difference." ● "Teachers are often under-trained and unable to provide supports required for success for children with Autism Spectrum Disorder in the school setting." ● "We need funding for the younger years such as First STEPS, Child Care, Preschool and education for children, families and community supports. We have the research that says the first years (birth to three) are critical in skill development, by age 7 a child's mind and body is pretty well set as far as learning, desire to learn." ●

Waiver Caps, Wait Lists (10 responses)	"Limited access to services and effective educational support staff. Michelle P Waiver wait list is too long preventing many children from receiving the dose of therapy required for effective therapeutic progress." "We have a tremendous population in our area. You have to be on a waiver to receive ANY supports and services. There is now a waiting list for ALL D/ID waivers, even emergency waivers. People have the need NOW."