

Five-Year Vision for People with Developmental Disabilities in Saint Louis County

Report on the Three-Phase Needs Assessment

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Executive Summary

The purpose of conducting the 2016-2017 needs assessment was to determine the levels of current and future need for individuals with developmental disabilities who reside in St. Louis County. The study not only included individuals served with funds provided by Productive Living Board (PLB), but also those individuals served by Department of Mental Health (DMH) and those individuals served by the Special School District of St. Louis County (SSD).

The PLB contracted with University of Missouri-Kansas City, Institute of Human Development (UMKC-IHD) to conduct the needs assessment. Major activities included: 1) work with an advisory committee made up of St. Louis County stakeholders; 2) conduct a DD trend analysis for St. Louis County (page 16); 3) convene focus groups with individuals, families, agencies, and advisory committee members (page 35); and 4) administer an individual/family survey of current support needs and anticipated future needs (page 70). The results of this study are intended to be a basis for future policy formulation and resource prioritization.

Participants

The focus group sessions included 101 participants from all regions of St. Louis County. Fifteen percent of the focus group participants were individuals with developmental disabilities, 31% were family members of an individual with a developmental disability and 48% were professionals (service providers and stakeholders) in the field.

The needs assessment survey was distributed to 13,468 people with developmental disabilities and/or their family members. This represents approximately 1.5% of the St. Louis County population. Two thousand and twenty nine (2,029) individuals/family members returned surveys for a return rate of approximately 15%, a statistically valid sample size. Other important information about the survey participants includes:

- The survey sample was evenly split between school age individuals with developmental disabilities (between 0 – 21 years of age) and individuals with developmental disabilities beyond school age (older than 21 years of age)
- 90% of the surveys were completed on behalf of an individual with a disability
- Almost 80% of individuals surveyed currently live with parents/family
- 60% of those surveyed indicated autism or intellectual disability as a primary diagnosis
- Over 40% of those surveyed listed their primary day activity as attending school, followed by 12.9% of adults who have no day activity and 12.4% who are employed in a sheltered workshop
- Over 65% of the survey participants reported that they currently receive service coordination/case management from DMH
- The survey sample is representative of the overall race/ethnicity of St. Louis County
- The four regions of St. Louis County (North, South, West, and Central) were evenly represented

Trend Analysis

UMKC-IHD identified the support and service trends for people with developmental disabilities. Information from that analysis can be found beginning on page 16 of this report.

Needs Identified through the Focus Groups

Table 1 lists the top 5 current needs of high importance (in descending order) identified by each focus group. The complete listing of all needs can be found on page 42, Figure 14 of this report. The “N” represents the number of people in each participant group.

Table 1				
Focus Groups – Top 5 Current Needs of High Importance				
Importance	Individuals with DD (N=15)	Family Members (N=31)	Service Providers (N=48)	Advisory Committee (N=7)
1	Provider Supports	Provider Supports	Provider Supports	Funding
2	Transportation	Transportation	Funding	Collaboration
3	Inclusive Employment	Social Life	Collaboration	Education
4	Housing	Inclusive Employment	Transportation	Inclusive Employment
5	Financial	Funding	Education	Policy

Needs Identified through the Survey

The following tables list the top 5 current needs, current unmet needs, and future needs (in descending order) reported by each age group. Current unmet needs are identified as needs of a high importance that are not currently being received. Future needs are those needs that an individual will need within the next five years. The complete listing of all current and future needs can be found in Table 16 on page 73 of this report.

Top 5 Needs for All Ages – 1,872 Participants

Table 2			
Survey - Top 5 Current Needs of High Importance for All Ages (N=1,872)			
Importance	Current Needs	Current Unmet Needs	Future Needs
1	Living with Parent/Family	Fitness/Wellness Activities or Programs	Living with Parent/Family
2	Social Skills Training	Healthy Relationship Training	Social Skills Training
3	Fitness/Wellness Activities or Programs	Community Membership in Organizations or Clubs	Fitness/Wellness Activities or Programs
4	Self-Advocacy & Self-Determination	Parks and Recreation Activities	Self-Advocacy & Self-Determination
5	Healthy Relationship Training	Social Skills Training	Independent Living Skills Training

See Table 19, page 80 for a complete list

Top 5 Needs for those between 0 and 5 Years of Age – 45 Participants

Individuals in this age range are currently living with their family and as Table 3 indicates they expect to do so for the foreseeable future. Results indicate that adaptive equipment and in-home supports are high priority current needs that sometimes go unmet. Future needs indicate in-home supports will remain at the same level, with increased need for recreation/fitness activities.

Table 3 Survey - Top 5 Current Needs of High Importance for Ages 0 – 5 <i>(N=45)</i>			
Importance	Current Needs	Current <i>Unmet</i> Needs	Future Needs
1	Living with Parent/Family	Summer Recreation	Living with Parent/Family
2	Summer Recreation	Personal Care	Summer Recreation
3	Parks and Recreation Activities	Occasional In-Home Support	Parks and Recreation Activities
4	Occasional In-Home Support	Adaptive Equipment	Occasional In-Home Support
5	Adaptive Equipment for Health and Safety	Out-of-Home Support	Fitness and Wellness Activities or Programs

See Table 19, page 80 for a complete list

Top 5 Needs for those between 6 and 15 Years of Age – 517 Participants

Individuals in this age range are currently living with their family and as Table 4 indicates that most will do so for the foreseeable future. Results indicate a focus on recreation activities and social skills are important to this age group both currently and in the future. Important unmet needs include healthy relationship training and self-advocacy. A slightly lower level of need is indicated in like areas when comparing current needs to the future.

Table 4 Survey - Top 5 Current Needs of High Importance for Ages 6-15 (N=517)			
Importance	Current Needs	Current <i>Unmet</i> Needs	Future Needs
1	Living with Parent/Family	Social Skills	Living with Parent/Family
2	Social Skills Training	Summer Recreation	Social Skills Training
3	Summer Recreation	Self-Advocacy & Self-Determination	Self-Advocacy & Self-Determination
4	Self-Advocacy and Self-Determination	Behavioral Supports	Summer Recreation
5	Fitness and Wellness	Relationship Training	Healthy Relationship Training

See Table 19, page 80 for a complete list

Top 5 Needs for those between 16 and 21 Years of Age – 390 Participants

Individuals in this age range identify living with their family as an important current need. This age range does not indicate a need for the person to live with the family in five years, nor does it list a desired alternative. This could be indicative of a lack of information regarding services and supports that are available, given that was the number one barrier identified. This is a critical age range in preparing for transitions from a school environment to another day activity, which is indicated by the need for transition planning and support with a meaningful day. Transition planning is an important current need, and is anticipated to be as important in the future as it is currently. Opportunities for employment with supports in the community are particularly important, hence the prioritized need for pre-employment services, and skills that will support inclusive employment such as social skills training, independent living skills training, and self-advocacy training which are important currently and will continue into the future.

Table 5 Survey - Top 5 Current Needs of High Importance for Ages 16 – 21 (N=390)			
Importance	Current Needs	Current <i>Unmet</i> Needs	Future Needs
1	Living with Parent/Family	Planning for Transition from School to Work/Adult Life	Working with Supports in the Community
2	Planning for Transition from School to Work/Adult Life	Independent Living Skills Training	Planning for Transition from School to Work/Adult Life
3	Social Skills Training	Social Skills Training	Independent Living Skills Training
4	Independent Living Skills Training	Self-Advocacy and Self-Determination	Social Skills Training
5	Pre-Employment Training	Relationship Training	Support with a Meaningful Day Activity

See Table 19, page 80 for a complete list

Top 5 Needs for those between 22 and 49 Years of Age – 686 Participants

Individuals in this age range identify living with their family as an important current and future need. Independent living skills training is identified as a consistent need in this age range. Opportunities for employment with supports in the community are particularly important currently and in the future, hence the ongoing need for social skills training, self-advocacy, and relationship training. Fitness and wellness needs resurface in this age range and are anticipated to remain significant into the future.

Table 6 Survey - Top 5 Current Needs of High Importance for Ages 22 – 49 (N=686)			
Importance	Current Needs	Current <i>Unmet</i> Needs	Future Needs
1	Living with Parent/Family	Self-Advocacy and Self-Determination	Living with Parent/Family
2	Working with Supports in the Community	Social Skills Training	Fitness and Wellness Activities or Programs
3	Independent Living Skills Training	Independent Living Skills Training	Independent Living Skills Training
4	Fitness and Wellness Activities or Programs	Relationship Training	Parent/Family Working with Supports in the Community
5	Social Skills Training	Support with a Meaningful Day Activity	Social Skills Training

See Table 19, page 80 for a complete list

Top 5 Needs for those between 50 and 64 Years of Age – 186 Participants

Individuals in this age range identify living with their family as an important current and future need. However, a need is identified for living in the community with limited supports, which may explain unmet needs of financial management, fitness and wellness, and personal care assistance. There is an emerging need to plan for aging and retirement, as indicated by the current need for working with supports in the community and a future need for support with a meaningful day. Independent living skills training remains important in this age range.

Table 7 Survey - Top 5 Current Needs of High Importance for Ages 50 – 64 (N=186)			
Importance	Current Needs	Current <i>Unmet</i> Needs	Future Needs
1	Living with Parent/Family	Fitness and Wellness Activities or Programs	Independent Living Skills Training
2	Independent Living Skills Training	Retirement Supports	Living with Parent/Family
3	Working with Supports in the Community	Personal Care Assistance	Support with a Meaningful Day Activity
4	Living Independently in the Community with Supports (0-20 hours each week)	Support with a Meaningful Day Activity	Financial Management
5	Fitness and Wellness Activities or Programs	Financial Management	Fitness and Wellness Activities or Programs

See Table 19, page 80 for a complete list

Top 5 Needs for those 65 Years of Age and Older – 48 Participants

This age range does not indicate a current or future living arrangement. This could be indicative of a lack of information regarding services and supports that are available, given that was the number one barrier identified. Needs appear less focused on independent living, and more related to supports a family caregiver may have been providing but is no longer able or available to provide, such as personal care, financial management, and socialization activities with their peers. The need for adaptive equipment returns to this age group, after not appearing since the 0-5 age group, and may be indicative of decreased physical abilities of the individual or their caregiver. The need for self-advocacy and self-determination is highly rated in this age group and may be indicative of an increased importance in communicating for themselves in the absence of a family caregiver.

Importance	Current Needs	Current <i>Unmet</i> Needs	Future Needs
1	Personal Care Assistance	Support with a Meaningful Day Activity	Support with a Meaningful Day Activity
2	Support with a Meaningful Day Activity	Occasional Out-of-Home Support	Personal Care Assistance
3	Financial Management	Parenting Skills Training	Financial Management
4	Self-Advocacy and Self-Determination	Working with Supports in the Community	Adaptive Equipment for Health and Safety
5	Adaptive Equipment for Health and Safety	Disability Specific Activities	Self-Advocacy and Self-Determination

See Table 19, page 80 for a complete list

Challenges

The challenges experienced most frequently by respondents across the entire spectrum of services (Employment, Living Options, Life Transitions, Family and Socialization/Wellness) include:

- Not knowing what services and supports are available
- Not knowing what they need
- Not knowing who to ask about resources
- What the services cost

Conclusions

It is clear that current and future needs vary by the age of the individual. However, survey results reinforce focus group themes identified by individuals, as well as the family and agencies that support them. These results highlight the desire for a life filled with meaningful activities that provide opportunities to build and use skills for living and working independently, and that is enriched with a strong network of friends and social interactions that ensure emotional wellness and physical health.

Respondents believe that the person with developmental disabilities will most likely remain in the natural family home and given that likelihood, services that support the family as a whole, such as in-home supports, recreation programs, and services that ensure maximum independence and health are very important.

In the age categories beyond graduating from school, employment in the community with supports, and supports with a meaningful day activity are important into the future and will require services that prepare individuals for successful and safe interactions with others.

As respondents approach retirement, adaptive equipment, self-determination and personal care are increasingly important, as family caregivers may no longer be in a position to fulfill this role. This is an area in which further information will need to be cultivated given a lower response rate for those 50 years of age and older.

While 65% of the respondents report having a DMH service coordinator/case manager, lack of information regarding services and supports available and knowing who to ask was prevalent, and the impact of this lack of information regarding identification of future needs is unknown. Ongoing assessments are therefore warranted.

Recommendations

While numerous areas of need arose in this study, a few overarching needs were identified. The areas where special focus should be given are:

- Expand services that help support the individual with developmental disabilities in their natural home where they currently live with a parent or family member;
- Identify and implement solutions to help families access information to address challenges across the spectrum of services and navigate the current delivery system;
- Examine opportunities to collaborate with other funders and stakeholders in providing a continuum of services for autism spectrum disorders focused on areas of greatest need (i.e., social skills training);
- Collaborate with regional partners (SSD, DMH, Department of Vocational Rehabilitation (VR) and provider agencies) to prepare for the future increase in school age individuals seeking inclusive, supported employment;
- Monitor the living options desired/required by families, as this may shift given the growing population of older adults;

- Seek further information regarding the needs of the aging population as they transition into retirement.

Introduction

The Productive Living Board (PLB), was established in 1979 when St. Louis County voters approved a special property tax to fund services for St. Louis County citizens with developmental disabilities. The mission of the PLB is:

To ensure funding for a spectrum of high quality services that create opportunities for St. Louis County residents with developmental disabilities to thrive in the home, community and employment settings of their choosing.

The PLB does not provide any services directly. Instead, the PLB oversees the distribution of funds to local agencies through service/support projects. These agencies provide community and employment services and supports for over 4,300 individuals in St. Louis County annually.

Scope of the Project

In order to better achieve their mission, the PLB periodically surveys those receiving services through PLB funds to assess whether these individuals are receiving the services they need and what future unmet services they anticipate. The PLB contracted with University of Missouri- Kansas City, Institute of Human Development (UMKC-IHD) in 2016 to administer the needs assessment development, focus groups facilitation and survey of current and future service needs. This report is a culmination of information collected and data analysis of that project.

The following are objectives for the present study:

1. Provide an opportunity for consumers and their families to identify and communicate their unique needs

2. Identify areas of current unmet need in the community
3. Identify areas of future need in the community that will have an impact on future PLB funding
4. Identify the major challenges facing individuals with developmental disabilities and their families
5. Generate meaningful information for use in the identification and prioritization of needed services and supports for individuals with developmental disabilities in St. Louis County
6. Focus on the services and supports currently funded by PLB

Methodology

In partnership with staff from PLB, the research team from UMKC-IHD conducted 10 focus group sessions with people who have DD (2 groups), family members of people who have DD (4 groups), service providers (3 groups), and the needs assessment steering committee (1 group). In order to help participants share their opinions freely, each session began with a vision mapping process. Facilitators gave each participant a large piece of paper that was broken into four sections. Each section of the visioning map corresponded to a specific focus group question (see Appendix A).

Next, in PLB and UMKC-IHD used the focus group data to develop a needs assessment survey constructed to collect basic demographic information and opinions about current and future service needs. Surveys were mailed to 13,468 individuals currently receiving services in St. Louis County. The individuals selected were those who received services funded by PLB, the State of Missouri Department of Mental Health – Division of Developmental Disability Services and the St. Louis County Special School District. It was assumed that individuals would

complete the survey with assistance from others if needed. The title of the survey was “2017 Consumer Needs Assessment Survey”.

Surveys (see Appendix B for a copy of the survey) were mailed to four distinct target groups:

- Individuals who only received services funded by PLB.
- Individuals who only received services funded by DMH.
- Individuals who received services funded by both PLB and DMH.
- Individuals who received services provided by Special School District.

Surveys were coded to allow for the collection and reporting of the results based on those target groups.

After collection of demographic information, the instructions for the first part read, “Using the Current Needs Table below, please tell us about your current need for support.” The instructions of the second part read, “Using the Future Needs Table below, please tell us about your changing need for supports over the next five (5) years.”

Thirteen thousand four hundred and sixty eight (13,468) surveys were mailed. That equates to approximately 1.5% of the population of St. Louis County. Individuals could choose to enter their responses online or an individual could complete their survey and return to (UMKC-IHD) via a business reply envelope for tabulation and analysis. Two thousand and twenty nine (2,029) surveys were returned for analysis which is an approximate 15% return rate.

Disability Trends

The purpose of this section is to review two existing data sets in order to identify support and service trends for people with intellectual and developmental disabilities (IDD) in St. Louis County, Missouri. The data discussed in this report come from: 1) The American Community Survey (ACS), a continuous survey conducted by the United States Census Bureau; and 2) The Missouri Comprehensive Data System (MCDS), a publicly accessible resource administered by the Missouri Department of Education and Secondary Education (DESE). Ultimately, the information gleaned from these two sources will be matched with service and supports data provided by the Productive Living Board for St. Louis County Citizens with Developmental Disabilities (PLB), the Special School District of St. Louis County (SSD), and possibly other data sources that have yet to be identified. Ultimately, the information from all identified data sets will be compared with the results of focus group and survey data collected during the needs assessment process to develop a clear portrait of the support and service needs of citizens with IDD in St. Louis County.

American Community Survey (ACS). The ACS is a survey that is used by the U.S. Census Bureau to collect information about jobs, occupations, educational attainment, veterans, disability status, and many other topics. It is administered each year to a randomly selected sample in all 50 states and the District of Columbia and Puerto Rico. The ACS is a mandatory survey that is part of the decennial census. The ACS replaced the “long form” previously sent to households every 10 years. Approximately 3.5 million U.S. citizens participate in the survey each year. By comparison, in 2015 a total of 50,265 Missourians completed the ACS.

Missouri Comprehensive Data System (MCDS). The MCDS is a resource that allows the public to access education-related data in Missouri. Data is collected from schools in the

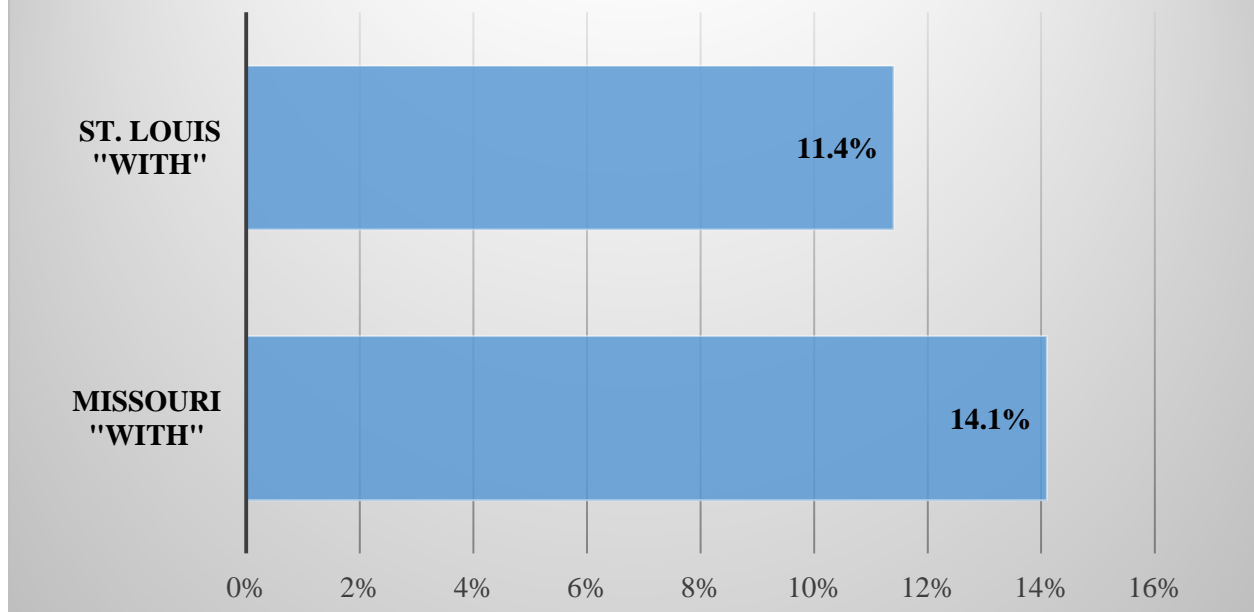
Missouri public school system All data are de-identified and do not show information for groups with 10 or fewer students. The MCDS database includes information on accountability, college and career, district and school info, early childhood education, education staff, special education, state assessment, and student characteristics. DESE uses two data collections systems managed by the Office of DATA System Management to collect education data. First, the Core Data System uses integrated computers to directly populate the database with files submitted by the school districts. Second, the MOSIS data uses individual-level data to derive counts for the aggregate database. School districts report MOSIS data in six cycles during the year (Missouri Department of Elementary & Secondary Education, 2016).

Results

State and County Populations

People with Disabilities. The ACS includes six questions related to disability. They are designed to identify limitations in four basic areas of functioning (vision, hearing, mobility, and cognitive functioning) as well as limitations with self-care and independent living. The estimates derived from these questions “can be analyzed individually or combined as one measure to assess the equalization of opportunity for people with disabilities, and the need for services in particular areas” (U.S. Census Bureau, 2016). The ACS data set indicates that there are 835,980 people in the state of Missouri who have a disability and do not live in an institutionalized setting, which as Figure 1 depicts, represents 14.1 percent of the total Missouri population (5,914,681). Within St. Louis County, there are 112,930 noninstitutionalized people with a disability, representing 11.4 percent of the total county population (988,257). Table 9 presents a matrix that describes the population of people with disabilities based on age group and ACS disability type. The most common disability type in both Missouri and St. Louis County for people between the ages of 5

Figure 1
Total Civilian Noninstitutionalized Population with a Disability at the County and State Level



and 17 is “cognitive difficulty.” In Missouri, children and youth with cognitive difficulty represent 78% of all children and youth with a disability. In St. Louis County, they represent 76% of the overall population of children and youth with a disability in the County.

Interestingly, this trend changes for adults with a disability (18 to 64 years) and “ambulatory difficulty” becomes the most common disability, with cognitive difficulty being the

Table 9
Disability Population by Age and Type of Disability

Missouri Disability Population	<i>With a hearing difficulty</i>	<i>With a vision difficulty</i>	<i>With a cognitive difficulty</i>	<i>With an ambulatory difficulty</i>	<i>With a self-care difficulty</i>	<i>With an independent living difficulty</i>
<i>Population 5 to 17 years (61,298)</i>	7,122 (11.6)	8,863 (14.5)	47,661 (77.8)	6,830 (11.1)	9,604 (15.7)	N.A.
<i>Population 18 to 64 years (454,126)</i>	93,945 (20.7)	76,648 (16.9)	196,461 (43.3)	241,103 (53.1)	79,856 (17.6)	161,950 (35.7)

Table 9						
Disability Population by Age and Type of Disability						
<i>Population 65 years and over (317,638)</i>	135,603 (42.7)	57,121 (18.0)	75,624 (23.8)	202,443 (63.7)	66,804 (21.0)	128,062 (40.3)
St. Louis County Disability Population	<i>With a hearing difficulty</i>	<i>With a vision difficulty</i>	<i>With a cognitive difficulty</i>	<i>With an ambulatory difficulty</i>	<i>With a self-care difficulty</i>	<i>With an independent living difficulty</i>
<i>Population 5 to 17 years (9,661)</i>	1,253 (13.0)	1,071 (11.1)	7,335 (75.9)	1,304 (13.5)	1,714 (17.7)	N.A.
<i>Population 18 to 64 years (53,472)</i>	9,637 (18.0)	7,861 (14.7)	23,758 (44.4)	26,518 (49.6)	9,529 (17.8)	19,678 (36.8)
<i>Population 65 years and over (49,349)</i>	18,689 (37.9)	7,992 (16.2)	11,786 (23.9)	31,813 (64.5)	11,303 (22.9)	23,133 (46.9)
*Values in the parentheses are percentages; percentages equal more than 100% in sections due to individuals selecting multiple "difficulties".						

second most common. For adults with a disability over the age of 65, ambulatory difficulties are by far the most common in the state and St. Louis County. Also, for people in this age group, hearing difficulty and independent living difficulty are more prevalent than cognitive difficulties. Clearly, the majority of these individuals do not have a IDD. However, the salient point is that when children and youth with IDD transition into adulthood, they are now competing with a very large population of people with disabilities for limited funding, services, and supports.

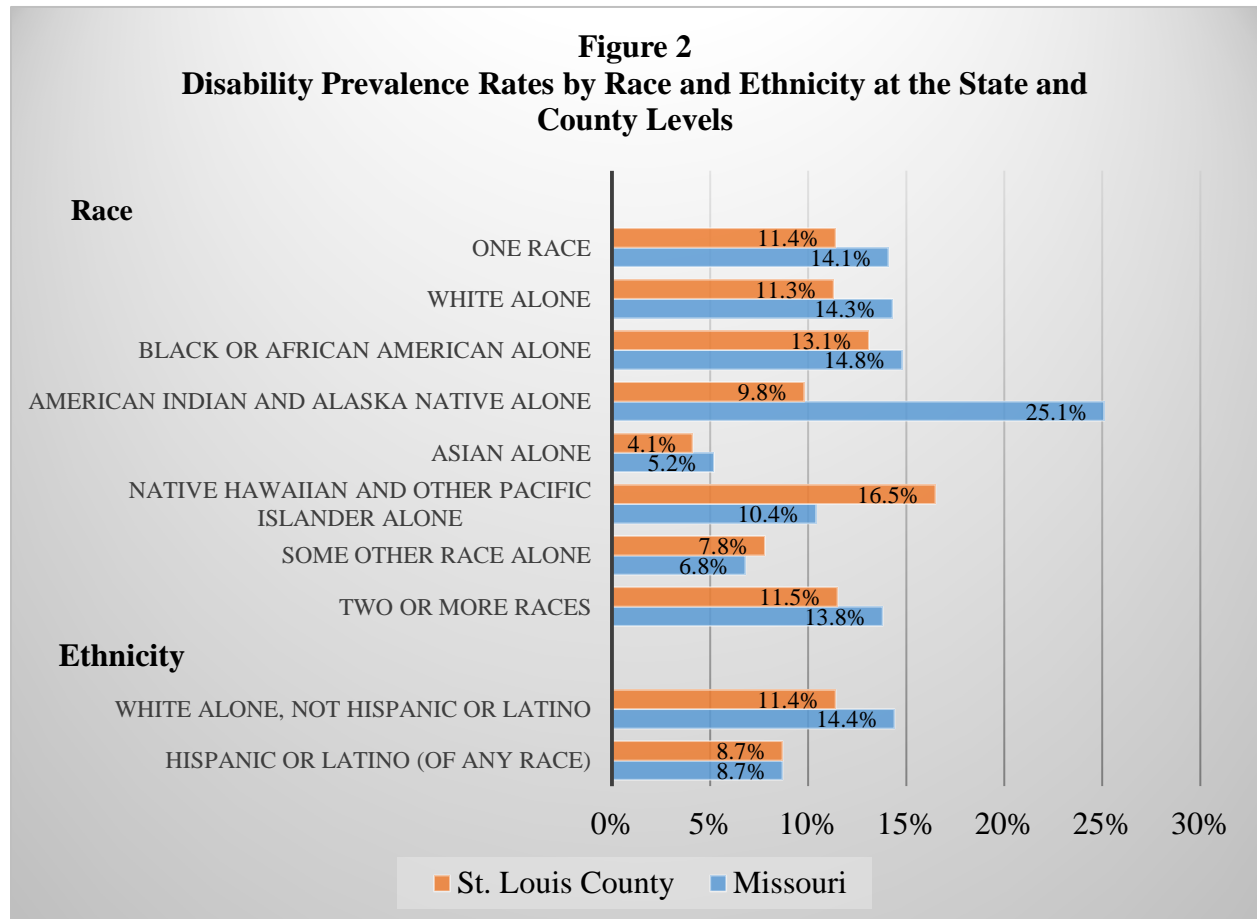
Race and Ethnicity. Not surprisingly, Table 10 demonstrates that “White Alone” is the most common racial group in both Missouri (83.0%) and St. Louis County (70.0%). There is a higher percentage of people who identify as “Black or African American alone” in St. Louis County (23.2%) than in the state as a whole (11.3%). The vast majority of the people who responded to the ACS in both the state and St. Louis County, indicated that they belong to only

one racial group. People who identified with two or more races only made up 2.38 percent of the population in the state and 2.42 percent in the County. In terms of ethnicity, a very small percentage of the state and St. Louis County populations indicate that they are Hispanic or Latino. In the state, the Hispanic or Latino population represent a larger percentage (3.75%) than it does in St. Louis County.

Table 10				
Number and Percent of Race and Ethnicity Compared to the Total Population of People in Missouri and St. Louis County				
Race and Ethnicity	Missouri		St. Louis County	
Race	#	%	#	%
<i>One Race</i>	5,773,680	97.6	964,317	97.6
<i>White alone</i>	4,910,276	83.0	691,568	70.0
<i>Black or African American alone</i>	670,196	11.3	229,570	23.2
<i>American Indian and Alaska Native alone</i>	23,419	0.4	1,424	0.1
<i>Asian alone</i>	101,243	1.7	35,741	3.6
<i>Native Hawaiian and Other Pacific Islander alone</i>	5,745	0.1	91	0.0
<i>Some other race alone</i>	62,801	1.1	5,923	0.6
<i>Two or more races</i>	141,001	2.4	23,940	2.4
Ethnicity	#	%	#	%
<i>White alone not Hispanic or Latino</i>	4,772,504	80.7	673,554	68.2
<i>Hispanic or Latino (of any race)</i>	221,524	3.8	26,075	2.6
Total Population	5,914,681	100.0	988,257	100.0

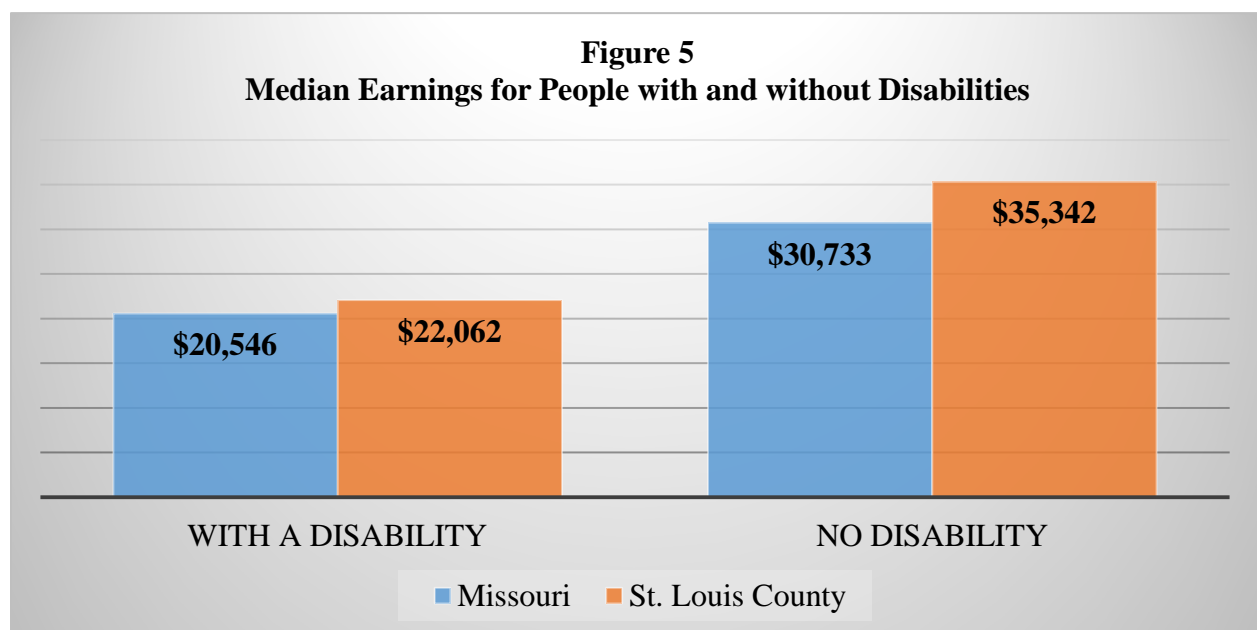
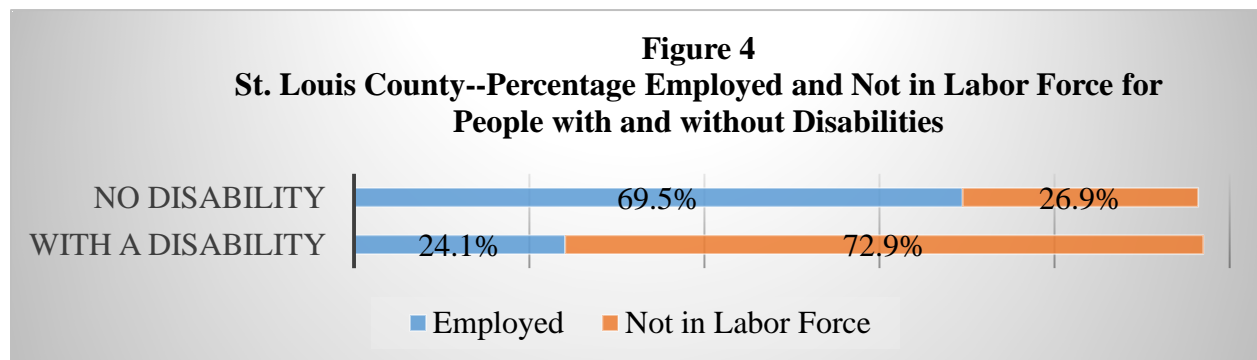
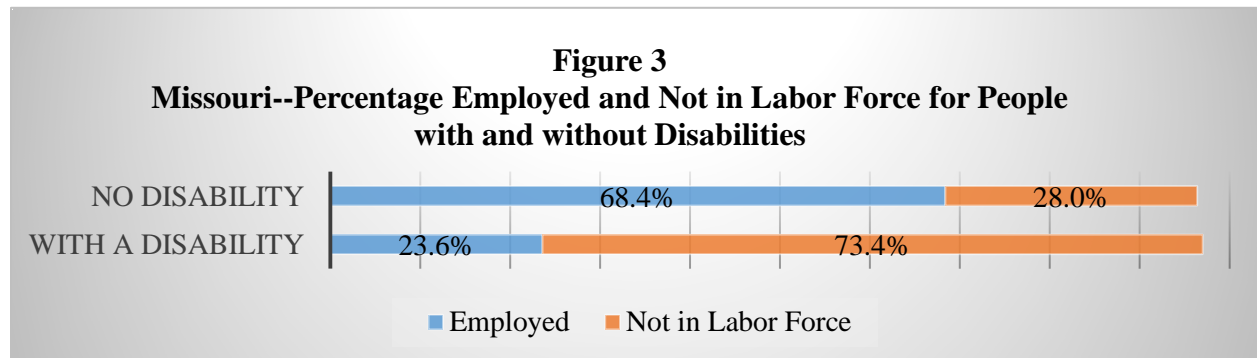
Figure 2, on the following page provides information about the percentage of people from each racial and ethnic group who self-identified as falling into one of the six disability categories identified by the ACS (vision, hearing, mobility, cognitive functioning, self-care, and independent living). At the state level, one of the most compelling statistics is that a quarter of

all American Indians and Alaska Natives identified as having a disability. With the exception of Native Hawaiians and other Pacific Islanders, the disability prevalence is consistently lower among race and ethnic groups in St. Louis County than it is at the state as a whole. Figure 2 demonstrates that among the two most common racial groups in St. Louis County, Black or African Americans have a higher disability prevalence rate than people who identified as White.



Employment and Earnings Data. In terms of employment, it is not surprising that nearly three quarters of people with a disability in Missouri (see Figure 3) and in St. Louis

County (see Figure 4) are not in the labor force. People without disabilities make 49.58% more than people with disabilities in Missouri and 60.19% more in St. Louis County (see Figure 5).



Figures 6 and 7 below demonstrate that people with disabilities are much more likely to make between \$1 and \$14,999 annually than their counterparts who do not have a disability. In St. Louis County 38.9 percent of people with disabilities make between \$1 and \$14,999, compared to 23.5 percent of the people who do not have a disability. Conversely, people without a disability are much more likely to make over \$75,000 annually than people with a disability. This is particularly true in St. Louis County where nearly 20 percent of people without a disability make over \$75,000 annually compared to 9.4% of people with disabilities.

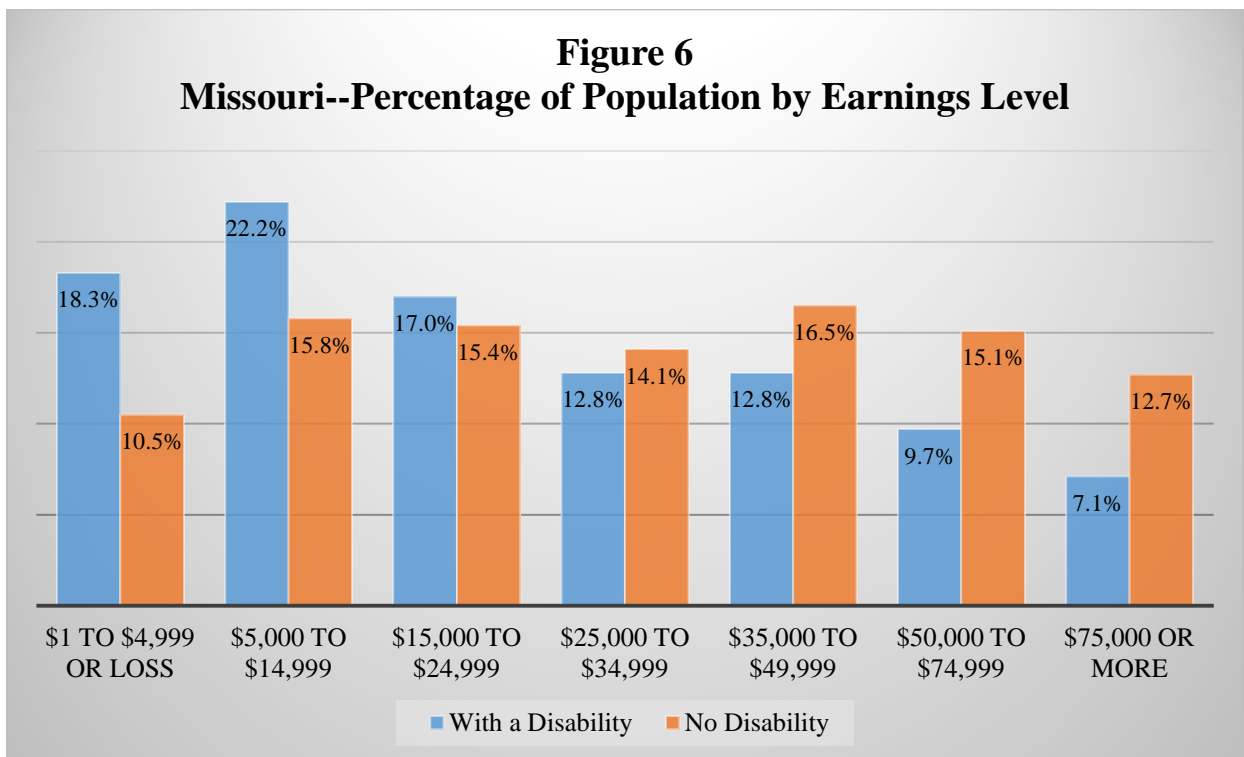
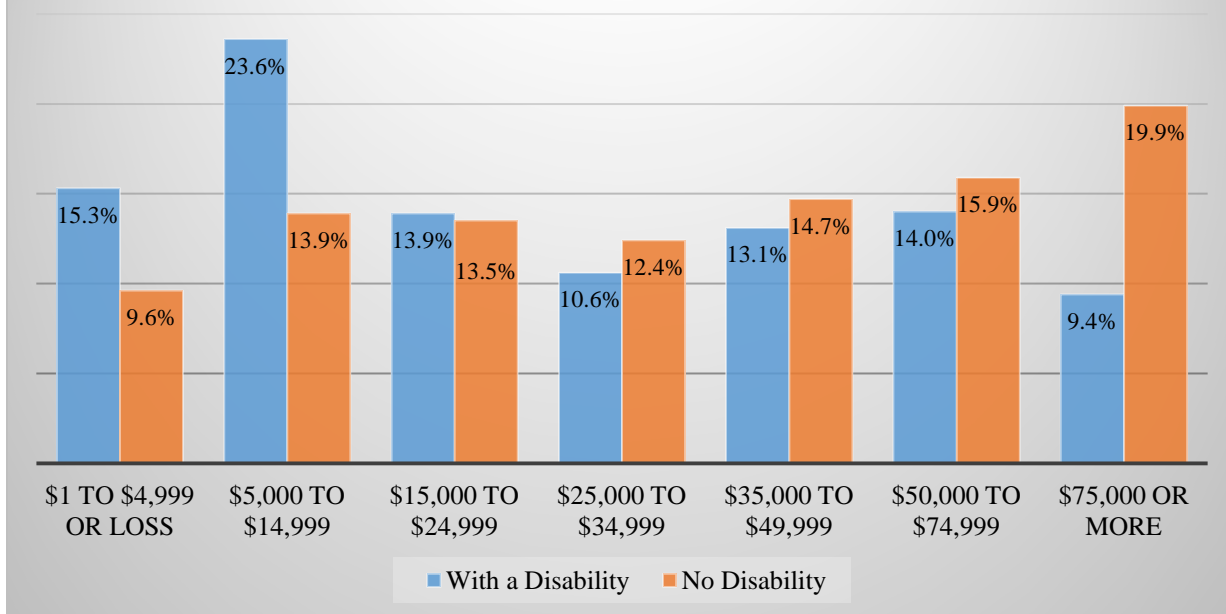


Figure 7
St. Louis County--Percentage of Population by Earnings Level



Trends in Education

The information in this section comes from DESE’s MCDS database. Table 11 shows that there were 4,957 students with developmental disabilities (DD) enrolled in St. Louis County schools in 2016. This represents nearly four percent of the total population of students (138,550) in the County. Table 12 presents a trend line analysis that assumes that populations of students in different categories will continue to increase or decrease in the near future at the same rate or pace that they have over the last ten years (2007-2016). Trend line prediction using the data from 2007 through 2016 indicate that there will be 5,231 (3.8%) students with a DD in 2017 representing an increase of 274 students. Using the same method there would be 5,949 (4.4%) students with a DD by 2021 an increase of 992 students. While the population of students with DD is growing (average of 4.3% per year since 2007), the overall population of students in St. Louis County schools is decreasing (average of 0.7% per year since 2007). This leads to an even larger overall percentage of students with DD in the St. Louis County school system.

Of the students with DD in 2016, 2,868 (58%) identify as having Autism, 1,600 (32%) have an intellectual disability, 351 (7%) multiple disabilities, and 138 (3%) identify as either having an orthopedic impairment, deafness and blindness, or a traumatic brain injury (TBI). Since 2007, the number of students with autism has grown by an average 8.4 percent per year, intellectual disabilities by 0.8 percent a year, and multiple disabilities by 0.2 percent. The orthopedic impairment/deaf and blind/TBI population has decreased by an average of 2.2 percent per year since 2007.

The trend line data in Table 12 and Figure 10 demonstrate that students with autism are growing at a rapid pace. According to the trend line analysis, autism will increase to 3,086 students and 59 percent of the DD population in 2017 and 3,750 students and 64 percent of the DD population by 2021. This is an increase of 882 students with autism over the next 5 years. This means that 89 percent of the total increase in students who have DD over the next 5 years will be students with autism.

Table 11

Number and Percentage of Students with Intellectual and Developmental Disabilities in St. Louis County between 2007 - 2016

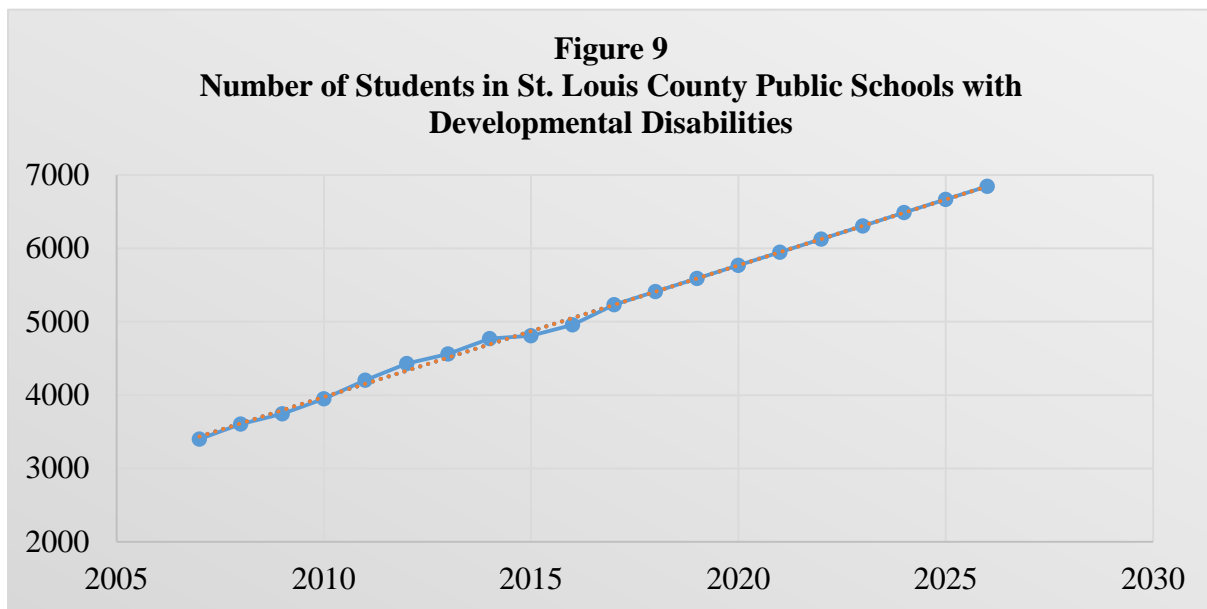
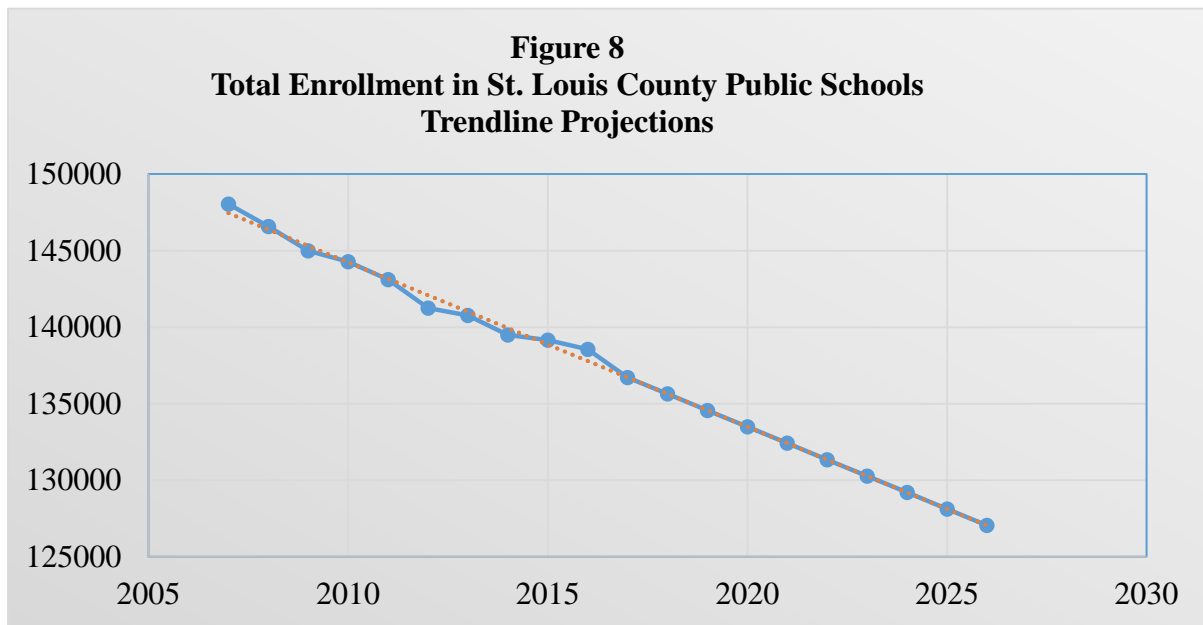
School Year	Total Enrollment	Total # of Students with Dev. Disabilities	Total % of Students with Dev. Disabilities	Intellectual Disability		Orthopedic Impairment/ Deaf and Blind/ TBI		Multiple Disabilities		Autism	
				#	%	#	%	#	%	#	%
2007	148,039	3,401	2.3	1,491	43.8	170	5.0	348	10.2	1,392	40.9
2008	146,573	3,607	2.5	1,528	42.4	170	4.7	345	9.6	1,564	43.4
2009	144,999	3,745	2.6	1,485	39.7	172	4.6	354	9.5	1,734	46.3
2010	144,272	3,951	2.7	1,499	37.9	169	4.3	357	9.0	1,926	48.7
2011	143,116	4,202	2.9	1,523	36.2	175	4.2	367	8.7	2,137	50.9
2012	141,243	4,432	3.1	1,578	35.6	180	4.1	343	7.7	2,331	52.6
2013	140,772	4,563	3.2	1,564	34.3	165	3.6	359	7.9	2,475	54.2
2014	139,502	4,773	3.4	1,675	35.1	164	3.4	342	7.2	2,592	54.3
2015	139,159	4,808	3.5	1,602	33.3	153	3.2	349	7.3	2,704	56.2
2016	138,550	4,957	3.6	1,600	32.3	138	2.8	351	7.1	2,868	57.9

Table 12**Trend Line Predictions of Disability Prevalence in St. Louis County between 2017 – 2021**

School Year	Total Enrollment	Total # of Students with Dev. Disabilities	Total % of Students with Dev. Disabilities	Intellectual Disability		Orthopedic Impairment/ Deaf and Blind/ TBI		Multiple Disabilities		Autism	
				Number	%	Number	%	Number	%	Number	%
2017	136,717	5,231	3.8	1,644	31.4	150	2.9	351	6.7	3,086	59.0
2018	135,643	5,411	4.0	1,661	30.7	148	2.7	351	6.5	3,252	60.1
2019	134,570	5,590	4.2	1,677	30.0	145	2.6	350	6.3	3,418	61.1
2020	133,496	5,770	4.3	1,694	29.4	142	2.5	350	6.1	3,584	62.1
2021	132,422	5,949	4.5	1,710	28.7	139	2.3	350	5.9	3,750	63.0

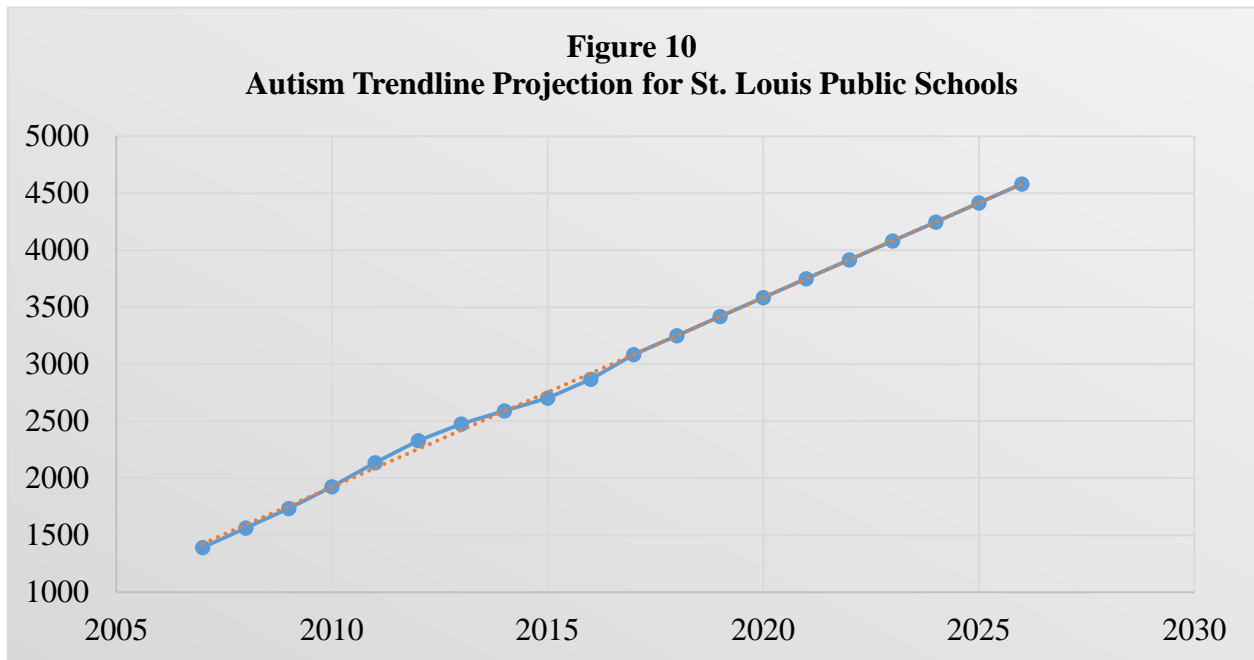
Education Trend Lines for St. Louis County

School Enrollment. Figure 8 illustrates the consistent decrease in enrollment for all children at St. Louis County public schools since 2007. The trend line shows that the total enrollment could be down to 136,570 by 2017 and 132,422 by 2021. Conversely, Figure 9 demonstrates that the trend for students with DD is growing. They are becoming a larger



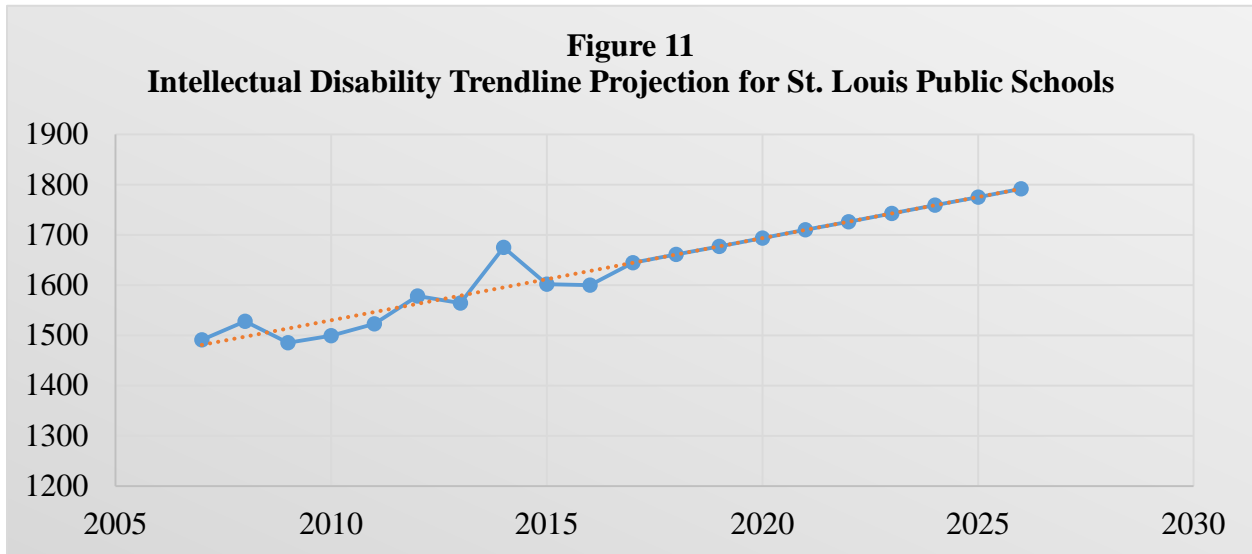
percentage of the total student population. In 2017, there could be 5,231 students with disabilities in St. Louis County public schools and 5,949 by the year 2021. This is an increase of 992 students.

Autism. Figure 10 illustrates the increase of students with autism in the St. Louis County public schools. In 2007, there were 1,392 students with autism representing 41 percent of the total DD population. In 2016, there were 2,868 students with autism representing 58 percent of the DD population. As mentioned above, the autism population is increasing 8.4 percent a year. In 2017, an estimated 3,086 students will have autism in the St. Louis County public schools. By the year 2021, this number could be 3,750. Due to this large growth, 89 percent of the increase in students who have DD over the next 5 years will be students with autism.

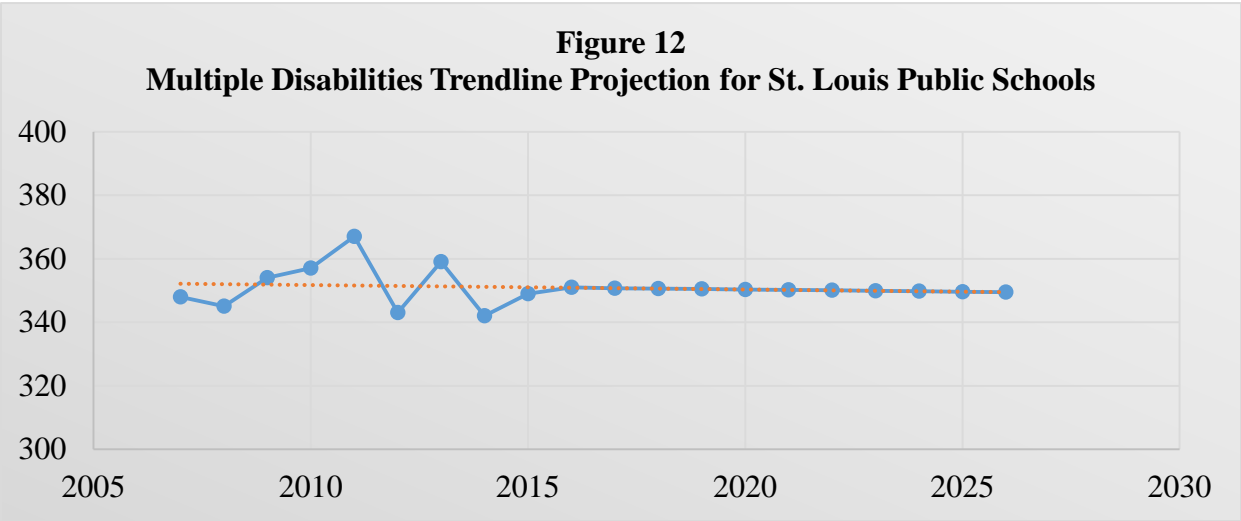


Intellectual Disabilities. Figure 11 illustrates the increase of students with intellectual disabilities (ID). This number is expected to continue to grow at a steady pace. In 2017, there

will be an estimated 1,644 students with ID and 1,710 by 2021. That is an increase of 110 students with intellectual disabilities over the next 5 years.

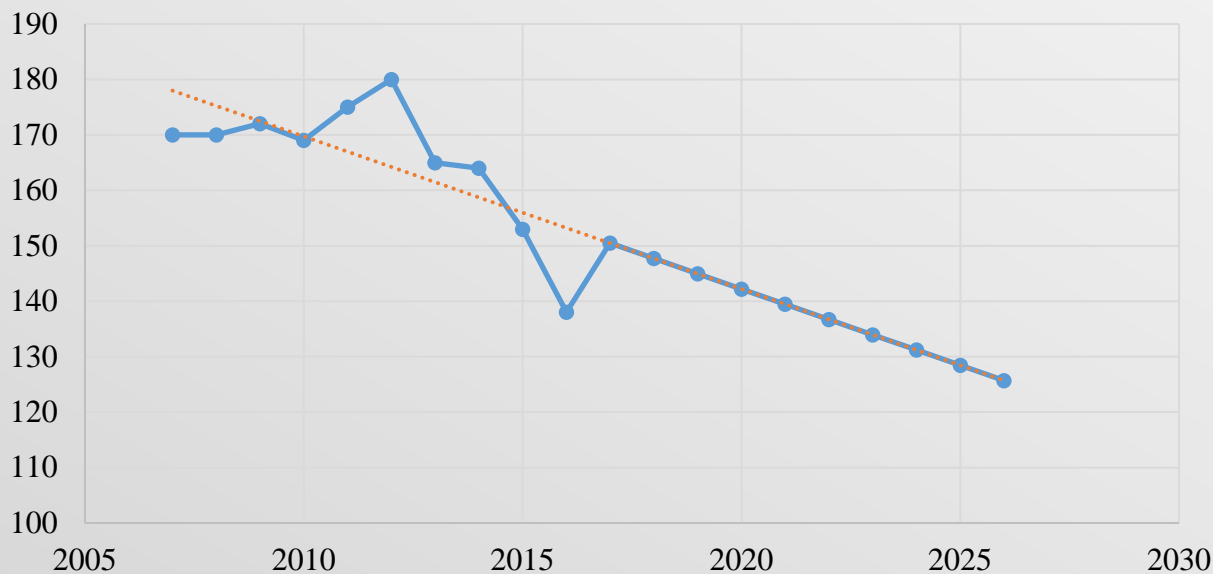


Multiple Disabilities. Figure 12 shows the flat rate of growth for students with multiple disabilities. In 2007, there were 348 students with multiple disabilities. In 2016, there are 351 students with multiple disabilities. Over the last ten years, there was a high of 367 students with multiple disabilities in 2011 and a low of 342 students in 2014. The trend line estimates 351 students in 2017 and 350 students in 2021. Even though there has been an increase in students with multiple disabilities since 2007 the trend line is going down slightly.



Orthopedic Impairments, Deaf/Blind, and Traumatic Brain Injury. Finally, Figure 13 shows the decrease of students with orthopedic impairments, students who are deaf and blind, and students with a TBI. In 2007, there were 170 students in this category. By 2016, there were only 138. This number really fell off in 2015 and 2016. It was 164 students in 2014, 153 in 2015, and 138 in 2016. There were as many as 180 students in this category in 2012. Trend line analysis over the last 10 years factors in years of growth and decline. Therefore the estimated number of students in the category for the year 2017 is 150 which is an increase from 2016, but down to 139 students by the year 2021.

Figure 13
OI/DB/TBI Trendline Projection for St. Louis Public Schools



Summary

The purpose of this report is to begin the process of identifying support and service trends for people with IDD in St. Louis County. The data discussed in this report come from: 1) The American Community Survey (ACS), a continuous survey conducted by the United States Census Bureau; and 2) The Missouri Comprehensive Data System (MCDS), a publicly accessible resource administered by the Missouri Department of Education and Secondary Education (DESE). Based on these two data sets we have identified several trends that have the potential to impact the service and support system for people with IDD in St. Louis County. These include the following:

1. According to the ACS, the most common disability type in both Missouri and St. Louis County for people between the ages of 5 and 17 is “cognitive difficulty.”

2. This trend changes for adults with a disability (18 to 64 years) with “ambulatory difficulty” becoming the most common disability.
3. Whites (70.0%) and African Americans (23.2%) make up 93.21 percent of the population in St. Louis County. The disability prevalence rate for Whites is 11.3 percent and for African Americans it is 13.1 percent. Both groups report a lower disability prevalence rate than the state as a whole.
4. With the exception of Native Hawaiians and other Pacific Islanders (only 91 people in St. Louis County), St. Louis County has lower prevalence rates than the state of Missouri as a whole.
5. Nearly three quarters of people with a disability in Missouri (73.4%) and in St. Louis County (72.9%) are not in the labor force.
6. The median earnings for people *without* a disability in St. Louis County is 60 percent higher than the median earnings for people *with* a disability.
7. While the population of students with DD is growing (average of 4.3% per year since 2007), the overall population of students in St. Louis County schools is decreasing (average of 0.7% per year since 2007).
8. Since 2007, the number of students with autism has grown by an average 8.4 percent per year, intellectual disabilities by 0.8 percent a year, and multiple disabilities by 0.2 percent.
9. According to the trend line analysis, autism will increase to 3,086 students and 59 percent of the DD population in 2017 and 3,750 students and 63 percent of the DD population by 2021. This is an increase of 664 students with autism over the next 5 years. This means

that by 2021, 89 percent of the total increase of students with DD (992) will be students with autism.

Focus Group Sessions

The purpose of this section is to present the results of 10 focus group sessions with 101 people from Saint Louis County, Missouri between November 16 and 18, 2016. The objective of the focus group sessions was to develop an understanding of people's feelings or thoughts about the most pressing needs facing people with developmental disabilities (DD) in the next five years. In order to gather the most relevant opinions, applied researchers from the Community Services Team at the University of Missouri, Institute for Human Development conducted focus group interviews with people who have a DD, family members of people who have a DD, and professionals who work for organizations that provide paid services and supports to people who have a DD.

This report is one piece of a larger needs assessment for the Productive Living Board (PLB) for Saint Louis County Citizens with Developmental Disabilities. The primary purpose of this needs assessment is to identify the current and anticipated future needs of Saint Louis County citizens with DD. The needs assessment will result in a prioritization of needs and provide recommendations that guide the development and provision of current and future services and supports provided by the PLB. This needs assessment is based in the principles of community-based participatory research (CBPR). The keystone principle of CBPR is the inclusion of community members in the research process, from the development of research questions to the interpretation of data to the identification of recommendations. As such, an advisory committee that includes people with DD, family members, staff from PLB, and other professionals who work with people with DD in Saint Louis County guides the needs assessment

activities. The advisory committee will review and approve the final version of this report, including any recommendations.

Methodology

Focus Groups Sessions

In partnership with staff from PLB, the research team from UMKC-IHD conducted 10 focus group sessions with people who have DD (2 groups), family members of people who have DD (4 groups), service providers (3 groups), and the needs assessment steering committee (1 group). The research team carefully planned the focus group sessions in an effort to obtain candid perceptions about the current and future service and support needs of people with DD in Saint Louis County. In order to help participants share their opinions freely, each session began with a vision mapping process. Facilitators gave each participant a large piece of paper that was broken into four sections. Each section of the visioning map corresponded to a specific focus group question (see Appendix A). These questions were:

1. In five years what are three to five things that you definitely **do not** want for yourself, your family member, or people with DD?
2. In five years what are the top three to five things you do want for yourself, your family member, or people with DD?
3. What do you need in order to do the things you want?
4. What will get in the way of doing the things you want?

Guided by the facilitator, participants spent the first 10 to 15 minutes of each session filling out their maps. Beginning sessions with the visioning maps allowed each participant to share their opinion on paper without feeling intimidated about talking in front of a group. The facilitator

was then able to go around the room to ask each person what they noted on their visioning map. The research team audio recorded each interview and collected the visioning maps.

Analysis

Data analysis began with the visioning maps. The research team used an item level analysis to examine the mapping data. This involved two members of the research team sifting through the complete set of maps individually and developing a codebook. They then compared and discussed their codes until they reached consensus on the names and definitions for each code. By design, they used broad terms in order to keep the number of codes manageable. Once the codebook was complete (see Table 13), the researchers individually analyzed the data using

Code	Definition	# (%)
Accessibility	Pertaining to accessibility of services, supports, structures, etc.	17 (0.8)
Aging	Issues related to the aging of individuals with IDD and/or their family members.	17 (0.8)
Autonomy	Ability of the individual with IDD to control or influence their environment and/or activities	109 (5.3)
Collaboration	Collaboration / Partnerships between organizations and/or communities in an effort to improve supports for people with IDD and their families.	61 (3.0)
Discrimination	Prejudicial feelings and/or actions towards people with IDD	47 (2.3)
Education	Learning opportunities for people with IDD	114 (5.5)
Equality	Placing the needs/desires of people with IDD on same level as others in the community	16 (0.8)
Family Support	Services and supports provided to the family of a person with IDD.	3 (0.2)
Family-Provided Supports	Supports provided by the family member of a person with IDD.	18 (0.9)
Family Training	References to training and/or education for family members of people with IDD.	30 (1.5)
Fear	Fear of changes or risks that will impact the lives of people with IDD.	11 (0.5)
Financial	Personal money issues associated with everyday needs	86 (4.2)

Table 13 Codebook		
Code	Definition	# (%)
Funding	State, federal, or grant provided funding that enables individuals with DD to have paid supports.	144 (7.0)
Health Care	Concerns associated with the overall health of individuals with IDD	87 (4.2)
Housing	References to the places where people with IDD live.	131 (6.3)
Inclusion	Including people with IDD in activities, decision making at all levels and across the lifespan.	44 (2.1)
Inclusive Employment	Access people with IDD have to inclusive employment in the community. May also refer to services or programs that promote inclusive employment/	168 (8.1)
Isolation	References to few or no contacts with activities that occur in the community.	31 (1.5)
Mental Health	Feelings associated with self-perception or the treatment of associated issues.	23 (1.1)
Natural Supports	Supports provided by community members (neighbors, friends, co-workers, etc.).	21 (1.0)
Other	Comments that occur in isolation	47 (2.3)
Policy	Policies or policy issues at the organizational, community, or state levels that impact the lives of people with IDD.	57 (2.8)
Policy Maker Training	References to training and/or education for people who make policies that impact the lives of people with IDD.	4 (0.2)
Professional Training	References to training and/or education for service providers of people with IDD.	2 (0.1)
Provider Supports	Generic supports provided by a person or persons employed by a service organization. Paid supports.	281 (13.6)
Provider Training	References to training and/or education of people who provide paid supports to people with IDD.	28 (1.4)
Respite	Respite provided through paid supports, family supports, or natural supports.	17 (0.8)
Safety	Home or community issues leading to well-being and security of individuals with IDD	30 (1.5)
Segregated	Systemic marginalization of individuals with IDD	22 (1.1)
Self-Advocacy	Ability of people with IDD or their representatives to advocate for their needs and desires	34 (1.7)
Sheltered Employment	Employment opportunities within a workshop or supported employment facility.	34 (1.7)
Social Life	Access to social experiences with friends and family	123 (6.0)
Technology	Device or software that potentially increases quality of life for people with IDD	27 (1.3)
Transition	Transition from one life stage to the next; transition from one funding source or service to another.	13 (0.6)

Table 13 Codebook		
Code	Definition	# (%)
Transportation	Public or personal vehicle capable of transporting a person from one place to another	161 (7.8)
Volunteer	Volunteer opportunities for people with IDD.	8 (0.4)
Total Observations		2,066 (100.0)

ATLAS.ti, a software package for qualitative data analysis, and then met to compare their individual coding structures. Any time there was not agreement across all codes team members discussed the areas of disagreement, revised the codebook, and recoded the data until agreement level reached 100 percent. They repeated this process until all the mapping data analysis was complete. In addition to using ATLAS.ti, the research team entered code-frequency data into Excel, which enabled them to present the data in tables and graphs. Finally, once the research team coded the visioning maps, they used the audio recordings to pull representative quotes for each of the ideas expressed during the focus group sessions.

Participants

The focus group sessions included 101 participants from all regions of Saint Louis County. PLB staff asked them to participate in the focus group sessions based on their specialized knowledge related to the current and future support and service needs for people with DD.

Table 14 provides more information about the focus group participants. Professionals and white women were the two groups represented most often in the sample of participants.

Table 14 Numbers and Percentages of Focus Group Participants			
	Females # (%)	Males # (%)	TOTAL # (%)
Black or African American	6 (5.9)	1 (0.9)	7 (6.9)

Table 14 Numbers and Percentages of Focus Group Participants			
White	74 (73.3)	20 (19.8)	94 (93.1)
Person with DD	10 (10.0)	5 (4.9)	15 (14.9)
Family Members	25 (24.8)	6 (5.9)	31 (30.7)
Professionals	37 (36.6)	11 (10.9)	48 (47.5)
Advisory Committee	4 (3.9)	3 (3.0)	7 (6.9)

Finally, participants included people from the following groups:

1. People with DD who received only PLB-funded services;
2. Family members who received PLB-funded services only;
3. Family members who received only Medicaid waiver funding;
4. Family members who may or may not receive services from the Missouri Department of Mental Health or PLB;
5. Service providers funded by PLB;
6. Service providers and other stakeholders not funded by PLB;
7. Members of the needs assessment advisory committee.

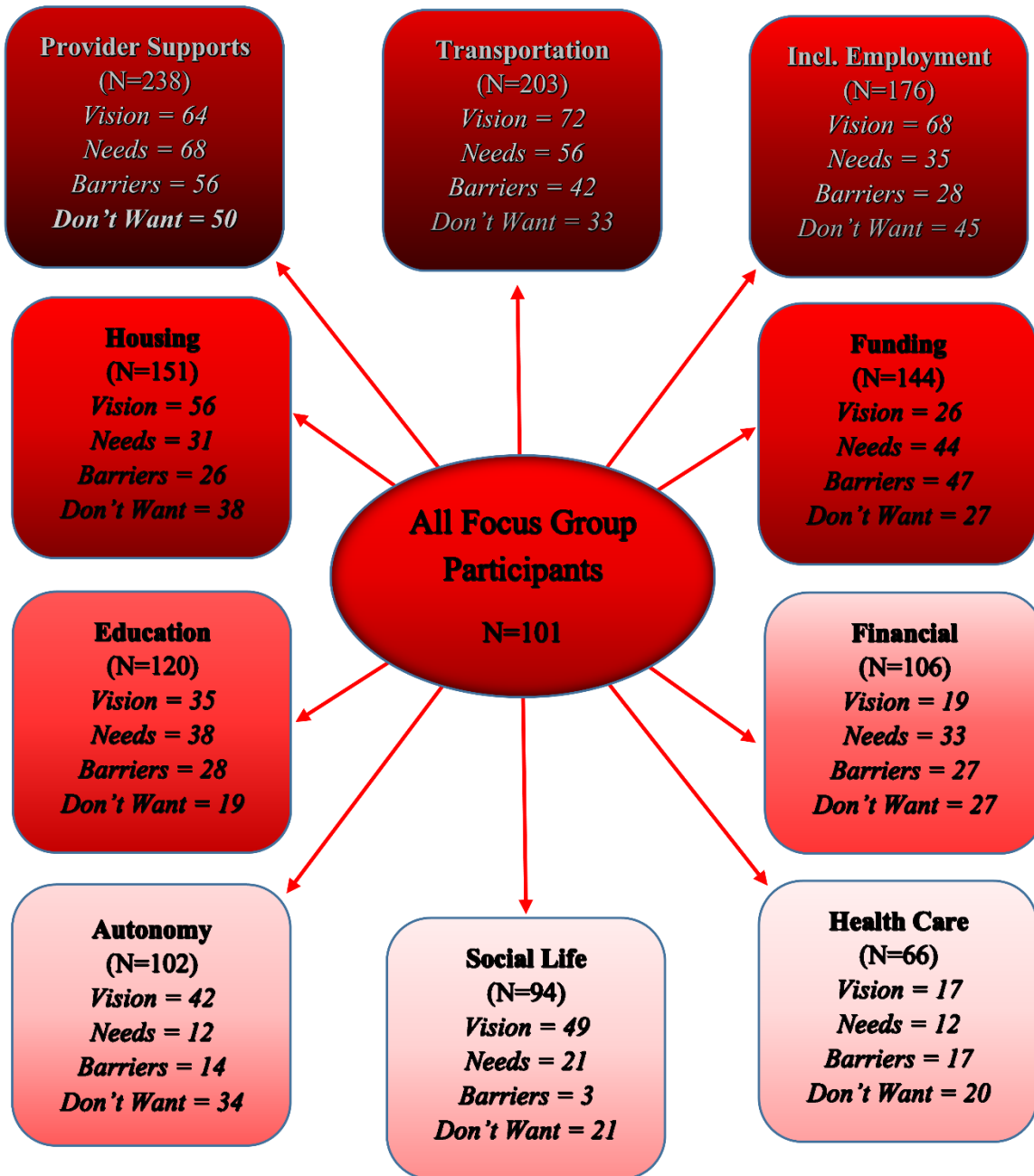
Results

Figure 14 presents the ten most frequently discussed topics by the focus group participants. Specifically, it presents the number of participants who mentioned each topic as a part of their *Vision, Needs, Barriers*, or things they *Do Not Want*. In order to make sense of Figure 1, it is important to understand that participants often discussed the same themes in response to each of the four questions. As a result, a person may discuss “good and reliable transportation” as a part of their five-year vision. The same person may also discuss “reliable

transportation” as a need that will enable them to have a good job. By the same token, “unreliable transportation” is a barrier to having a good job. Finally, not having any transportation is something that they “definitely don’t want.”

Overall, more people mentioned generic “provider supports” than any other topic. However, Figure 14 also reveals that when the participants discussed their visions for people with DD, more of them talked about transportation issues than any other topic. For example, “I want my son to have reliable transportation.” “Inclusive Employment,” “Housing,” and “Social Life” were other top-mentioned themes related to participants’ visions for people with DD. On the other hand, when people made their needs statements, the themes they discussed most often were “Provider Supports,” “Transportation,” and “Funding.” Interestingly, participants discussed these same three issues as the leading barriers. When these three items are good and in place, they help people with DD achieve. When they are not good, they create barriers to full achievement. Lastly, when participants discussed the things they don’t want, more of them mentioned issues related to “Provider Supports,” “Inclusive Employment,” and “Housing” than other topics.

Figure 14. Discussion Themes across All Focus Group Participants



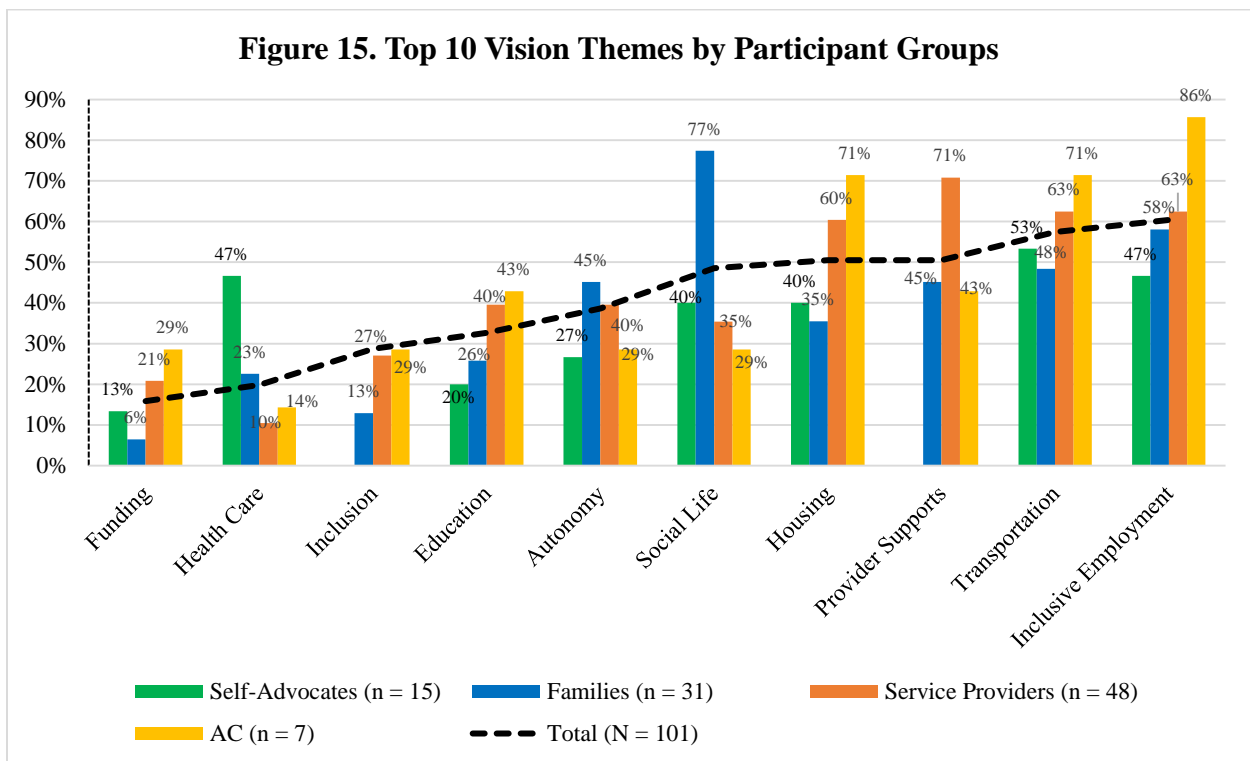
What Are Provider Supports?

As Figure 14 demonstrates, more participants discussed issues related to “Provider Supports” than any other topic. The definition for this code is “Generic supports provided by a person or persons employed by a service organization. Paid supports.” The research team applied the “Provider Supports” code any time a participant referred to needing a paid support. As Table 15 indicates, most of the time, the data analysts used “Provider Supports” in conjunction with another code. For example, “I need supports to help me go places.” The research team coded this example as both “Transportation” and “Provider Supports.” Additionally, participants also made broad statements such as, “I just need reliable supports.” The number of times that participants mentioned paid provider supports in conjunction with another concept indicates that people with DD in Saint Louis County need a broad range of supports. The most commonly mentioned paid supports identified by participants were supports that helped people with “Transportation,” “Inclusive Employment,” “Housing,” “Funding,” and “Social Life.”

Table 15				
Codes that Co-occurred with Provider Supports				
Code, #	Code, #	Code, #	Code, #	Code, #
Accessibility, 12	Equality, 8	Inclusion, 26	Policy Maker Training, 2	Sheltered Employment, 21
Aging, 10	Family-Provided Supports, 22	Inclusive Employment, 81	Provider Training, 10	Social Life, 50
Autonomy, 39	Financial, 44	Isolation, 6	Respite, 17	Technology, 16
Collaboration, 35	Funding, 61	Mental Health, 12	Safety, 20	Transition, 9
Discrimination, 21	Health Care, 36	Natural Supports, 15	Segregated, 10	Transportation, 102
Education, 51	Housing, 72	Policy, 31	Self-Advocacy, 19	Volunteer, 5

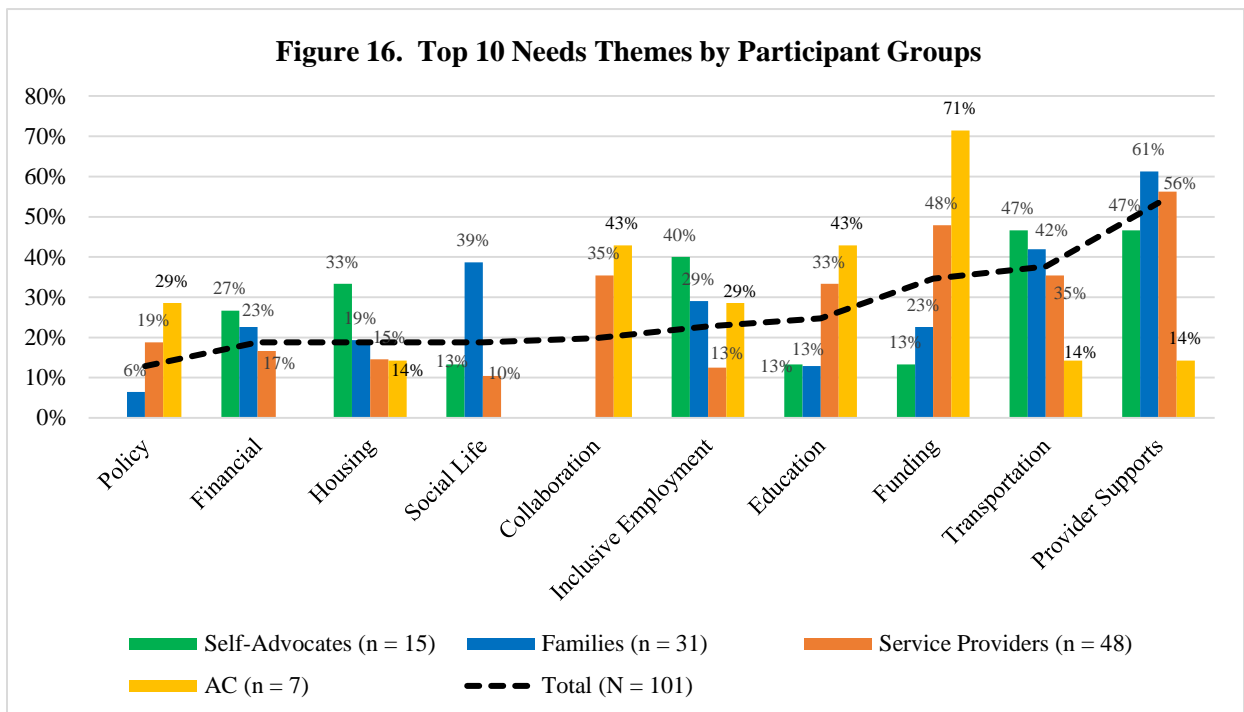
Participants' Vision Statements

Figure 15 provides an overview of the most common ideas people used to describe their visions for people with DD in Saint Louis County. One interesting theme that emerges is how important social activities outside the home are to family members. Over three quarters of the family member participants mentioned “Social Life” in their vision statements. The vision statements from service providers tended to focus on the types of supports that they provided to people with DD, such as housing, transportation, and inclusive employment supports. The vision statements for self-advocates were a bit more diffuse. No topic appears in more than half of the self-advocates’ vision statements although they mentioned multiple themes at about the same rate: “Health Care,” “Social Life,” “Housing,” “Transportation,” and “Inclusive Employment.” Interestingly, self-advocates did not include “Provider Supports” in their vision statement. They also mentioned “Health Care” at a much higher rate than the other participant groups.



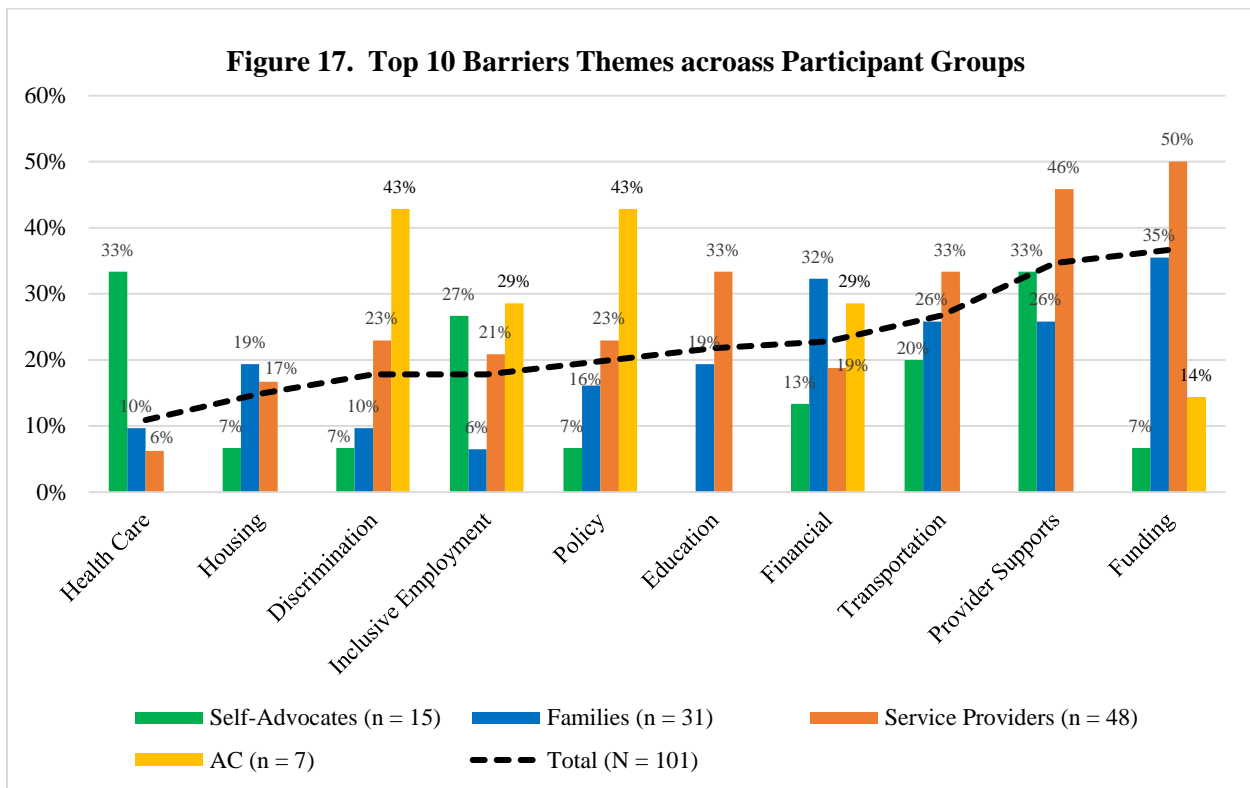
Participants' Needs Statements

Figure 16 provides an illustration of the items participants believed were needed in order to achieve their visions. It is notable that almost none of the items appeared in the needs statements of more than 50 percent of any participant group. The exceptions were: 56 percent of providers mentioned “Provider Supports” as a need, as did 61 percent of family members; and 71 percent of the advisory committee identified “Funding” as a need. Self-advocates mentioned “Transportation” as their greatest need. They also mentioned “Housing” issues as a need at a much higher rate than the other participant groups. Consistent with their visions statements, family members described issues related to “Social Life” as a need. Both service providers and the advisory committee mentioned “Collaboration” in their needs statements. Neither family members or self-advocates described this as a need. “Transportation” and generic “Provider Supports” are the two items that appear most commonly in the needs statements of all participant groups.



Participants' Barriers Statements

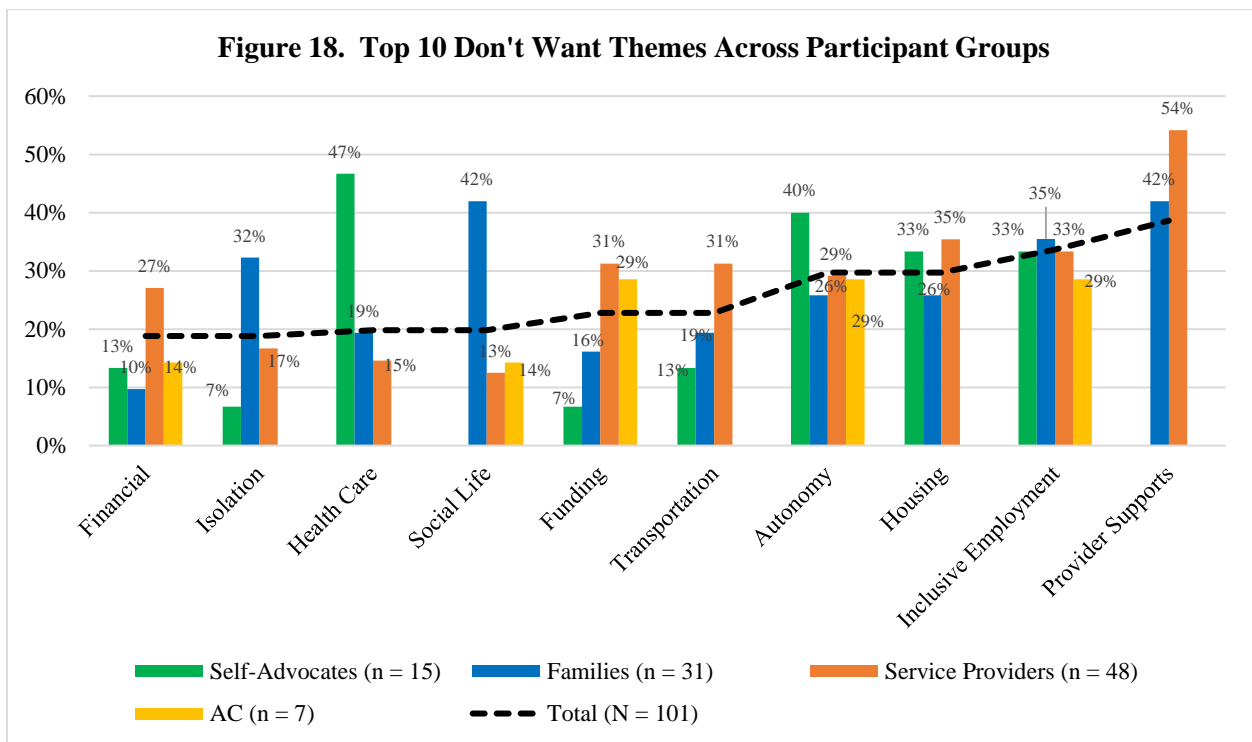
Figure 17 demonstrates that each participant group emphasized different barriers. Self-advocates described issues related to “Health Care,” “Inclusive Employment,” and “Provider Supports” as the barriers that concerned them most. Family members expressed concern about “Financial” and “Funding” issues. Service providers discussed “Provider Supports” and “Funding” in their statements about barriers. Lastly, the advisory committee members were most concerned about “Discrimination” and “Policy” issues.



Things Participants Do Not Want

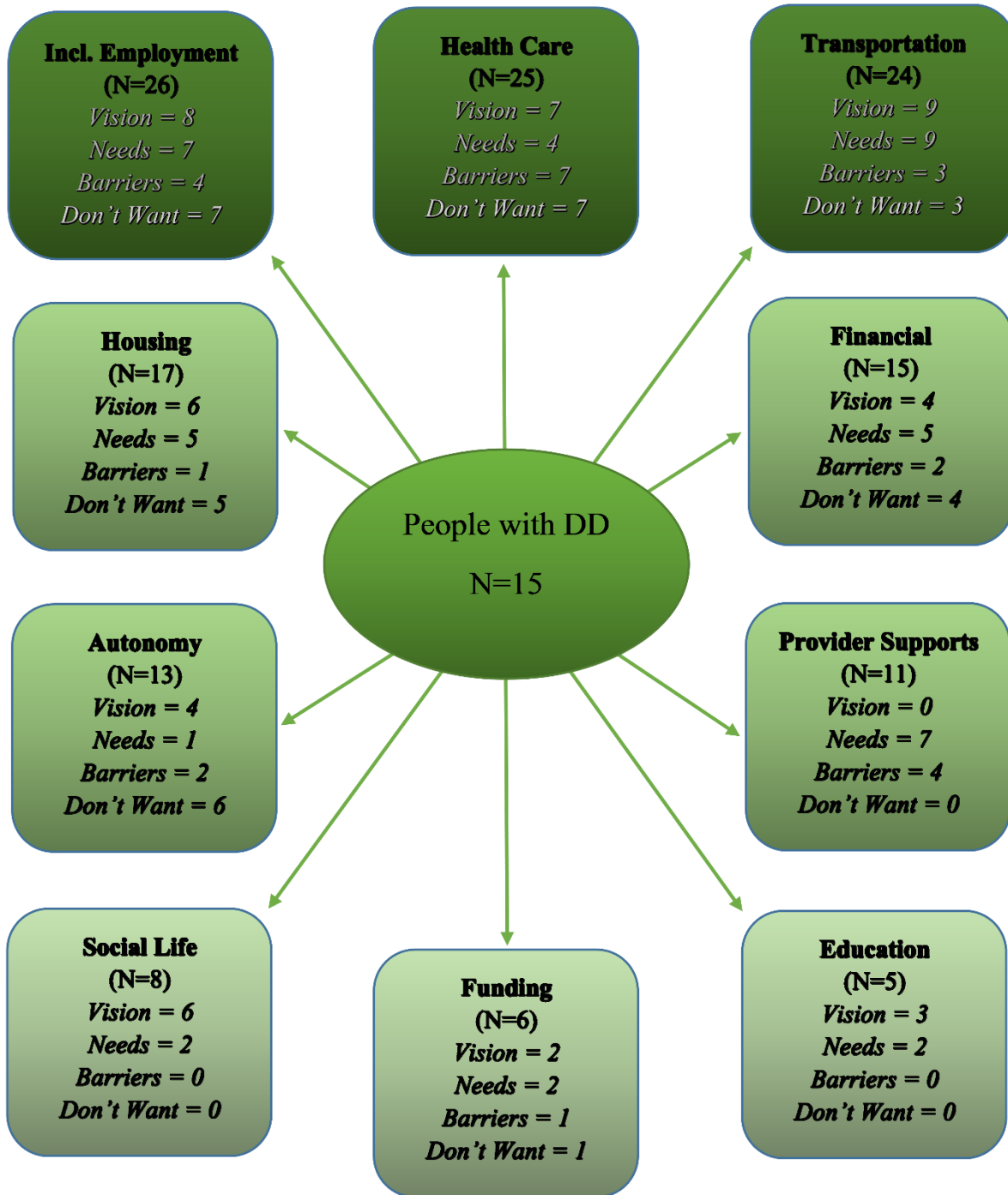
When discussing the things they did not want for people with DD, the focus group participants consistently mentioned lack of inclusive employment as a concern. As Figure 18 demonstrates, nearly one third of the people from each participant group addressed this issue.

For self-advocates, almost half had health-related concerns. They also expressed more concern about issues related to losing autonomy at a higher level than other participant groups. For family members, they did not want their children, grandchildren, or siblings with a DD to experience isolation or a lack of social opportunities. By far, the greatest concern for service providers was the support and services that they and their organizations provide to people with DD. They were especially concerned about employment, housing, and transportation supports. Finally, the advisory committee voiced concern about issues related to “Funding,” “Autonomy,” and “Inclusive Employment.”



People with Developmental Disabilities

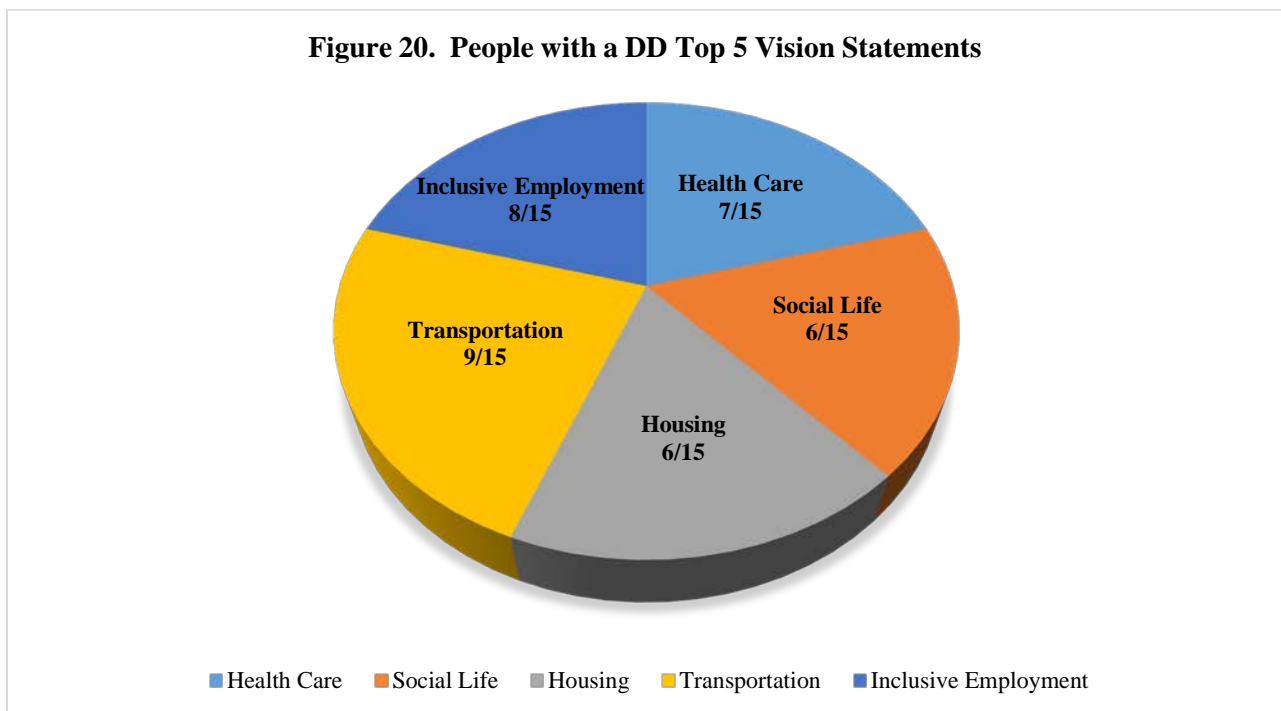
Figure 19. Discussion Themes among People with Developmental Disabilities



Focus group participants who have a DD were most interested in talking about issues related to “Inclusive Employment,” “Health Care,” and “Transportation.” These topics appeared in their vision, needs, barrier, and “don’t want” statements. Secondary issues included topics related to “Housing,” “Financial,” “Autonomy,” or “Provider Supports.” Interestingly, a discussion of “Provider Supports” did not appear in the vision statements of people with a DD.

Vision Statements

Figure 20 presents the five topics that people with a DD mentioned most often in their vision statements. The topic discussed most often was “Transportation.” The comments related to transportation were straight forward, as this example demonstrates: *“I would like to see greater public awareness and understanding of disabilities of all types. And better transportation.”* The following quote provides an example of both “Housing” and “Social Life”: *“To live in a nice big house with a roommate or two.”*



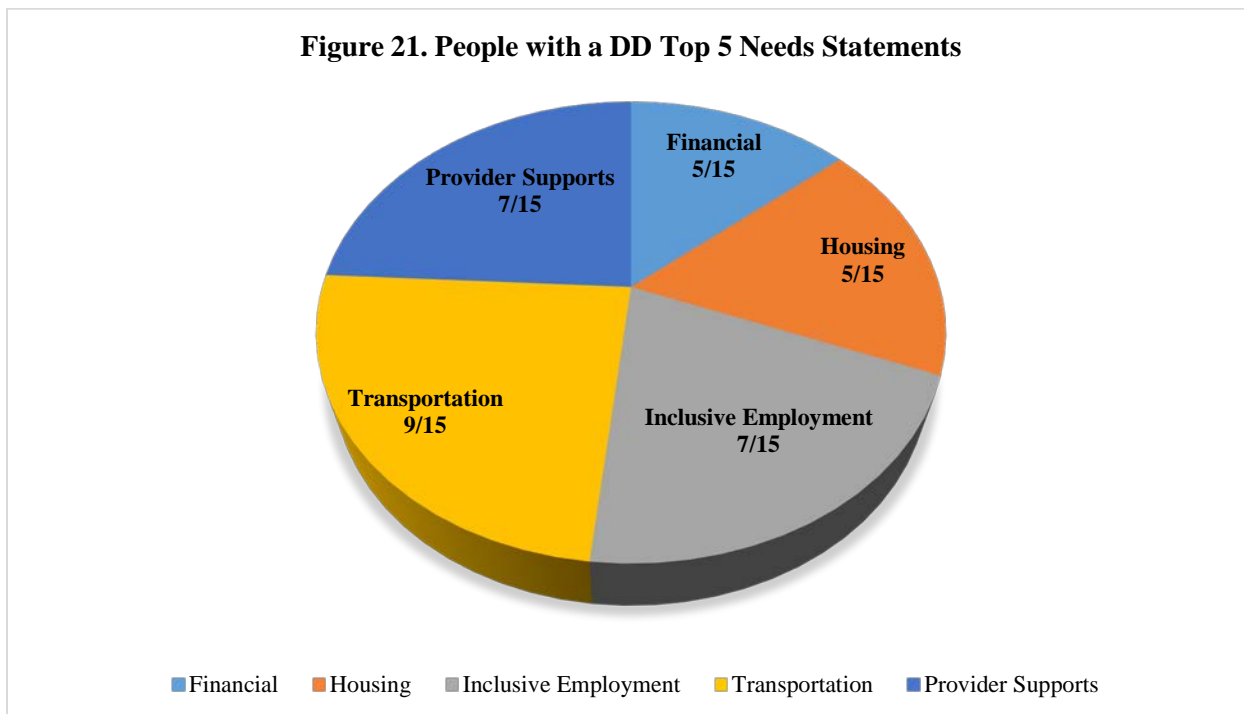
People with a DD also included comments about “Inclusive Employment” in their vision statements. The following quote provides one man’s employment vision.

“I would like for the government to not disincentivize work and to earn a good living because they say you can only earn so much money before you lose your benefits. They're telling us they do not want us to work or have economic freedom.”

Needs Statements

In their needs statements, people with a DD indicate that in order to achieve their visions, they need supports related to “Transportation,” “Inclusive Employment,” and “Housing.” They also need the financial means to make their visions happen. In terms of “Inclusive Employment,” one man said, “*You would like to see employers bring qualified people with disabilities to be office supports and other things.*” Another person provided a quote about the support needs of aging adults with DD, “*Family and friends, I might need more support that way. If my mom starts to forget me, I'm going to need more support.*”

Figure 21. People with a DD Top 5 Needs Statements



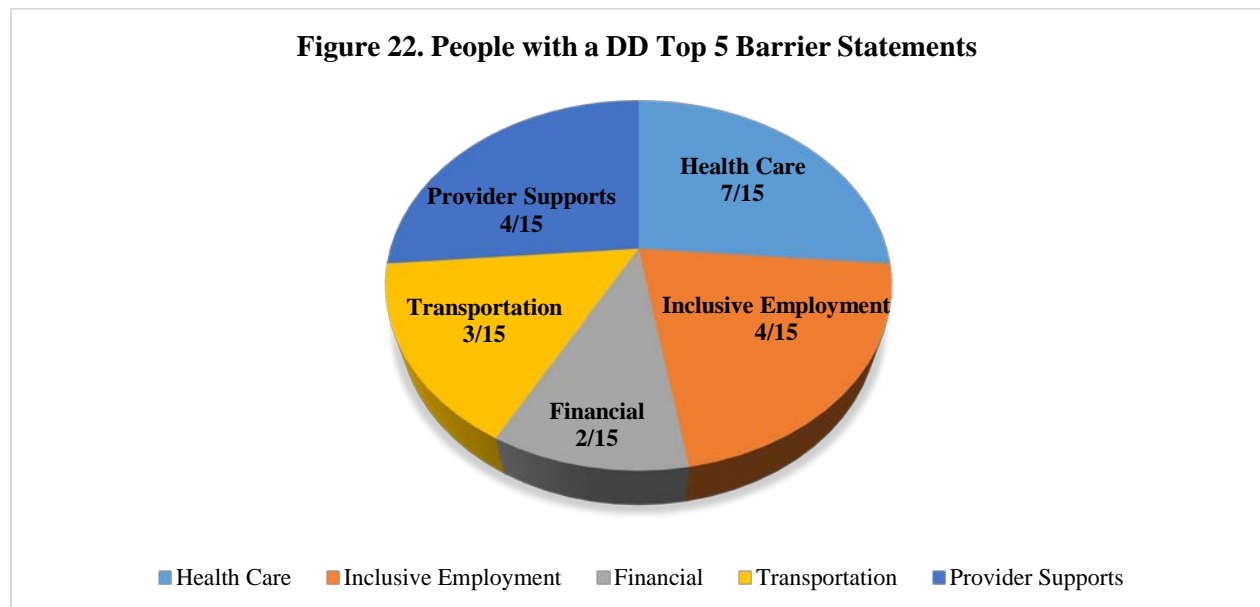
Barriers Statements

The topics people with a DD discussed in their barrier statements are similar to the comments they made regarding their visions and needs. The most forceful quote related to barriers came from a person with a DD who was discussing provider supports related to employment:

“My biggest problem is they are not consistent enough. I was told the other day they would be there by 2 PM. They showed up at 3 PM. Didn't text me, didn't call me, didn't tell me when they were going to be there. They were inconsistent with me. And then when I went to talk with the job coach she said "Well, he just had a meeting." I'm like, you're working with the public who doesn't understand what that means. For a lot of people a meeting could mean anything and you're telling me he was in a meeting for what? No, that doesn't make sense.”

Another person provided a long list of barriers, *“No funding, no tutoring service for school. A case manager who doesn't do their job...Not watching my weight.”*

Figure 22. People with a DD Top 5 Barrier Statements



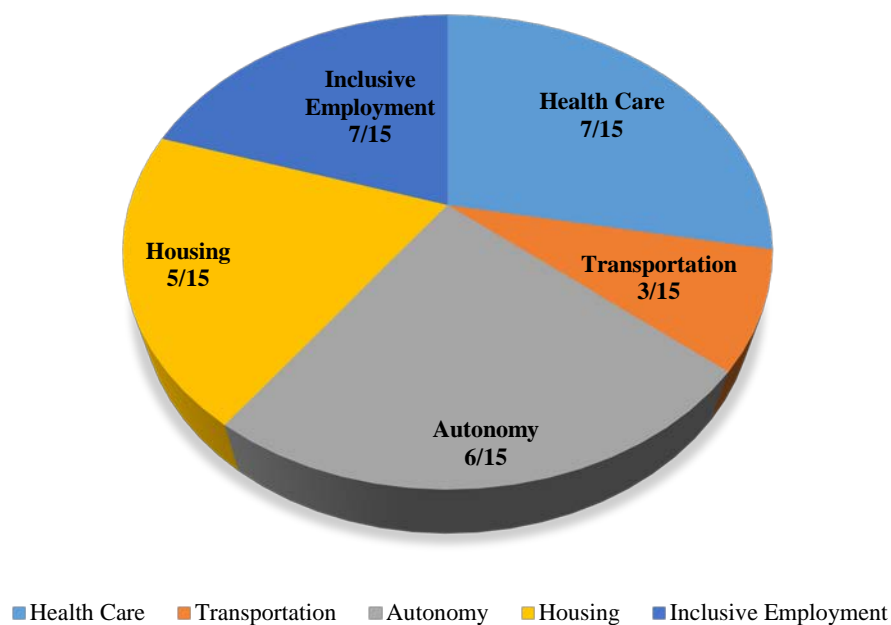
People with DD Do Not Want

A loss of autonomy and poor health were the two topics people with a DD discussed most when describing the things they did not want in five years. The following quote touches on these two topics and housing.

“I don’t want to see, when you wake up in the morning and know you are not feeling well...if you have your worker scheduled for that day, if you don’t want them to come over for some stupid or regular reason, they question you why. And then lay a guilt trip on you like, ‘Well, I’m going to lose my hours.’ So what! If I don’t want you in my home, that’s my right.”

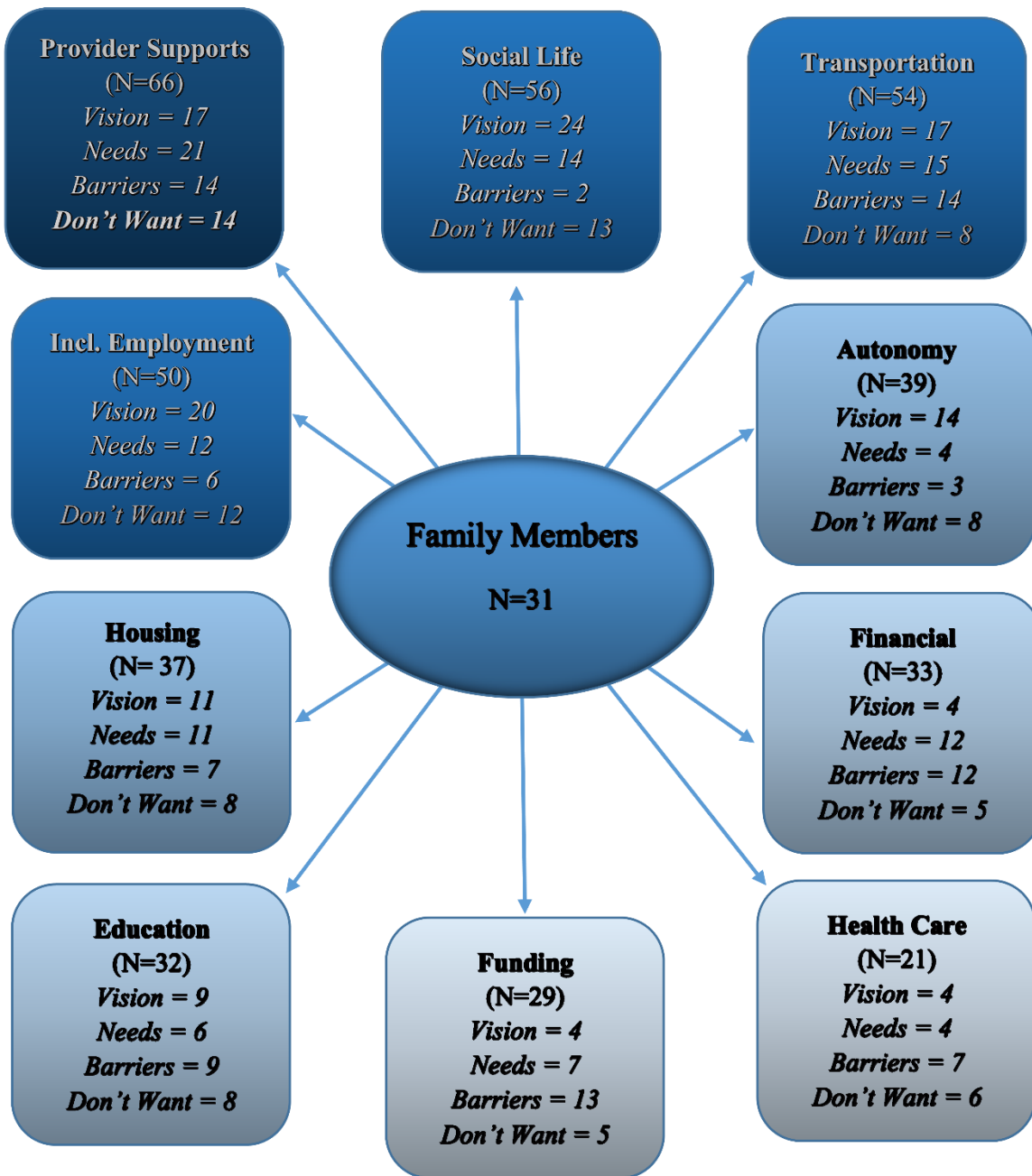
Another person with a DD also touched on these themes with this quote, *“I don’t want to be unhealthy in my eating habits and I don’t want to be on as much medicine anymore. And I don’t want to be as dependent. And I also don’t want to be as mentally unstable as I am right now.”*

Figure 23. People with a DD Top 5 Do Not Want Topics



Family Members

Figure 24. Discussion Themes among Family Members



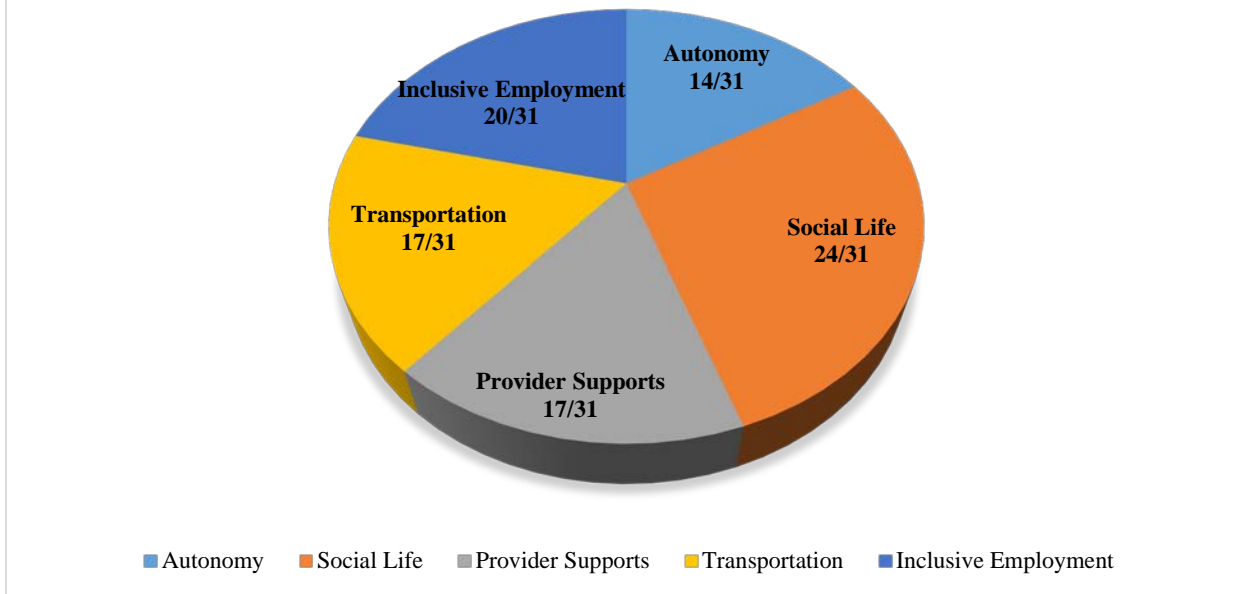
Family members who participated in a focus group session concentrated the majority of their comments across all four questions on “Provider Supports,” “Social Life,” “Transportation,” and “Inclusive Employment.” One of the more interesting aspects of the family members’ statements is the emphasis they placed on “Social Life.” As the comments in the following section demonstrate, parents did not want their children with DD to be confined to the house with few opportunities to get out into the community.

Vision Statements.

As family members discussed their visions for people with DD, the topic they discussed most often was “Social Life.” This topic is captured in the following comment from a parent, *“I want my son to have a place to go in the community where he has friends and something to do.”* Transportation was also important to the family members’ visions for people with DD, as the following quote indicates, *“Reliable access to transportation. That's huge. Affordable, too. More options for transportation. We don't have enough options for transportation in the St. Louis area. Residential or for employment.”* Lastly, the extensive quote that follows touches on a few of the topics that were important to the family members’ vision statements.

“We are coming out of an inclusive situation with school and moving to a secluded situation with the sheltered workshops, because that is what is offered. I would like to see something in between. Something group supported. Not saying one-on-one is the answer because it is costly. But I think our kids can learn in a smaller group and still be out in the community.”

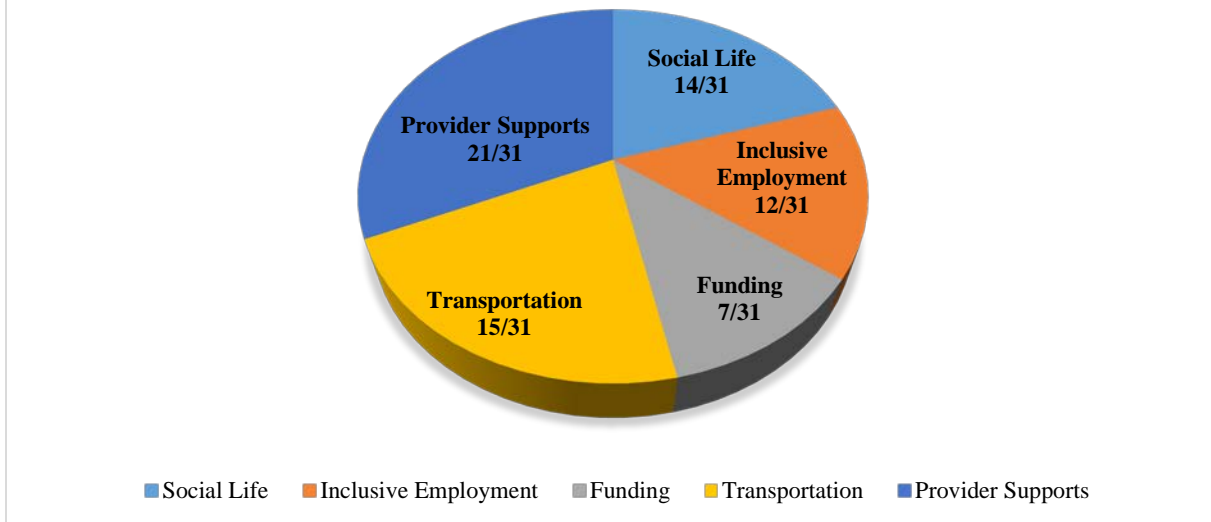
Figure 25. Families Top 5 Vision Statements



Needs Statements

In order to achieve the ideas set forth in their vision statements, the family members identified “Provider Supports,” “Transportation,” “Social Life,” “Inclusive Employment,” and “Funding” as the top five needs (see Figure 26). The first quote below

Figure 26. Families Top 5 Needs Statements



reflects a parent who recognizes the need for a provider support that functions as family navigator.

“If there was someone who was the clearinghouse of information to help parents early or to say, ‘Your child is only 5 but you need to start getting on the wait lists now.’ Or, ‘think about this...this is where you have to advocate here and...’ Because I think a lot of times by the time our kid gets to that place, we needed to be thinking about that 5 years ago and we didn't know the questions to ask because we're so overwhelmed with where we are right now that we're just putting out fires instead of thinking proactively.”

The next extensive quote demonstrates the types of need parents identified regarding helping their child with DD develop a social life.

“... at some point she will want to start dating and sometimes when the process is kind of an issue you can't necessarily dissect social cues and that makes it tricky because, ‘this person really likes me’ and ‘I have no idea what you're saying. You want to go out with somebody but that doesn't make you his girlfriend.’ And to have that in a safe situation is hard and it's hard to find that because you want that someday.”

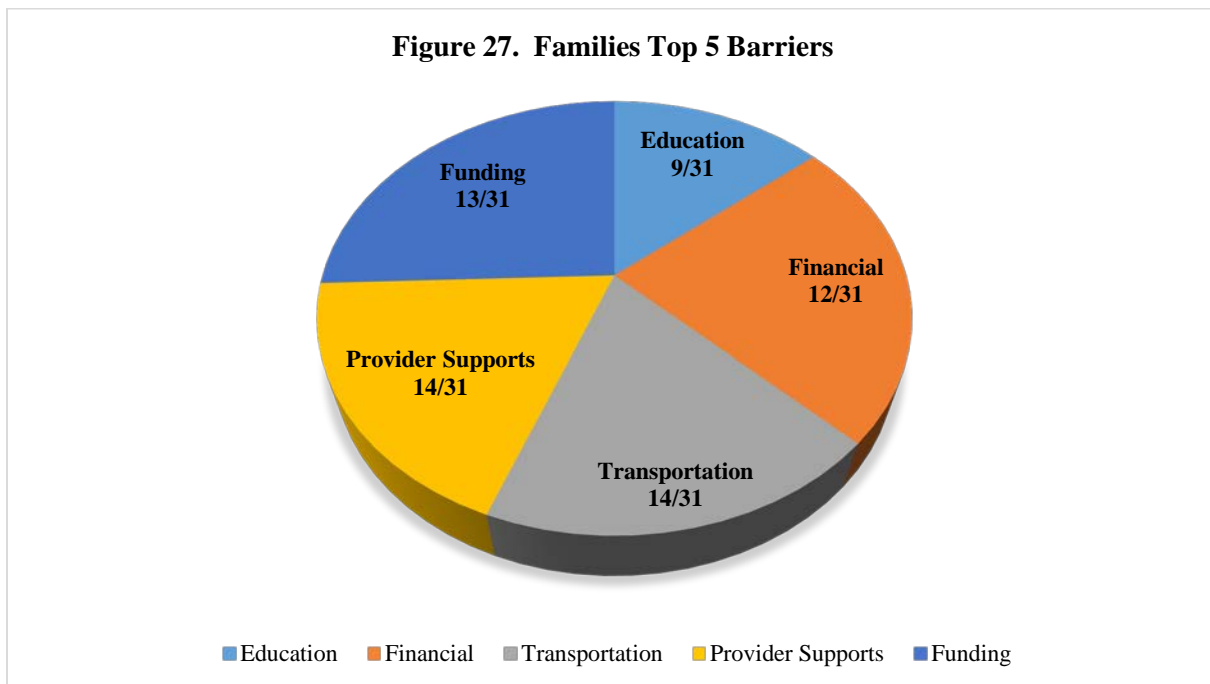
Barriers Statements

The topics discussed in families' barriers statements were not much different from those discussed in the vision and needs statement. However, in developing the barrier statements, family members placed an emphasis on money (Funding and Financial) and on education. In terms of funding and financial issues, one parent said the following:

“I am talking about the government and the barriers. The government in Missouri is a barrier. My son got a raise. He was so proud he got like a \$0.20 raise at his part-time

job and it knocked him out of paying \$97 or something to \$1,000 a month and I've had Easter Seals working on our behalf to try and figure out how much can we take back how many hours to cut off just to get back to where he was and they won't tell you that."

In talking about education, family members were concerned that people with DD were not getting what they needed out of education programs. *"What if they are not teaching our kids? You know, because they don't have enough time to teach them. Or they're supposed to find our kids a job and they don't find a job. Does anybody take the money away?"*

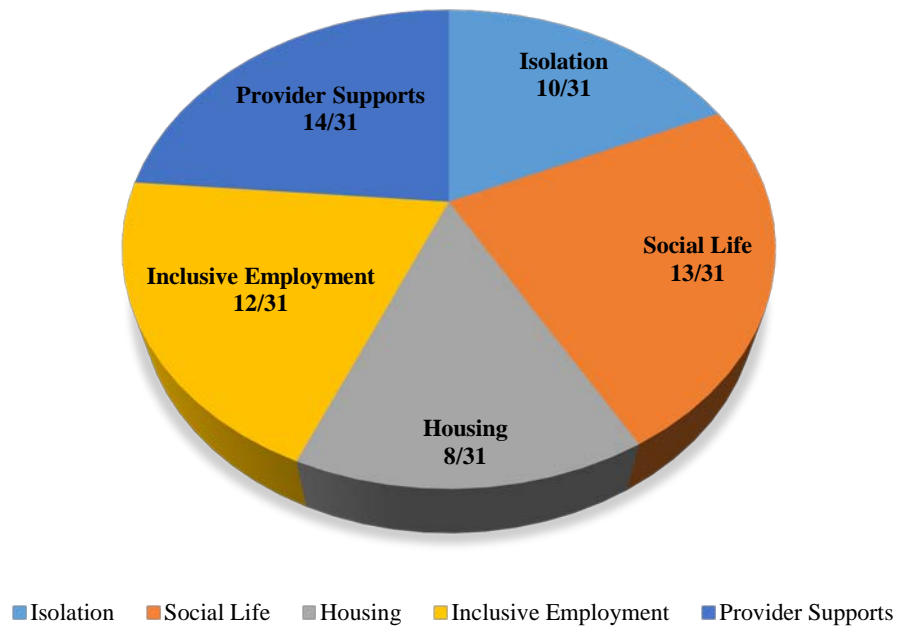


Family Members Do Not Want

Family members' concerns with social life issues continued to be a topic as they talked about what they did not want for their family member with a DD. Along those same lines, they discussed not wanting their family member with a DD to experience isolation. As one parent said, "I don't want my child living in an inappropriate environment and I do not want him to live at home with me." While parents wanted their children to be outside of the home and engaged

with their community, they had safety concerns. *“The people that are in charge are [not] actually looking out for his safety. He comes home with bruises he cannot explain.”* In addition to not wanting their family member with a DD to experience isolation and safety issues, parents did not want their children always be without *“Inclusive Employment.”* One parent said, *“I don’t want him volunteering forever without pay.”*

Figure 28. Families' Top 5 Do Not Want Statements



Service Providers

Figure 29. Discussion Themes among Service Providers

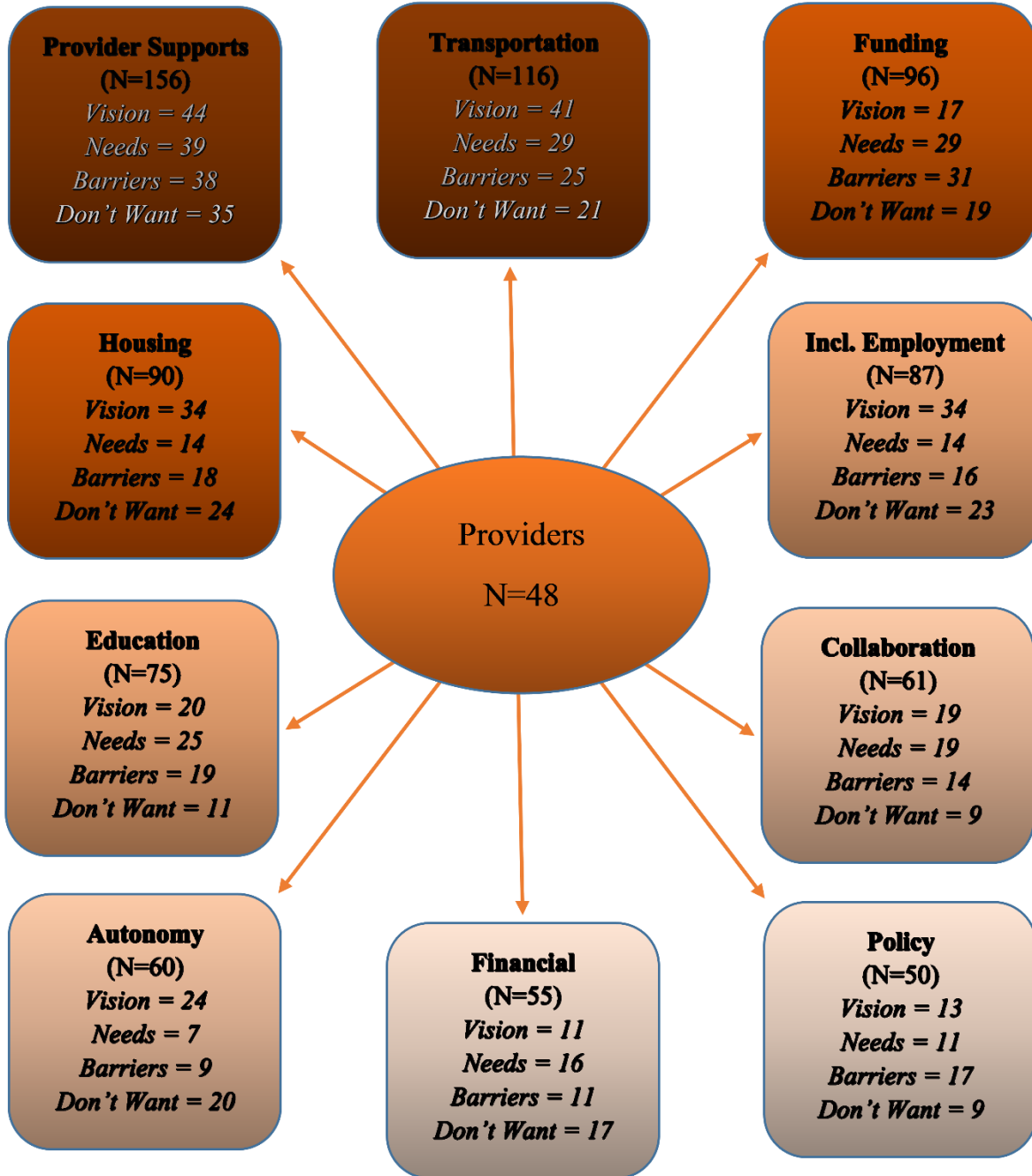
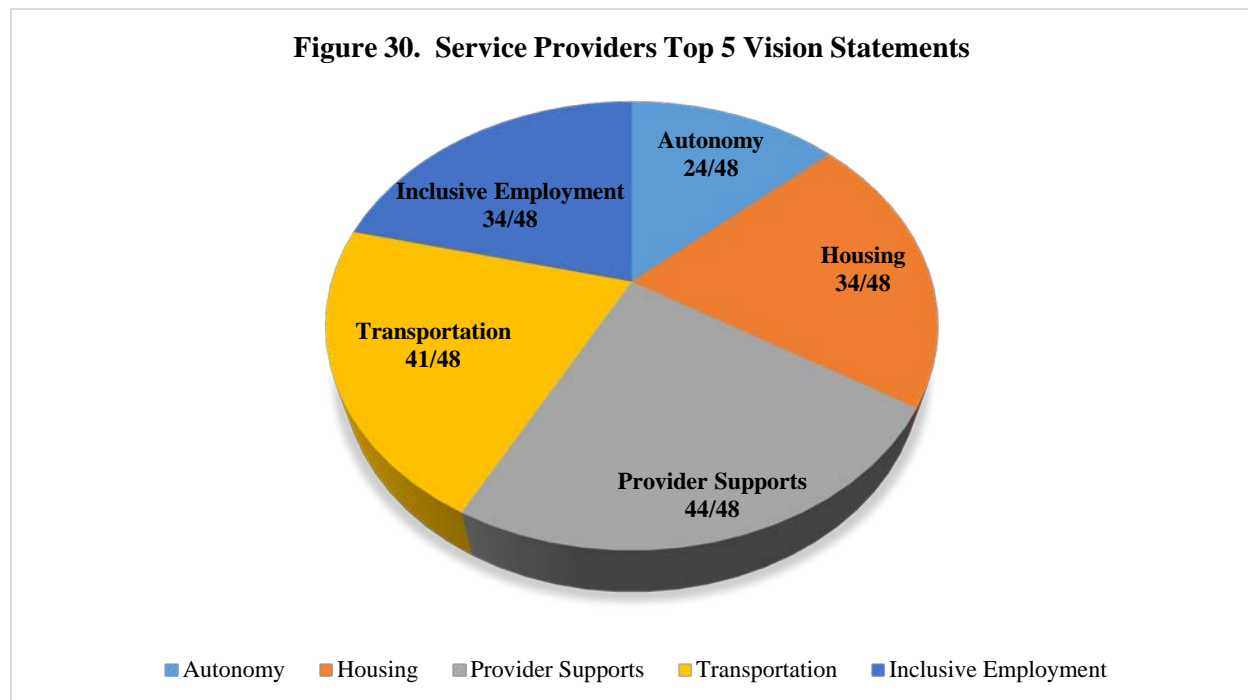


Figure 29 demonstrates that service providers were primarily concerned with the paid services and supports that impact the quality of life of people with DD and their family members. They were especially interested in “Transportation,” “Funding,” “Housing,” and “Inclusive Employment.” One exception to their interest in provider supports is the topic “Autonomy,” which for this project is defined as, “Ability of the individual with IDD to control or influence their environment and/or activities.” They mentioned “Autonomy” most often in their vision statements and their statements about things they do not want. Service providers also identified “Collaboration” as an important topic, which is not a direct provider support but has the potential to improve provider supports.

Vision Statements.

The vision statements from the service providers were primarily concerned with making sure paid services and supports were better in five years than they are currently. Although less prevalent, “Autonomy” also appeared in the service providers vision statements.



The following quote provides an example of how support providers hoped to support people with DD to have autonomy, *“Special events becoming regular occurrences - empowering individuals to make plans on their own.”* They also envisioned, *“Allowed and encouraged choices regarding everything in their life - living amazing, job friendly, boy/girlfriends.”* Regarding “Housing,” support providers said things such as, *“Housing options that are affordable and truly integrated in the community with natural supports - universally designed.”* Another example of “Provider Supports” related to “Housing” is the following: *“Access to in-house supports in lieu of residential placement.”* Their vision for “Transportation” was a *“Transportation model that is efficient and cost effective.”* Another service provider said the following, *“Transportation options (affordable) for people living and working in the county areas where bus service is not an option.”*

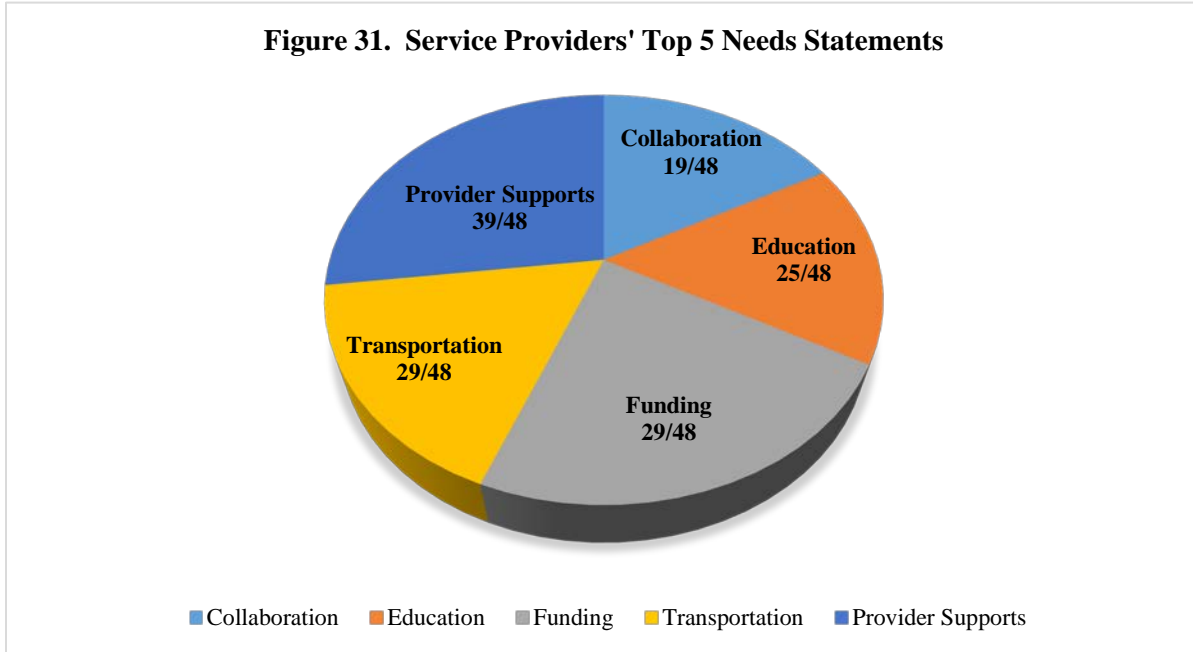
Needs Statements

Figure 31 provides an illustration of the top five needs identified by the service providers. The least common among them is “Collaboration.” The two quotes that follow provide examples of how support providers described “Collaboration” and what they thought it would accomplish.

“I'd like to see more collaboration and partnership between the agencies and service providers. It just feels like there is an air of competition. Individuals might be better served if they didn't have to shop around for the services we provided.”

“Collaboration between county lines, too. So if someone moves from St. Louis County to St. Charles County, they're not starting out fresh, or losing programs or appointments you can get

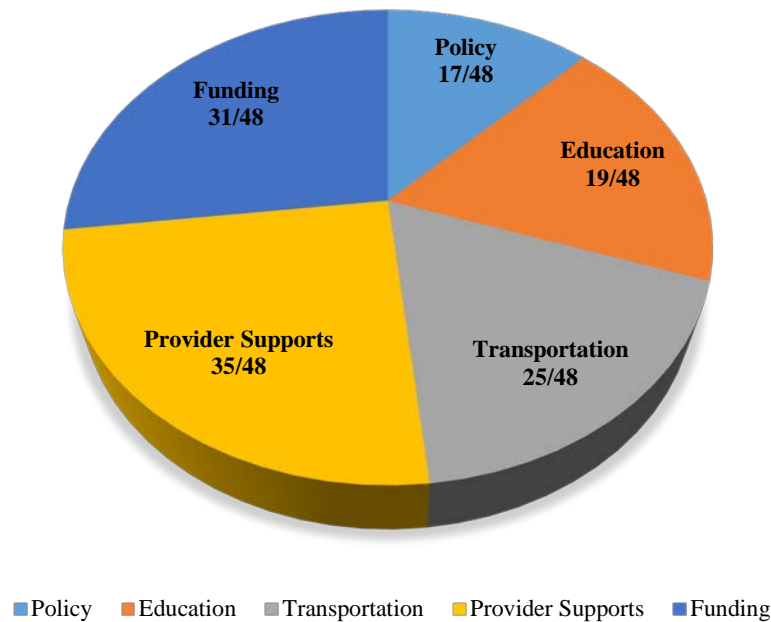
in one county but not in another county.”



Barriers Statement.

Figure 32 displays the five most commonly mentioned topics in the service providers’ barriers statements. They mentioned “Funding” most often in the barriers statements. One support provider expressed it this way, *“Not enough funds to meet the unique needs of all St. Louis County citizens with intellectual and developmental disabilities.”* Regarding “Provider Supports,” one of the service providers mentioned that a large barrier was *“the idea that all supports must be paid supports.”* Another person identified a barrier that impacts the lives of people with DD. *“Agencies pursuing goals that may benefit their particular mission and missing the individual’s mission/goals.”*

Figure 32. Service Providers Top 5 Barriers Statements

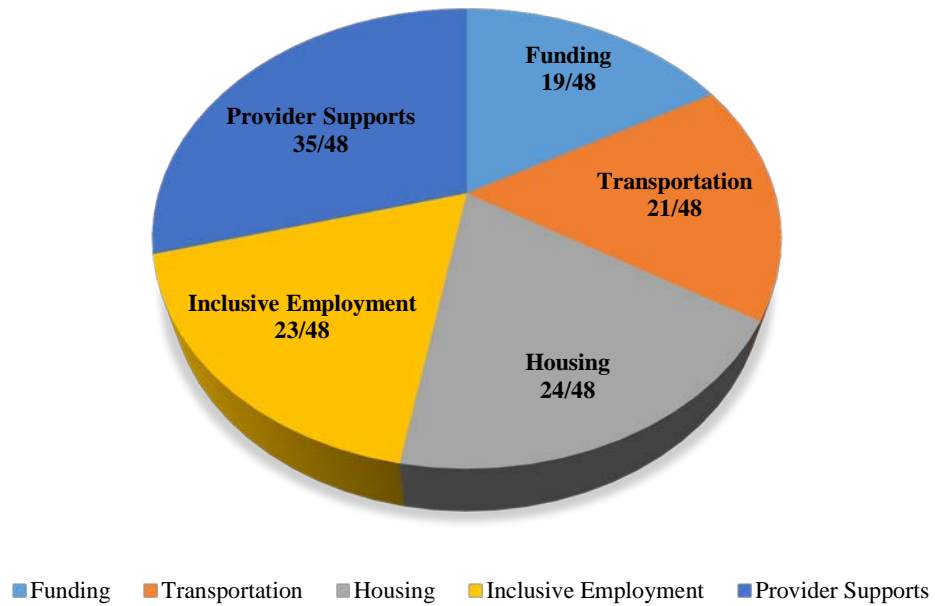


Service Providers Do Not Want

The topics that service providers highlighted as they discussed the things they did not want for people with DD are very familiar. They include “Housing,” “Inclusive Employment,” “Transportation,” and “Funding.” Regarding employment opportunities for people with DD, one support provider noted, *“I don't want to see choices eliminated. With threats to day programs, sheltered workshops, and other service models. One thing is not right for everyone.”* In contrast, another support provider said, *“Don't want us to go back to all segregated opportunities. Focus on full participation of individuals with intellectual and development disabilities in community!”* Regarding funding issues that she did not want to see, one provider commented, *“Failure of system to reimburse at rates that allow support staff to be paid competitive wages and make a career out of supporting people we serve.”* Another person

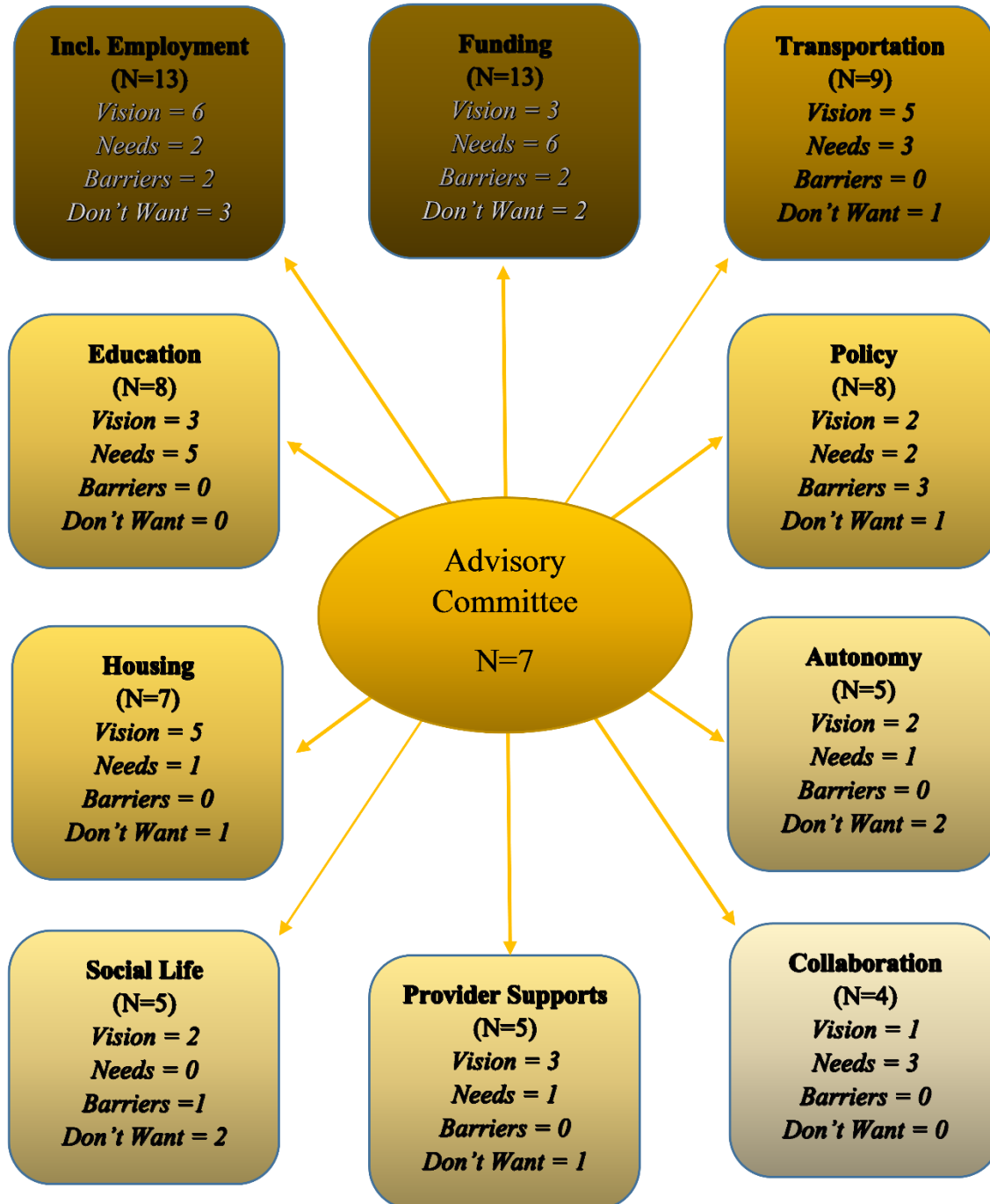
worried that a lack of funding would lead to isolation, “*Moving back home because of lack of finances/funding.*”

Figure 33. Service Providers Top 5 Do Not Want Statements



Project Advisory Committee

Figure 34. Discussion Themes among the Project Advisory Committee



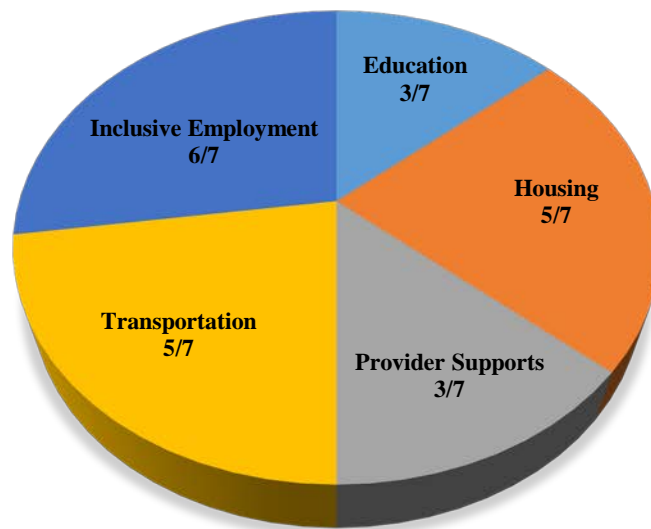
The project advisory committee is an interesting group because it includes an individual with DD, family members, and professionals who provide supports. As a result, during their focus group they discussed service-oriented topics such as “Funding,” “Transportation,” and “Housing.” But, they also discussed topics that focused on the lifestyles of people with DD. These included “Social Life” and “Autonomy.”

Vision Statements

The advisory committee included education in their vision statements to a greater degree than the other participant groups. The quote that follows links education to other aspects of the speaker’s vision statement.

“It's heartwarming, there was a program at school this week where they sang patriotic songs. There's a young girl that has taken a liking to her. She held her hand the entire time. When the kids went around in a circle, she had a partner that took her around in a circle. I just know it's good for her and those kids, too.”

Figure 35. Advisory Committee Top 5 Vision Statements



■ Education ■ Housing ■ Provider Supports ■ Transportation ■ Inclusive Employment

Needs Statements

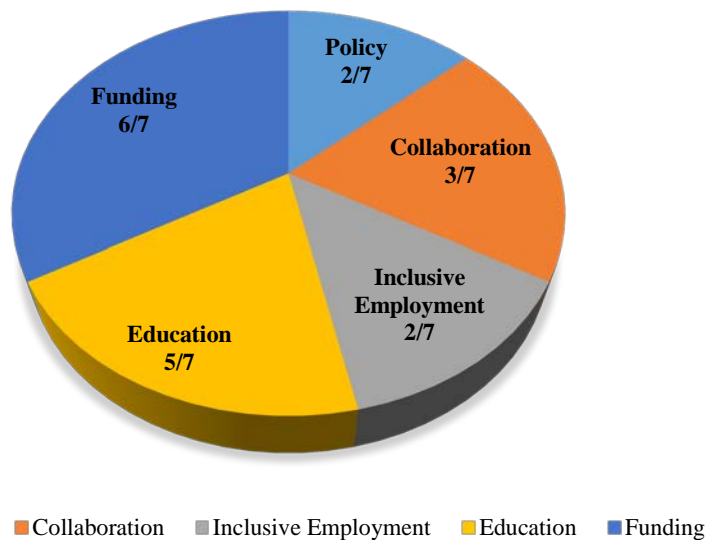
The needs statements created by the advisory committee participants also focused on education. One member of the advisory committee placed an emphasis on educating young people with DD on topics such as safety and relationships.

“I don't know if he will ever be able to discern what is safe and what is not safe in terms of social relationships. But I think very targeted training for him, going to a big class on social safety is not going to do it. For him it needs to be very targeted at his level and using language he can understand.”

“Funding” was also a topic that the advisory committee discussed. However, there was a discussion about expanding the scope of what funding should support.

“I think you need to, at least for the model I would like to see developed ...is to start to develop natural supports. But there has to be active cultivation of funders and investors for that kind of a model. You have to aggressively go out and create those opportunities.”

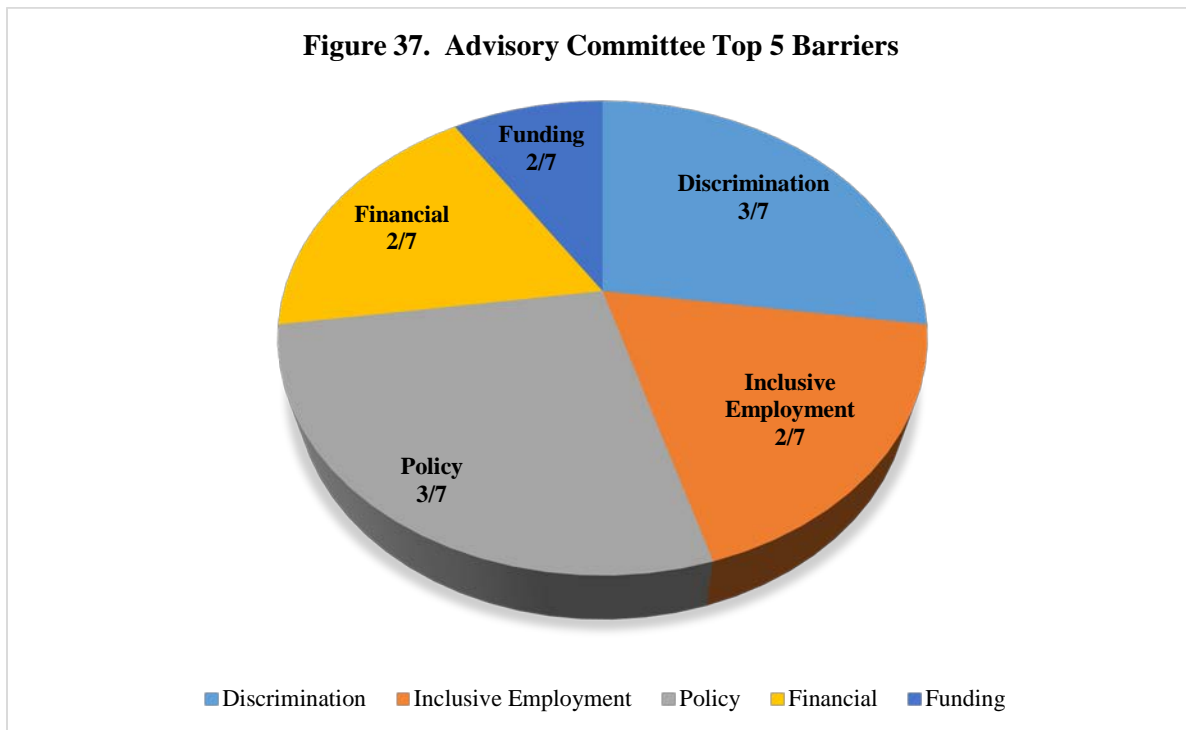
Figure 36. Advisory Committee Top 5 Needs Statements



Barriers Statements

The advisory committee placed an emphasis on topics such as “Policy” and “Discrimination” while at the same time discussing some of the barriers that concerned the other participant groups such as “Funding,” “Inclusive Employment,” and “Financial.” The extensive comment that follows incorporates many of these themes.

“People who have the Medicaid waiver who are funded by the state ... the Productive Living Board traditionally have not provided services for those people because it's been thought that those people are the state's responsibility and PLB likes to fill the gap. But what's happening is the state is not funding the people that need the Medicaid money because they don't have the money. And so those people whose need is greater are getting less service because they are not getting PLB services and they are not getting state services. People are falling in the gap there.”



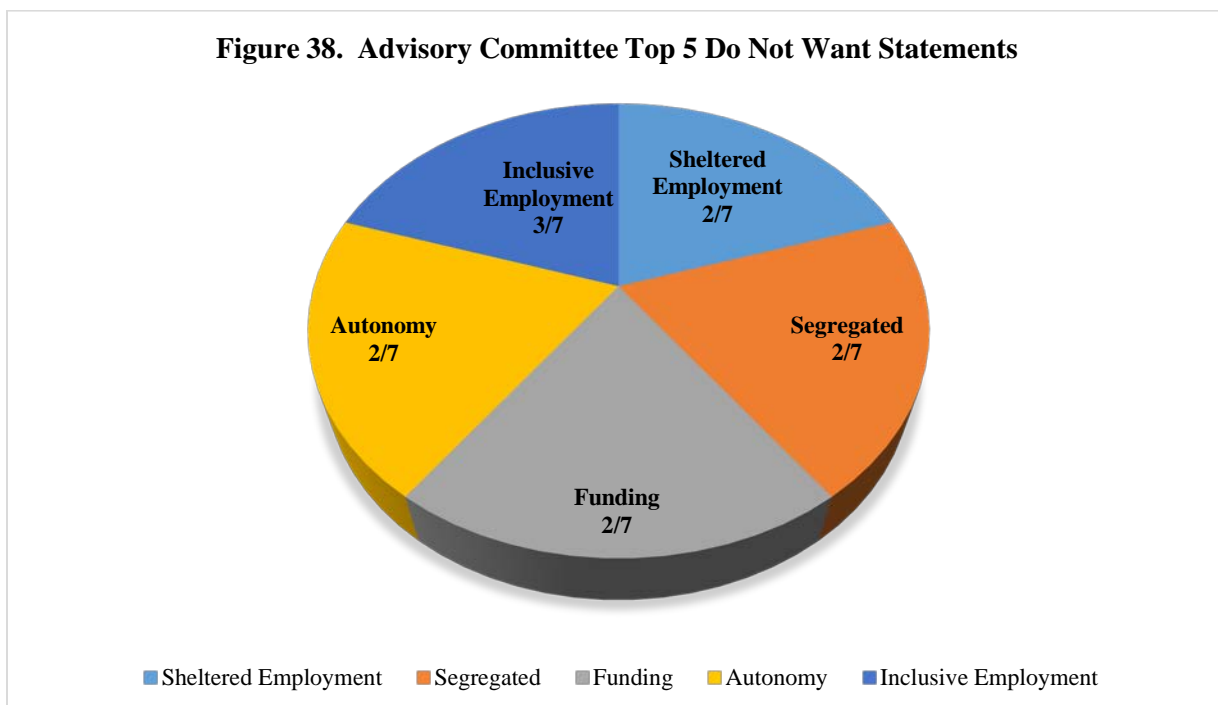
Advisory Committee Does Not Want.

Lastly, the advisory committee discussed those things that they did not want to see in Saint Louis County over the next five years. Interestingly, their comments included a discussion of both “Inclusive Employment” and “Sheltered Employment.”

“I don't want his employment opportunities limited. I don't want day programs or sheltered workshops totally gone either. There are some people for whom job opportunities are not really an option. Jobs in the community are not an option. I would want to make sure there are still programs for those people.”

The advisory committee also emphasized the topics of “Autonomy” and “Segregated.” One member said, *“I don't want my daughter isolated from children with typical needs. Although she has severe autism, her peers benefit from being around her in and out of the classroom setting and vice versa. I don't want her to be alone and without friends.”*

Figure 38. Advisory Committee Top 5 Do Not Want Statements



Needs Assessment Survey

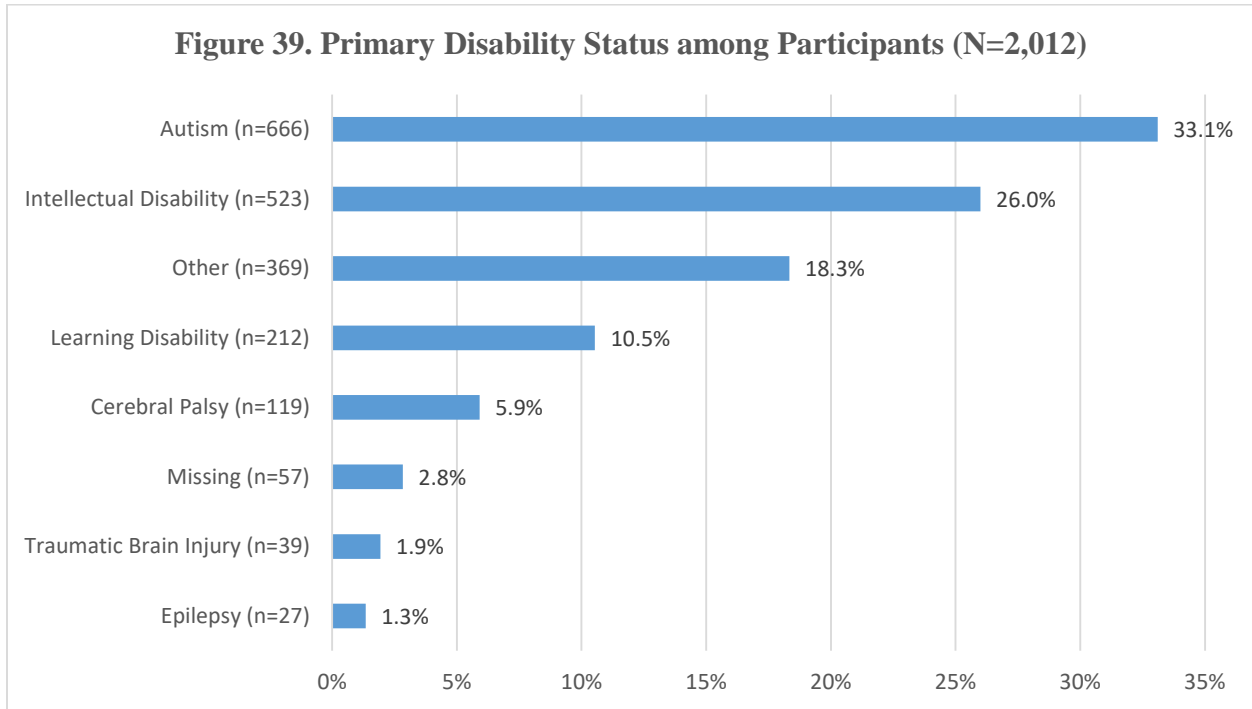
The purpose of Section III is to present the results of the countywide needs assessment survey. The survey collected information about five domain areas: 1) employment; 2) family; 3) living options; 4) life transitions; and 5) socialization/wellness. Specifically, the survey asked about the current and future levels of importance respondents placed on supports and services within each domain (see Appendix B for a copy of the survey). Additionally, the survey asked respondents whether they currently received specific supports and services within each domain and what the greatest barriers were to receiving supports and services.

A total of 13,468 surveys were distributed to individuals with IDD and/or their family members in St. Louis County. They were mailed to people who receive services from PLB only [1,097 (8.1%)], people who receive case management and/or services from the Department of Mental Health (DMH) only [3,600 (26.7%)], people who receive services from both PLB and case management services from DMH [3,527 (26.2%)], and Special School District (SSD) [5,244 (38.9%)]. We received 2,029 returned surveys for a 15.1% return rate. The return rates for each of the subgroups were: PLB only [176 (8.7%)], DMH only [454 (22.7%)], PLB and DMH [890 (44.4%)], and SSD [440 (22.0%)]. Of the 2,029 returned surveys, 17 were not completed, leaving us with 2,012 surveys, 14.9% of the distributed surveys.

Participant Demographics

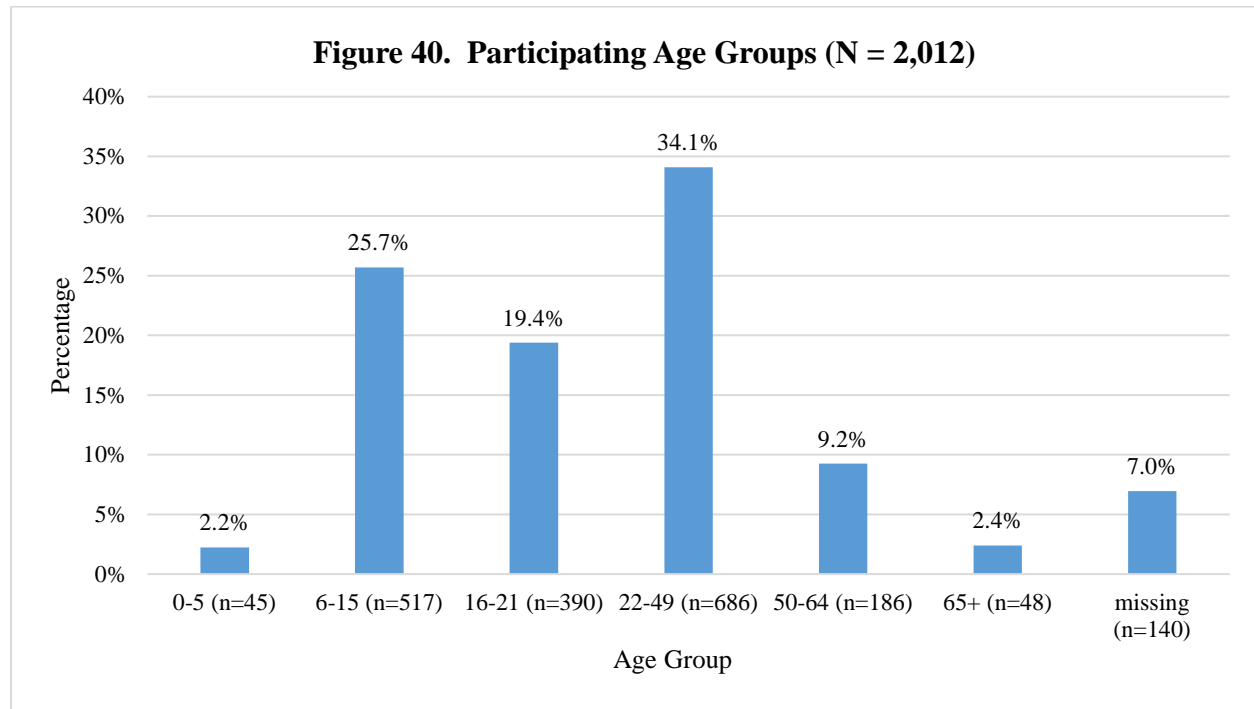
Survey questions asked about the person with DD but the majority of the surveys were completed on behalf of the person by family members [1,522 (75.6%)], support staff [72 (3.6%)], and non-family caregivers [21 (1.0%)]. Additionally, 272 (13.5%) individuals with IDD completed the survey for themselves. The disability groups represented in the sample are

presented in Figure 39. The majority of the people received service coordination [1,370 (68.1%)]. The vast majority of the people with DD who are represented in the sample lived with



their parents or other family members [1,597 (79.3%)]. Only eight percent [162] individuals lived in an apartment or home with supports, 3.7 % [76] lived in a group home, and 2.8% [57] lived independently without supports. The sample was evenly split between school age (0 to 21) individuals with disabilities [952 (47.3%)] and non-school age individuals (22+) [920 (45.7%)] (see Figure 40). The sample included more males [1,208 (60.0%)] than females [737 (36.6%)]. The vast majority of the surveys were filled out on behalf of a person whose racial/ethnic identity was white [1,369 (68.0%)]. People who were black, not of Hispanic origin, represented 21.2% [426] of the sample, followed by Asian or Pacific Islanders [59 (2.9%)], Other [54 (2.7%)], Hispanic/Latino [36 (1.8%)], and American Indian or Alaska Natives [15 (0.75%)]. Lastly, 1,910 (95.0%) of the respondents provided the zip codes for their residences, which were evenly

distributed between four regions of St. Louis County: South [571 (30.0%)], Central [427 (22.4%)], North [427 (22.4%)], and West [485 (25.4%)].



Global Rankings for Each Question

Current and Future Needs

The survey asked participants to indicate how important 36 supports and services were to them both currently and in the future (see Appendix B). They ranked items on a five-point scale that ranged between 1 (Not Important), 2 (Slightly Important), 3 (Moderately Important), 4 (Very Important), and 5 (Extremely Important). Table 16 provides a list of all items. The only item that had a mean score above 4 (Very Important) was the “Current Need” for “Living with parents/family. In the case of this item, respondents perceived that living with parents/family would be less important over the next five years than it was currently. However, it was still the most important future need. With this one exception, all items that had a mean score above 3 (Moderately Important) were perceived to be more important in the future than currently. Interestingly, all of the items in the “Socialization/Wellness” domain of the survey were

among the most important current and future supports. They all received a score above 3 (Moderately Important). These include: 1) Social skills training, 2) Fitness/wellness activities or programs, 3) Self-advocacy & self-determination, 4) Independent living skills training, 5) Healthy relationships training, 6) Parks and recreation activities, 7) Community membership in organizations or clubs, 8) Summer recreation, and 9) Disability specific activities. Three items from the “Life Transitions” domain also appeared among the most important support needs both currently and in the future: 1) Support with a meaningful day activity, 2) Financial management, and 3) Independent living skills training. Respondents to the survey indicated that most of the service and support items listed were less than moderately important. This was true for both the current and future needs.

Table 16									
Most Important Current and Future Needs									
Services/Supports	Current Needs					Future Needs (Next 5 Years)			
	#	%	Mean	SD		#	%	Mean	SD
Living with parents/family	1,780	88.47	4.16	1.36		1,624	80.72	3.78	1.48
Social skills training	1,663	82.65	3.51	1.47		1,556	77.34	3.63	1.45
Fitness/wellness activities or programs	1,658	82.41	3.39	1.41		1,559	77.49	3.55	1.41
Self-advocacy & self-determination	1,621	80.57	3.35	1.52		1,539	76.49	3.50	1.54
Independent living skills training (grocery shopping, cooking, home management)	1,645	81.76	3.13	1.63		1,572	78.13	3.49	1.59
Healthy relationship training	1,639	81.46	3.25	1.53		1,551	77.09	3.45	1.51
Working with supports in the community	1,730	85.98	3.03	1.61		1,660	82.50	3.44	1.56
Support with a meaningful day activity	1,623	80.67	3.08	1.68		1,543	76.69	3.37	1.64
Parks and recreation activities	1,633	81.16	3.16	1.46		1,541	76.59	3.27	1.48
Community membership in organizations or clubs	1,638	81.41	3.03	1.52		1,549	76.99	3.23	1.51
Occasional in-home support	1,645	81.76	3.04	1.71		1,539	76.49	3.21	1.68
Financial management	1,619	80.47	2.82	1.67		1,555	77.29	3.19	1.67
Occasional out-of-home support	1,652	82.11	3.01	1.68		1,549	76.99	3.19	1.67
Summer recreation (day/residential camping)	1,609	79.97	3.01	1.64		1,516	75.35	3.11	1.63
Disability specific activities (e.g., People First)	1,593	79.17	2.96	1.54		1,497	74.40	3.11	1.57
Personal care assistance	1,622	80.62	2.68	1.69		1,526	75.84	2.98	1.70
Pre-employment training	1,584	78.73	2.50	1.65		1,500	74.55	2.89	1.69
Behavioral supports	1,627	80.86	2.77	1.63		1,512	75.15	2.82	1.65

Table 16
Most Important Current and Future Needs

Services/Supports	Current Needs				Future Needs (Next 5 Years)			
	#	%	Mean	SD	#	%	Mean	SD
Planning for transition from school to work/adult life	1,563	77.68	2.43	1.71	1,479	73.51	2.79	1.80
Working without supports in the community	1,598	79.42	2.20	1.46	1,510	75.05	2.71	1.62
Working in summer employment	1,614	80.22	2.22	1.58	1,525	75.80	2.68	1.70
Support to volunteer in the community	1,608	79.92	2.37	1.50	1,518	75.45	2.67	1.56
Working in a sheltered workshop	1,686	83.80	2.25	1.62	1,595	79.27	2.59	1.69
Living independently in the community with supports 0 to 20 hours each week	1,511	75.10	2.08	1.54	1,467	72.91	2.57	1.66
Assistive technology	1,586	78.83	2.45	1.64	1,481	73.61	2.56	1.70
Living in a 24-hour supervised residential setting	1,574	78.23	1.97	1.52	1,522	75.65	2.53	1.69
Adaptive equipment for health and safety	1,607	79.87	2.32	1.62	1,502	74.65	2.51	1.69
Family/individual short-term counseling	1,608	79.92	2.38	1.52	1,489	74.01	2.47	1.53
Adult education (GED/continuing education)	1,604	79.72	1.99	1.48	1,495	74.30	2.35	1.65
Living independently in the community with supports 20 to 50 hours each week	1,475	73.31	1.82	1.37	1,443	71.72	2.32	1.60
Living independently in the community with supports over 50 hours each week	1,472	73.16	1.78	1.37	1,449	72.02	2.30	1.61
Living independently in the community without support	1,459	72.51	1.75	1.38	1,427	70.92	2.22	1.62
Retirement supports	1,537	76.39	1.84	1.43	1,485	73.81	2.13	1.60
Before or after school care	1,558	77.44	2.06	1.58	1,447	71.92	2.13	1.62
Planning for transition from work to retirement	1,528	75.94	1.78	1.38	1,473	73.21	2.08	1.57
Parenting skills training	1,578	78.43	1.92	1.38	1,465	72.81	2.01	1.44

Note. Mean = average importance ratings; SD = standard deviation, indicating the extent to which the importance rating spread out from the mean.

Currently Met and Unmet Needs

In addition to identifying the level of importance for the 36 services and supports, the respondents also indicated whether or not their current needs were met. Table 17 below provides information about whether a support need was currently met or unmet. The top ten service and support needs that were met are highlighted in green. The top ten unmet needs are highlighted in red. Additionally, in an effort to understand how important unmet needs were to people, we calculated the mean level of importance for all unmet service and support needs. Almost all of the most important unmet needs are related to service and supports that enhance social opportunities and independence. Interestingly, four of the supports and services that were the most important unmet needs were also identified as the most frequently met needs: 1) Social skills training, 2) Fitness/wellness activities or programs, 3) Parks and recreation activities, and 4) Summer recreation (day/residential camping). However, the number of people who identified these supports and services as unmet needs outnumbered those who identified them as met needs.

Services/Supports	Met	Do Not Need	Unmet	Importance of Unmet Need*	
	n(%)	n(%)	n(%)	Mean	SD
Living with parents/family	1364 (83.6)	166 (10.2)	101 (6.2)	2.74	1.68
Social skills training	584 (39.0)	285 (19.1)	627 (41.9)	3.88	1.25
Fitness/wellness activities or programs	505 (33.8)	297 (19.9)	692 (46.3)	3.7	1.21
Self-advocacy & self-determination	409 (28.1)	442 (30.4)	605 (41.6)	3.89	1.24
Independent living skills training (grocery shopping, cooking, home management)	430 (28.4)	562 (37.1)	524 (34.6)	3.78	1.36
Healthy relationship training	430 (28.7)	405 (27.1)	662 (44.2)	3.79	1.29
Working with supports in the community	525 (32.3)	620 (38.2)	478 (29.5)	3.45	1.45
Support with a meaningful day activity	494 (32.3)	632 (41.3)	403 (26.4)	3.65	1.43
Parks and recreation activities	497 (33.6)	360 (24.4)	621 (42.0)	3.50	1.30
Community membership in organizations or clubs	438 (29.4)	416 (27.9)	636 (42.7)	3.36	1.39
Occasional in-home support	558 (36.4)	521 (33.9)	456 (29.7)	3.35	1.52

Table 17
Currently Met and Unmet Needs

Services/Supports	Met	Do Not Need	Unmet	Importance of Unmet Need*	
	n(%)	n(%)	n(%)	Mean	SD
Financial management	362 (24.1)	689 (45.9)	449 (29.9)	3.54	1.48
Occasional out-of-home support	489 (32.0)	547 (35.8)	493 (32.2)	3.54	1.42
Summer recreation (day/residential camping)	446 (29.9)	481 (32.2)	565 (37.9)	3.42	1.49
Disability specific activities (e.g., People First)	332 (22.9)	511 (35.3)	606 (41.8)	3.51	1.38
Personal care assistance	491 (32.6)	620 (41.1)	397 (26.3)	3.32	1.58
Pre-employment training	255 (16.8)	809 (53.3)	453 (29.9)	3.32	1.53
Behavioral supports	448 (29.9)	593 (39.6)	456 (30.5)	3.47	1.49
Planning for transition from school to work/adult life	290 (19.0)	865 (56.6)	372 (24.4)	3.22	1.67
Working without supports in the community	103 (7.1)	977 (67.1)	376 (25.8)	2.21	1.57
Working in summer employment	221 (14.5)	874 (57.3)	429 (28.1)	2.85	1.58
Support to volunteer in the community	280 (18.4)	753 (49.6)	485 (31.9)	2.89	1.4
Working in a sheltered workshop	303 (19.1)	871 (55)	410 (25.9)	2.5	1.53
Living independently in the community with supports 0 to 20 hours each week	185 (12.4)	916 (61.3)	394 (26.4)	2.58	1.63
Assistive technology	332 (22.2)	755 (50.5)	409 (27.3)	3.18	1.55
Living in a 24-hour supervised residential setting	199 (13.3)	911 (60.7)	391 (26.0)	2.47	1.64
Adaptive equipment for health and safety	343 (22.9)	786 (52.5)	367 (24.5)	2.87	1.61
Family/individual short-term counseling	305 (20.5)	679 (45.7)	503 (33.8)	2.97	1.48
Adult education (GED/continuing education)	244 (15.9)	935 (60.9)	356 (23.2)	2.6	1.54
Living independently in the community with supports 20 to 50 hours each week	103 (7.0)	980 (66.5)	390 (26.5)	2.47	1.55
Living independently in the community with supports over 50 hours each week	89 (6.0)	992 (67.4)	391 (26.6)	2.44	1.58
Living independently in the community without support	103 (7.1)	977 (67.1)	376 (25.8)	2.21	1.57
Retirement supports	93 (6.2)	1048 (69.8)	360 (24.0)	2.59	1.63
Before or after school care	229 (15.2)	886 (59.0)	387 (25.8)	2.99	1.73
Planning for transition from work to retirement	92 (6.1)	1050 (70.1)	355 (23.7)	2.54	1.61
Parenting skills training	211 (14.2)	851 (57.1)	428 (28.7)	2.65	1.52

*The mean and SD scores for "Importance of Unmet Need" are calculated only for the people who indicated that a service/support need was unmet. These scores do not include the whole sample.
 Note. Mean = average importance ratings; SD = standard deviation, indicating the extent to which the importance rating spread out from the mean.

Challenges

The challenges experienced most frequently by respondents across each of the domains in the survey relate to not knowing what services and supports are available, not knowing what they need, and not knowing who to ask about resources. Cost of service and transportation are challenges that respondents mentioned frequently.

Challenges	Employment	Living Options	Life Transitions	Family	Socialization/ Wellness
	<i>n(%)</i>	<i>n(%)</i>	<i>n(%)</i>	<i>n(%)</i>	<i>n(%)</i>
Cost of service	227 (11.3)	536 (26.6)	498 (24.8)	562 (27.9)	615 (30.6)
Does not apply	748 (37.2)	668 (33.2)	510 (25.3)	480 (23.9)	334 (16.6)
Location of service providers	275 (13.7)	314 (15.6)	345 (17.1)	331 (16.5)	388 (19.3)
Not knowing what I need	395 (19.6)	463 (23.0)	634 (31.5)	436 (21.7)	513 (25.5)
Not knowing what is available	600 (29.8)	703 (34.9)	815 (40.5)	714 (35.5)	831 (41.3)
Not knowing who to ask about resources	409 (20.3)	491 (24.4)	777 (27.6)	509 (25.3)	573 (28.5)
Other	199 (9.9)	186 (9.2)	113 (5.6)	106 (5.3)	112 (5.6)
Quality of service	284 (14.1)	414 (20.6)	388 (19.3)	389 (19.3)	364 (18.1)
Service I need is not available	140 (7.0)	154 (7.7)	126 (6.3)	185 (9.2)	133 (6.6)
Service is available, but level of support is insufficient	223 (11.1)	192 (9.5)	200 (9.9)	243 (12.1)	234 (11.6)
Transportation	574 (28.5)	451 (22.4)	451 (22.4)	340 (16.9)	463 (23.0)

Global Responses across Age Groups

In addition to analyzing the data globally, we also analyzed it with reference to specific age groups. As Table 19 demonstrates, we analyzed six separate age groups. The information below describes some of the lessons learned from this analysis.

Employment

Working with supports in the community was the most important employment option for the people who participated in this needs assessment. This was particularly true for transition age individuals (16 – 21 years old) who rated working with supports as a “Very Important” future outcome. This was also the most important current and future employment outcome for working-age adults (22 – 49 years old). The only other employment support that respondents rated as “Moderately Important” or better was “Working in summer employment,” which was important to transition age individuals.

Living Options

The data indicate that the respondents only felt one living option was important: “Living with parents/family.” It is important to remember that the majority of people who completed the survey were parents or family members [1,522 (75.6%)]. The only group for whom “Living with parents/family” fell below “Moderately Important” was those who were 65 years old or older. For them, the most important living option was “Living independently in the community with supports 0 to 20 hours each week.”

Life Transitions

Respondents were asked to rate the importance of nine life transition supports. “Planning for transition from school to work” was a moderately important future need for school-age youth (ages 6 – 15). It was rated as a very important current and future need for transition age youth (ages 16 - 21). The two most important life transition supports for working-age adults were “Financial management” and “Independent living skills training.” Older adults between 50 and 64 also felt that these two supports were the most important for their lives.

Family

School-age individuals (6 – 15 years old) placed more importance on the supports and services in the “Family” domain than any other age group. Respite care (“Occasional out-of-home support” and “Occasional in-home support”) and “Behavioral supports” were the two most important supports both currently and in the future. This group also rated “Before or after school care” and “Assistive technology” as moderately important both currently and in the future. “Assistive technology” and “Adaptive equipment for health and safety” were the two supports that were important for children between the ages of 0 and 5.

Socialization/Wellness

The socialization and wellness domain of the survey contained eight service and support items (see Table 19). Respondents deemed each item important but “Social skills training” was perhaps the most important. It was moderately to very important for people between the ages of 0 and 49. “Self-advocacy and self-determination” were moderately to very important for all people, even those who were 65 years old or older. And, “Healthy relationships training” was particularly important to those who were between the ages of six and 49. All of the service and support items in this domain ranked as moderately to very important future needs for people who were 21 or younger. In nearly every case, respondents rated the future need as more important than the current need.

Table 19. Responses across Age Groups

Services/Supports	Age 0-5 (n=45)				Age 6-15 (n=517)				Age 16-21 (n=390)				Age 22-49 (n=686)				Age 50-64 (n=186)				Age ≥ 65 (n=48)			
	Current		Future		Current		Future		Current		Future		Current		Future		Current		Future		Current		Future	
	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)
Employment																								
Working with supports in the community	38 (84.4)	2.3 (1.6)	38 (84.4)	2.4 (1.6)	457 (88.4)	2.4 (1.6)	458 (88.6)	3.3 (1.6)	369 (94.6)	3.5 (1.4)	363 (93.1)	4.0 (1.3)	604 (88.0)	3.3 (1.6)	562 (81.9)	3.4 (1.5)	143 (76.9)	2.9 (1.6)	127 (68.3)	2.9 (1.7)	39 (81.3)	2.4 (1.6)	37 (77.1)	2.4 (1.6)
Working without supports in the community	35 (77.8)	1.7 (1.3)	37 (82.2)	1.8 (1.3)	440 (85.1)	2.0 (1.4)	432 (83.6)	2.9 (1.6)	345 (88.5)	2.6 (1.5)	341 (87.4)	3.3 (1.6)	542 (79.0)	2.2 (1.4)	487 (71.0)	2.4 (1.5)	133 (71.5)	2.0 (1.4)	118 (63.4)	2.1 (1.5)	35 (72.9)	1.7 (1.1)	34 (70.8)	1.9 (1.2)
Working in a sheltered workshop	36 (80.0)	1.7 (1.4)	36 (80.0)	1.6 (1.2)	436 (84.3)	1.6 (1.2)	436 (84.3)	2.4 (1.6)	352 (90.3)	2.2 (1.5)	336 (86.2)	2.7 (1.7)	595 (86.7)	2.7 (1.7)	546 (79.6)	2.8 (1.7)	151 (81.2)	2.6 (1.9)	137 (73.7)	2.6 (1.8)	38 (79.2)	2.0 (1.7)	36 (75.0)	1.9 (1.6)
Working in summer employment	35 (77.8)	1.5 (1.2)	37 (82.2)	1.5 (1.2)	440 (85.1)	1.9 (1.4)	443 (85.7)	3.1 (1.7)	366 (93.8)	3.2 (1.6)	350 (89.7)	3.4 (1.6)	538 (78.4)	2.0 (1.5)	486 (70.8)	2.2 (1.6)	127 (68.3)	1.8 (1.4)	115 (61.8)	1.9 (1.4)	37 (77.1)	1.3 (0.9)	34 (70.8)	1.3 (0.9)
Living Options																								
Living with parents/family	43 (95.6)	4.2 (1.4)	39 (86.7)	4.1 (1.5)	488 (94.4)	4.6 (0.9)	447 (86.5)	4.3 (1.2)	370 (94.9)	4.4 (1.0)	333 (85.4)	3.7 (1.3)	618 (90.1)	4.0 (1.4)	562 (81.9)	3.7 (1.5)	143 (76.9)	3.2 (1.9)	130 (69.9)	3.1 (1.8)	34 (70.8)	2.4 (1.8)	34 (70.8)	2.4 (1.8)
Living in a 24-hour supervised residential setting	38 (84.4)	1.5 (1.2)	34 (75.6)	1.5 (1.2)	427 (82.6)	1.6 (1.2)	405 (78.3)	2.1 (1.5)	332 (85.1)	1.8 (1.4)	335 (85.9)	2.7 (1.7)	540 (78.7)	2.3 (1.6)	521 (75.9)	2.8 (1.7)	128 (68.8)	2.3 (1.8)	123 (66.1)	2.6 (1.8)	38 (79.2)	2.6 (1.8)	36 (75.0)	3.3 (1.8)
Living independently in the community with supports 0 to 20 hours each week	36 (80.0)	1.1 (0.4)	34 (75.6)	1.3 (1.0)	403 (77.9)	1.5 (1.2)	398 (77)	2.2 (1.6)	320 (82.1)	2.1 (1.5)	326 (83.6)	2.8 (1.6)	516 (75.2)	2.2 (1.6)	485 (70.7)	2.5 (1.6)	131 (70.4)	2.9 (1.8)	121 (65.1)	3.0 (1.8)	34 (70.8)	2.6 (1.7)	32 (66.7)	2.9 (1.7)
Living independently in the community with supports 20 to 50 hours each week	35 (77.8)	1.1 (0.3)	34 (75.6)	1.3 (1.0)	400 (77.4)	1.4 (1.1)	399 (77.2)	2.1 (1.6)	314 (80.5)	1.8 (1.3)	319 (81.8)	2.6 (1.6)	502 (73.2)	2.0 (1.5)	481 (70.1)	2.3 (1.6)	119 (64.0)	1.9 (1.5)	107 (57.5)	2.1 (1.6)	34 (70.8)	2.3 (1.5)	32 (66.7)	2.3 (1.5)
Living independently in the community with supports over 50 hours each week	37 (82.2)	1.2 (0.8)	34 (75.6)	1.4 (1.1)	400 (77.4)	1.4 (1.1)	400 (77.4)	2.1 (1.5)	314 (80.5)	1.9 (1.4)	331 (84.9)	2.6 (1.7)	501 (73.0)	1.9 (1.4)	475 (69.2)	2.3 (1.6)	120 (64.5)	1.8 (1.5)	110 (59.1)	2.1 (1.6)	32 (66.7)	2.0 (1.5)	31 (64.6)	2.2 (1.7)
Living independently in the community without support	36 (80.0)	1.2 (0.7)	34 (75.6)	1.3 (1.0)	399 (77.2)	1.5 (1.2)	395 (76.4)	2.2 (1.6)	313 (80.3)	1.8 (1.4)	326 (83.6)	2.6 (1.7)	495 (72.2)	1.8 (1.4)	464 (67.6)	2.0 (1.5)	121 (65.1)	2.0 (1.6)	111 (59.7)	2.0 (1.5)	32 (66.7)	1.9 (1.4)	31 (64.6)	1.7 (1.4)
Life Transitions																								
Adult education	36 (80.0)	1.4 (1.2)	34 (75.6)	1.5 (1.2)	419 (81.0)	1.9 (1.5)	401 (77.6)	2.7 (1.8)	347 (89.0)	2.4 (1.6)	335 (85.9)	2.7 (1.7)	559 (81.5)	1.9 (1.4)	509 (74.2)	2.0 (1.5)	137 (73.7)	1.7 (1.3)	118 (63.4)	1.7 (1.3)	35 (72.9)	1.3 (1.0)	29 (60.4)	1.5 (1.1)
Support to volunteer in the community	36 (80.0)	1.4 (1.0)	32 (71.1)	1.6 (1.1)	412 (79.7)	2.1 (1.4)	406 (78.5)	2.8 (1.6)	345 (88.5)	2.8 (1.5)	342 (87.7)	3 (1.6)	566 (82.5)	2.4 (1.5)	516 (75.2)	2.5 (1.5)	136 (73.1)	2.2 (1.5)	123 (66.1)	2.2 (1.5)	38 (79.2)	1.8 (1.3)	31 (64.6)	1.8 (1.2)
Pre-employment training	35 (77.8)	1.4 (1.1)	34 (75.6)	1.4 (0.9)	411 (79.5)	2.2 (1.6)	414 (80.1)	3.2 (1.7)	357 (91.5)	3.6 (1.5)	348 (89.2)	3.8 (1.5)	547 (79.7)	2.3 (1.6)	498 (72.6)	2.4 (1.6)	132 (71.0)	1.7 (1.3)	116 (62.4)	1.8 (1.3)	31 (64.6)	1.2 (0.7)	26 (54.2)	1.5 (1.1)
Planning for transition from school to work/adult life	35 (77.8)	1.3 (0.9)	33 (73.3)	1.5 (1.1)	422 (81.6)	2.5 (1.7)	422 (81.6)	3.5 (1.7)	361 (92.6)	3.9 (1.5)	351 (90.0)	4.0 (1.4)	523 (76.2)	1.8 (1.4)	476 (69.4)	1.8 (1.4)	122 (65.6)	1.3 (0.9)	110 (59.1)	1.4 (1.1)	31 (64.6)	1.1 (0.3)	25 (52.1)	1.3 (0.9)

Table 19. Responses across Age Groups

Services/Supports	Age 0-5 (n=45)				Age 6-15 (n=517)				Age 16-21 (n=390)				Age 22-49 (n=686)				Age 50-64 (n=186)				Age ≥ 65 (n=48)			
	Current		Future		Current		Future		Current		Future		Current		Future		Current		Future		Current		Future	
	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)
Support with a meaningful day activity	38 (84.4)	2.4 (1.7)	35 (77.8)	2.6 (1.7)	419 (81.0)	2.7 (1.7)	409 (79.1)	3.3 (1.7)	352 (90.3)	3.6 (1.5)	348 (89.2)	3.9 (1.5)	566 (82.5)	3.1 (1.7)	527 (76.8)	3.2 (1.6)	134 (72.0)	2.9 (1.7)	124 (66.7)	3.1 (1.6)	38 (79.2)	3.3 (1.5)	32 (66.7)	3.8 (1.4)
Planning for transition from work to retirement	34 (75.6)	1.3 (0.9)	34 (75.6)	1.4 (1.1)	397 (76.8)	1.4 (1.1)	400 (77.4)	1.9 (1.5)	331 (84.9)	1.8 (1.4)	336 (86.2)	2.0 (1.6)	526 (76.7)	1.9 (1.4)	489 (71.3)	2.1 (1.5)	136 (73.1)	2.2 (1.5)	121 (65.1)	2.5 (1.6)	34 (70.8)	2.0 (1.5)	28 (58.3)	2.2 (1.7)
Financial management	35 (77.8)	1.5 (1.2)	34 (75.6)	1.6 (1.2)	409 (79.1)	2.2 (1.6)	415 (80.3)	3 (1.7)	348 (89.2)	3.3 (1.5)	347 (89.0)	3.6 (1.5)	578 (84.3)	3.0 (1.6)	538 (78.4)	3.2 (1.7)	138 (74.2)	2.9 (1.7)	120 (64.5)	3.0 (1.6)	40 (83.3)	3.2 (1.8)	35 (72.9)	3.4 (1.7)
Independent living skills training	37 (82.2)	1.5 (1.2)	34 (75.6)	1.7 (1.2)	422 (81.6)	2.6 (1.7)	419 (81.0)	3.4 (1.7)	355 (91.0)	3.7 (1.4)	351 (90.0)	4.0 (1.4)	575 (83.8)	3.3 (1.5)	536 (78.1)	3.4 (1.5)	144 (77.4)	3.2 (1.6)	133 (71.5)	3.3 (1.6)	36 (75.0)	2.8 (1.7)	32 (66.7)	3.1 (1.7)
Retirement supports	34 (75.6)	1.3 (1)	34 (75.6)	1.4 (1)	401 (77.6)	1.5 (1.1)	397 (76.8)	1.9 (1.5)	329 (84.4)	1.8 (1.4)	335 (85.9)	2.0 (1.6)	530 (77.3)	1.9 (1.4)	498 (72.6)	2.1 (1.6)	134 (72.0)	2.4 (1.7)	125 (67.2)	2.8 (1.6)	37 (77.1)	2.8 (1.7)	31 (64.6)	3.0 (1.8)
Family																								
Occasional out-of-home support	39 (86.7)	3.1 (1.8)	39 (86.7)	3.1 (1.7)	444 (85.9)	3.3 (1.6)	420 (81.2)	3.5 (1.6)	356 (91.3)	3.0 (1.7)	345 (88.5)	3.1 (1.7)	565 (82.4)	2.9 (1.6)	525 (76.5)	3.0 (1.6)	134 (72.0)	2.4 (1.7)	120 (64.5)	2.7 (1.7)	33 (68.8)	2.8 (1.8)	33 (68.8)	2.7 (1.8)
Occasional in-home support	41 (91.1)	3.5 (1.6)	38 (84.4)	3.5 (1.6)	441 (85.3)	3.4 (1.7)	420 (81.2)	3.5 (1.6)	351 (90.0)	3.1 (1.7)	339 (86.9)	3.2 (1.7)	568 (82.8)	2.9 (1.7)	523 (76.2)	3.1 (1.7)	130 (69.9)	2.4 (1.7)	120 (64.5)	2.7 (1.7)	34 (70.8)	2.4 (1.7)	35 (72.9)	2.5 (1.8)
Personal care assistance	42 (93.3)	2.8 (1.8)	39 (86.7)	2.7 (1.8)	431 (83.4)	2.7 (1.7)	407 (78.7)	3.1 (1.7)	350 (89.7)	2.7 (1.7)	347 (89)	3.0 (1.7)	557 (81.2)	2.6 (1.7)	514 (74.9)	2.9 (1.7)	127 (68.3)	2.6 (1.7)	118 (63.4)	2.8 (1.7)	37 (77.1)	3.5 (1.7)	36 (75.0)	3.7 (1.6)
Family/individual short-term counseling	40 (88.9)	2.5 (1.6)	37 (82.2)	2.7 (1.6)	437 (84.5)	2.7 (1.5)	411 (79.5)	2.9 (1.5)	342 (87.7)	2.4 (1.5)	338 (86.7)	2.4 (1.5)	549 (80.0)	2.2 (1.5)	489 (71.3)	2.2 (1.5)	129 (69.4)	1.9 (1.4)	118 (63.4)	2.1 (1.4)	34 (70.8)	1.7 (1.2)	33 (68.8)	1.7 (1.1)
Parenting skills training	42 (93.3)	2.9 (1.5)	37 (82.2)	2.9 (1.5)	439 (84.9)	2.6 (1.5)	413 (79.9)	2.7 (1.5)	342 (87.7)	1.8 (1.3)	334 (85.6)	1.9 (1.3)	527 (76.8)	1.5 (1.1)	476 (69.4)	1.6 (1.2)	122 (65.6)	1.2 (0.8)	114 (61.3)	1.3 (1)	33 (68.8)	1.4 (1.1)	33 (68.8)	1.2 (0.7)
Behavioral supports	41 (91.1)	3.2 (1.7)	37 (82.2)	3 (1.7)	449 (86.8)	3.5 (1.5)	424 (82.0)	3.5 (1.5)	346 (88.7)	2.8 (1.6)	341 (87.4)	2.8 (1.6)	551 (80.3)	2.4 (1.6)	496 (72.3)	2.5 (1.6)	126 (67.7)	1.9 (1.4)	117 (62.9)	2.0 (1.4)	34 (70.8)	2.0 (1.4)	34 (70.8)	1.9 (1.3)
Adaptive equipment for health and safety	42 (93.3)	3.4 (1.7)	39 (86.7)	3.4 (1.7)	430 (83.2)	2.6 (1.7)	403 (77.9)	2.7 (1.7)	348 (89.2)	2.2 (1.6)	340 (87.2)	2.3 (1.6)	543 (79.2)	2.1 (1.5)	495 (72.2)	2.3 (1.6)	131 (70.4)	2.1 (1.5)	124 (66.7)	2.5 (1.7)	39 (81.3)	2.9 (1.5)	39 (81.3)	3.2 (1.6)
Before or after school care	40 (88.9)	2.7 (1.7)	38 (84.4)	3.0 (1.6)	442 (85.5)	3.0 (1.7)	414 (80.1)	3.1 (1.7)	343 (87.9)	2.1 (1.6)	336 (86.2)	2.1 (1.6)	508 (74.1)	1.4 (1.1)	457 (66.6)	1.5 (1.2)	121 (65.1)	1.3 (0.9)	111 (59.7)	1.4 (1.1)	32 (66.7)	1.2 (0.7)	32 (66.7)	1.1 (0.2)
Assistive technology	43 (95.6)	3.2 (1.7)	40 (88.9)	3.5 (1.7)	438 (84.7)	3.0 (1.7)	413 (79.9)	3.1 (1.7)	345 (88.5)	2.5 (1.6)	337 (86.4)	2.5 (1.7)	533 (77.7)	2.1 (1.5)	481 (70.1)	2.2 (1.6)	123 (66.1)	1.9 (1.5)	118 (63.4)	2.0 (1.6)	33 (68.8)	2.0 (1.6)	32 (66.7)	2.1 (1.6)

Table 19. Responses across Age Groups

Services/Supports	Age 0-5 (n=45)				Age 6-15 (n=517)				Age 16-21 (n=390)				Age 22-49 (n=686)				Age 50-64 (n=186)				Age ≥ 65 (n=48)			
	Current		Future		Current		Future		Current		Future		Current		Future		Current		Future		Current		Future	
	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)
<i>Socialization / Wellness</i>																								
Healthy relationship training	38 (84.4)	2.9 (1.8)	36 (80.0)	2.8 (1.8)	438 (84.7)	3.5 (1.5)	419 (81.0)	3.9 (1.3)	349 (89.5)	3.5 (1.4)	336 (86.2)	3.7 (1.4)	560 (81.6)	3.1 (1.5)	528 (77.0)	3.2 (1.5)	140 (75.3)	2.4 (1.5)	127 (68.3)	2.5 (1.5)	33 (68.8)	2.4 (1.5)	32 (66.7)	2.5 (1.6)
Social skills training	37 (82.2)	3.1 (1.7)	35 (77.8)	3.3 (1.6)	448 (86.7)	4.1 (1.3)	425 (82.2)	4.2 (1.2)	354 (90.8)	3.8 (1.3)	341 (87.4)	3.9 (1.3)	574 (83.7)	3.2 (1.5)	527 (76.8)	3.3 (1.5)	141 (75.8)	2.6 (1.5)	130 (69.9)	2.7 (1.5)	33 (68.8)	2.2 (1.5)	32 (66.7)	2.3 (1.5)
Summer recreation	38 (84.4)	3.7 (1.3)	37 (82.2)	3.9 (1.1)	441 (85.3)	3.9 (1.3)	423 (81.8)	3.9 (1.3)	342 (87.7)	3.1 (1.6)	334 (85.6)	3.2 (1.6)	549 (80)	2.5 (1.6)	505 (73.6)	2.6 (1.6)	133 (71.5)	2.2 (1.5)	120 (64.5)	2.3 (1.6)	33 (68.8)	1.8 (1.4)	33 (68.8)	1.8 (1.4)
Community membership in organizations or clubs	35 (77.8)	3.0 (1.5)	35 (77.8)	3.3 (1.3)	444 (85.9)	3.3 (1.5)	424 (82.0)	3.6 (1.4)	348 (89.2)	3.2 (1.5)	339 (86.9)	3.3 (1.5)	562 (81.9)	2.9 (1.5)	523 (76.2)	3.0 (1.5)	136 (73.1)	2.5 (1.5)	126 (67.7)	2.5 (1.6)	37 (77.1)	2.4 (1.5)	35 (72.9)	2.5 (1.6)
Parks and recreation activities	39 (86.7)	3.7 (1.3)	37 (82.2)	3.8 (1.2)	449 (86.8)	3.6 (1.3)	426 (82.4)	3.7 (1.3)	345 (88.5)	3.2 (1.4)	340 (87.2)	3.4 (1.4)	554 (80.8)	2.9 (1.5)	513 (74.8)	3.0 (1.5)	135 (72.6)	2.7 (1.5)	123 (66.1)	2.7 (1.5)	37 (77.1)	2.6 (1.5)	36 (75.0)	2.6 (1.5)
Fitness/wellness activities	37 (82.2)	3.2 (1.6)	36 (80.0)	3.5 (1.5)	443 (85.7)	3.6 (1.4)	420 (81.2)	3.8 (1.3)	346 (88.7)	3.5 (1.4)	336 (86.2)	3.6 (1.4)	574 (83.7)	3.3 (1.4)	532 (77.6)	3.5 (1.4)	143 (76.9)	2.9 (1.5)	132 (71.0)	2.9 (1.5)	36 (75)	2.3 (1.2)	36 (75.0)	2.6 (1.3)
Disability specific activities	39 (86.7)	3.3 (1.3)	38 (84.4)	3.5 (1.2)	428 (82.8)	3.2 (1.5)	405 (78.3)	3.4 (1.5)	340 (87.2)	3.0 (1.5)	332 (85.1)	3.2 (1.6)	537 (78.3)	2.8 (1.5)	499 (72.7)	2.9 (1.6)	136 (73.1)	2.6 (1.6)	120 (64.5)	2.7 (1.6)	37 (77.1)	2.7 (1.4)	36 (75.0)	2.8 (1.5)
Self-advocacy and self-determination	37 (82.2)	3.1 (1.7)	36 (80.0)	3.5 (1.5)	440 (85.1)	3.7 (1.5)	424 (82.0)	4.0 (1.4)	344 (88.2)	3.6 (1.4)	334 (85.6)	3.7 (1.4)	551 (80.3)	3.1 (1.5)	517 (75.4)	3.2 (1.6)	138 (74.2)	2.8 (1.6)	125 (67.2)	2.9 (1.7)	39 (81.3)	3.2 (1.6)	38 (79.2)	3.2 (1.6)

Note. Percentages were calculated excluding missing responses; Mean = average importance ratings; SD = standard deviation, indicating the extent to which the importance rating spread out from the mean.

Global Responses across Diagnosis

In addition to analyzing the data based on age, we also analyzed it with reference to specific disability diagnosis. As Table 20 demonstrates, we analyzed six separate disability groups. The information below describes some of the lessons learned from this analysis.

Employment

“Working with supports in the community” was the most important current and future employment support across all disability groups. People with autism and learning disabilities rated it as a particularly important future need. People from these two groups also indicated that working without supports in the community was a moderately important future goal.

Living Options

Regardless of a person’s disability, the most important current and future living option was “Living with parents/family.” This was especially true for people with epilepsy. People with learning disabilities also rated “Living independently in the community with supports 0 to 20 hours each week” and “Living independently in the community without support” as important future needs.

Life Transitions

In terms of current and future life transition supports and services, only two consistently received more than a “moderately important” rating across all disabilities: “Support with a meaningful day activity” and “Independent living skills training.” However, “Financial management” was rated as an important future need for almost all disability groups.

Family

The importance of family supports and services varied across disability groups. For example, “Occasional out-of-home support” and “Occasional in-home support” were very

important future needs for people with cerebral palsy and epilepsy. These same two items were moderately important future needs for people with autism and intellectual disabilities. Personal care assistance was also very important for people with cerebral palsy and epilepsy. The most important support for people with TBI was “Assistive technology.” People with learning disabilities did not rate any of the family supports as even moderately important.

Socialization/Wellness

The socialization and wellness domain is the most important domain. Most of the service and support items in the socialization and wellness domain were rated as moderately important or more across all disability groups. People with autism considered “Social skills training” to be very important and all of the other groups rated it as moderately important. Respondents from all disability groups consistently rated “Fitness/Wellness activities” as more than moderately important.

Table 20. Responses across Disability Diagnosis

Services/Supports	Autism (n=666)				Intel. Disability (n=523)				Learning Disability (n=212)				TBI (39)				Cerebral Palsy (n=119)				Epilepsy (27)			
	Current		Future		Current		Future		Current		Future		Current		Future		Current		Future		Current		Future	
	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)
Employment																								
Working with supports in the community	604 (90.7)	3.0 (1.6)	602 (90.4)	3.6 (1.5)	450 (86.0)	2.8 (1.7)	423 (80.9)	3.2 (1.7)	178 (84.0)	3.5 (1.4)	157 (74.1)	3.8 (1.3)	34 (87.2)	2.9 (1.6)	31 (79.5)	3.1 (1.6)	105 (88.2)	2.8 (1.7)	100 (84.0)	3.1 (1.7)	25 (92.6)	3.2 (1.5)	21 (77.8)	3.0 (1.7)
Working without supports in the community	572 (85.9)	2.3 (1.5)	559 (83.9)	3.1 (1.6)	405 (77.4)	1.9 (1.3)	385 (73.6)	2.2 (1.5)	159 (75.0)	2.7 (1.5)	133 (62.7)	3.1 (1.5)	30 (76.9)	2.1 (1.3)	27 (69.2)	2.3 (1.5)	97 (81.5)	1.8 (1.3)	87 (73.1)	2.1 (1.6)	22 (81.5)	2 (1.3)	20 (74.1)	2.1 (1.4)
Working in a sheltered workshop	579 (86.9)	1.9 (1.4)	562 (84.4)	2.4 (1.6)	461 (88.1)	2.7 (1.8)	435 (83.2)	2.9 (1.8)	161 (75.9)	2.4 (1.6)	144 (67.9)	2.6 (1.6)	32 (82.1)	1.8 (1.3)	29 (74.4)	1.9 (1.3)	99 (83.2)	1.9 (1.5)	94 (79.0)	2.2 (1.7)	25 (92.6)	2.1 (1.6)	20 (74.1)	2.2 (1.8)
Working in summer employment	582 (87.4)	2.3 (1.6)	565 (84.8)	3 (1.7)	412 (78.8)	1.9 (1.5)	385 (73.6)	2.3 (1.6)	153 (72.2)	2.7 (1.6)	140 (66.0)	3.1 (1.7)	30 (76.9)	1.9 (1.3)	26 (66.7)	1.9 (1.4)	96 (80.7)	1.9 (1.5)	86 (72.3)	2.1 (1.7)	24 (88.9)	2.5 (1.6)	20 (74.1)	2.9 (1.8)
Living Options																								
Living with parents/family	622 (93.4)	4.4 (1.1)	576 (86.5)	3.9 (1.4)	465 (88.9)	4 (1.6)	418 (79.9)	3.7 (1.6)	170 (80.2)	3.8 (1.5)	156 (73.6)	3.5 (1.5)	32 (82.1)	3.6 (1.5)	32 (82.1)	3.1 (1.7)	109 (91.6)	4.3 (1.3)	101 (84.9)	4 (1.4)	23 (85.2)	4.7 (0.9)	20 (74.1)	4.4 (1.1)
Living in a 24-hour supervised residential setting	553 (83.0)	1.8 (1.4)	546 (82.0)	2.4 (1.6)	417 (79.7)	2.2 (1.7)	400 (76.5)	2.8 (1.8)	147 (69.3)	1.9 (1.5)	139 (65.6)	2.3 (1.6)	29 (74.4)	2.1 (1.6)	29 (74.4)	2.6 (1.7)	98 (82.4)	1.8 (1.4)	90 (75.6)	2.4 (1.6)	22 (81.5)	1.8 (1.3)	20 (74.1)	2.6 (1.7)
Living independently in the community with supports 0 to 20 hours each week	531 (79.7)	1.9 (1.4)	533 (80.0)	2.5 (1.6)	397 (75.9)	2.1 (1.6)	372 (71.1)	2.5 (1.7)	146 (68.9)	2.9 (1.7)	143 (67.5)	3.3 (1.6)	29 (74.4)	2.0 (1.4)	27 (69.2)	1.7 (1.2)	96 (80.7)	2.0 (1.6)	90 (75.6)	2.3 (1.6)	18 (66.7)	2.2 (1.6)	19 (70.4)	2.5 (1.5)
Living independently in the community with supports 20 to 50 hours each week	518 (77.8)	1.7 (1.2)	532 (79.9)	2.3 (1.6)	383 (73.2)	1.8 (1.4)	364 (69.6)	2.2 (1.6)	145 (68.4)	2.2 (1.6)	135 (63.7)	2.7 (1.7)	27 (69.2)	1.6 (1.1)	26 (66.7)	1.5 (1.0)	92 (77.3)	1.8 (1.4)	89 (74.8)	2.2 (1.7)	18 (66.7)	2.0 (1.5)	19 (70.4)	2.3 (1.5)
Living independently in the community with supports over 50 hours each week	521 (78.2)	1.6 (1.2)	533 (80)	2.3 (1.6)	382 (73.0)	1.7 (1.3)	366 (70.0)	2.2 (1.6)	140 (66.0)	2.1 (1.6)	134 (63.2)	2.4 (1.7)	28 (71.8)	1.7 (1.3)	27 (69.2)	1.6 (1.2)	92 (77.3)	2.0 (1.6)	87 (73.1)	2.4 (1.7)	19 (70.4)	1.9 (1.4)	20 (74.1)	2.4 (1.6)
Living independently in the community without support	519 (77.9)	1.8 (1.4)	528 (79.3)	2.4 (1.7)	375 (71.7)	1.4 (1.1)	355 (67.9)	1.7 (1.3)	140 (66.0)	2.7 (1.7)	134 (63.2)	3.0 (1.7)	27 (69.2)	1.6 (1.3)	27 (69.2)	2.0 (1.6)	92 (77.3)	1.5 (1.2)	88 (73.9)	1.6 (1.3)	18 (66.7)	2.1 (1.5)	19 (70.4)	2.4 (1.6)
Life Transitions																								
Adult education	560 (84.1)	2.1 (1.5)	544 (81.7)	2.6 (1.7)	427 (81.6)	1.7 (1.3)	384 (73.4)	2.0 (1.5)	162 (76.4)	2.3 (1.6)	146 (68.9)	2.6 (1.7)	27 (69.2)	2.1 (1.7)	25 (64.1)	2.4 (1.6)	99 (83.2)	1.8 (1.4)	90 (75.6)	2.0 (1.5)	23 (85.2)	2.3 (1.7)	20 (74.1)	2.3 (1.7)
Support to volunteer in the community	559 (83.9)	2.4 (1.5)	553 (83.0)	2.8 (1.6)	426 (81.5)	2.3 (1.5)	394 (75.3)	2.5 (1.6)	159 (75.0)	2.4 (1.5)	145 (68.4)	2.5 (1.5)	31 (79.5)	2.6 (1.5)	27 (69.2)	2.7 (1.5)	98 (82.4)	2.4 (1.5)	93 (78.2)	2.7 (1.6)	24 (88.9)	2.5 (1.6)	20 (74.1)	2.5 (1.6)
Pre-employment training	559 (83.9)	2.7 (1.7)	555 (83.3)	3.3 (1.6)	406 (77.6)	2.2 (1.6)	375 (71.7)	2.4 (1.6)	157 (74.1)	2.7 (1.7)	142 (67.0)	3.0 (1.7)	30 (76.9)	2.3 (1.6)	28 (71.8)	2.4 (1.5)	97 (81.5)	2.1 (1.6)	92 (77.3)	2.3 (1.7)	22 (81.5)	2.5 (1.7)	18 (66.7)	2.4 (1.6)
Planning for transition from school to work/adult life	558 (83.8)	2.8 (1.7)	553 (83)	3.2 (1.8)	403 (77.1)	2.0 (1.6)	373 (71.3)	2.3 (1.7)	149 (70.3)	2.3 (1.6)	138 (65.1)	2.6 (1.8)	28 (71.8)	2.1 (1.6)	25 (64.1)	2.4 (1.6)	96 (80.7)	2.5 (1.7)	89 (74.8)	2.6 (1.7)	23 (85.2)	2.7 (1.8)	21 (77.8)	2.7 (1.9)
Support with a meaningful day activity	568 (85.3)	2.9 (1.7)	549 (82.4)	3.3 (1.7)	430 (82.2)	3.1 (1.7)	404 (77.2)	3.3 (1.7)	157 (74.1)	2.8 (1.6)	146 (68.9)	2.9 (1.6)	31 (79.5)	3.4 (1.6)	28 (71.8)	3.5 (1.4)	97 (81.5)	3.3 (1.7)	90 (75.6)	3.6 (1.6)	23 (85.2)	3.8 (1.4)	22 (81.5)	3.9 (1.4)

Table 20. Responses across Disability Diagnosis

Services/Supports	Autism (n=666)				Intel. Disability (n=523)				Learning Disability (n=212)				TBI (39)				Cerebral Palsy (n=119)				Epilepsy (27)			
	Current		Future		Current		Future		Current		Future		Current		Future		Current		Future		Current		Future	
	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)
Planning for transition from work to retirement	532 (79.9)	1.6 (1.3)	534 (80.2)	1.9 (1.5)	408 (78.0)	1.8 (1.3)	381 (72.8)	2.1 (1.5)	152 (71.7)	2.3 (1.6)	142 (67.0)	2.6 (1.7)	28 (71.8)	1.9 (1.4)	27 (69.2)	2.0 (1.6)	93 (78.2)	1.5 (1.0)	88 (73.9)	1.8 (1.3)	22 (81.5)	2.1 (1.6)	21 (77.8)	2.2 (1.7)
Financial management	557 (83.6)	2.8 (1.6)	558 (83.8)	3.4 (1.6)	425 (81.3)	2.7 (1.7)	398 (76.1)	2.9 (1.7)	164 (77.4)	3.4 (1.6)	146 (68.9)	3.5 (1.6)	30 (76.9)	3.0 (1.6)	28 (71.8)	3.1 (1.5)	98 (82.4)	2.4 (1.5)	93 (78.2)	2.7 (1.6)	25 (92.6)	3.0 (1.8)	22 (81.5)	2.9 (1.9)
Independent living skills training	566 (85.0)	3.1 (1.6)	561 (84.2)	3.6 (1.5)	428 (81.8)	3.1 (1.6)	401 (76.7)	3.4 (1.6)	165 (77.8)	3.4 (1.6)	153 (72.2)	3.6 (1.6)	31 (79.5)	2.9 (1.6)	29 (74.4)	3.0 (1.5)	98 (82.4)	2.7 (1.7)	93 (78.2)	3.0 (1.6)	24 (88.9)	3.1 (1.9)	22 (81.5)	3.1 (1.9)
Retirement supports	537 (80.6)	1.6 (1.3)	535 (80.3)	1.9 (1.5)	401 (76.7)	1.9 (1.4)	385 (73.6)	2.3 (1.6)	154 (72.6)	2.2 (1.6)	139 (65.6)	2.5 (1.7)	27 (69.2)	2.0 (1.5)	26 (66.7)	2.2 (1.6)	94 (79.0)	1.5 (1.1)	89 (74.8)	1.7 (1.2)	23 (85.2)	2.2 (1.8)	21 (77.8)	2.1 (1.8)
Family																								
Occasional out-of-home support	584 (87.7)	3.0 (1.7)	553 (83.0)	3.1 (1.6)	431 (82.4)	2.9 (1.7)	401 (76.7)	3.1 (1.7)	160 (75.5)	2.6 (1.6)	144 (67.9)	2.7 (1.7)	31 (79.5)	2.9 (1.7)	28 (71.8)	2.9 (1.7)	99 (83.2)	3.5 (1.7)	98 (82.4)	3.8 (1.6)	22 (81.5)	3.6 (1.7)	23 (85.2)	3.9 (1.5)
Occasional in-home support	581 (87.2)	3.0 (1.7)	553 (83.0)	3.1 (1.7)	428 (81.8)	3.0 (1.7)	401 (76.7)	3.2 (1.7)	156 (73.6)	2.4 (1.6)	138 (65.1)	2.6 (1.7)	30 (76.9)	2.7 (1.6)	26 (66.7)	2.9 (1.6)	100 (84)	3.7 (1.6)	96 (80.7)	4.0 (1.5)	22 (81.5)	3.9 (1.6)	23 (85.2)	4.0 (1.6)
Personal care assistance	563 (84.5)	2.4 (1.6)	541 (81.2)	2.7 (1.6)	421 (80.5)	2.7 (1.7)	397 (75.9)	3.0 (1.7)	163 (76.9)	2.3 (1.6)	142 (67.0)	2.4 (1.6)	29 (74.4)	3.5 (1.7)	28 (71.8)	3.6 (1.6)	102 (85.7)	3.5 (1.8)	98 (82.4)	4.1 (1.4)	24 (88.9)	3.4 (1.7)	24 (88.9)	3.8 (1.8)
Family/individual short-term counseling	568 (85.3)	2.5 (1.5)	534 (80.2)	2.6 (1.5)	417 (79.7)	2.1 (1.5)	387 (74.0)	2.2 (1.5)	158 (74.5)	2.5 (1.6)	141 (66.5)	2.6 (1.6)	29 (74.4)	2.4 (1.3)	27 (69.2)	2.3 (1.3)	98 (82.4)	2.2 (1.3)	94 (79.0)	2.5 (1.5)	19 (70.4)	2.6 (1.8)	19 (70.4)	2.7 (1.8)
Parenting skills training	563 (84.5)	2.2 (1.5)	534 (80.2)	2.3 (1.5)	403 (77.1)	1.5 (1.1)	373 (71.3)	1.5 (1.2)	157 (74.1)	2.0 (1.5)	136 (64.2)	2.1 (1.5)	31 (79.5)	2.2 (1.4)	28 (71.8)	2.1 (1.4)	95 (79.8)	1.5 (1.1)	90 (75.6)	1.8 (1.3)	22 (81.5)	2.0 (1.4)	20 (74.1)	2.3 (1.8)
Behavioral supports	585 (87.8)	3.3 (1.6)	555 (83.3)	3.3 (1.5)	417 (79.7)	2.3 (1.5)	390 (74.6)	2.3 (1.6)	162 (76.4)	2.6 (1.6)	138 (65.1)	2.6 (1.6)	28 (71.8)	2.8 (1.6)	26 (66.7)	2.7 (1.6)	97 (81.5)	2.0 (1.4)	93 (78.2)	2.3 (1.6)	21 (77.8)	2.4 (1.6)	20 (74.1)	2.7 (1.9)
Adaptive equipment for health and safety	555 (83.3)	2.0 (1.5)	526 (79.0)	2.1 (1.5)	423 (80.9)	2.0 (1.5)	395 (75.5)	2.3 (1.6)	162 (76.4)	2.3 (1.6)	142 (67.0)	2.4 (1.6)	31 (79.5)	3.2 (1.7)	29 (74.4)	3.2 (1.8)	102 (85.7)	3.7 (1.6)	99 (83.2)	4.0 (1.5)	24 (88.9)	2.9 (1.7)	23 (85.2)	3.5 (1.8)
Before or after school care	564 (84.7)	2.2 (1.6)	530 (79.6)	2.3 (1.6)	395 (75.5)	1.7 (1.4)	369 (70.6)	1.8 (1.5)	155 (73.1)	2.0 (1.5)	137 (64.6)	2.1 (1.6)	27 (69.2)	2.0 (1.5)	24 (61.5)	1.9 (1.5)	97 (81.5)	2.2 (1.7)	92 (77.3)	2.3 (1.8)	23 (85.2)	2.2 (1.7)	21 (77.8)	2.6 (1.9)
Assistive technology	559 (83.9)	2.4 (1.6)	532 (79.9)	2.4 (1.6)	411 (78.6)	2.1 (1.6)	386 (73.8)	2.2 (1.6)	156 (73.6)	2.3 (1.6)	137 (64.6)	2.5 (1.7)	29 (74.4)	3.1 (1.7)	27 (69.2)	3.0 (1.8)	101 (84.9)	3.3 (1.7)	96 (80.7)	3.6 (1.7)	24 (88.9)	2.9 (1.7)	22 (81.5)	3.2 (1.8)
Socialization / Wellness																								
Healthy relationship training	581 (87.2)	3.6 (1.4)	564 (84.7)	3.8 (1.4)	442 (84.5)	3.0 (1.6)	415 (79.3)	3.2 (1.6)	154 (72.6)	3.3 (1.5)	141 (66.5)	3.4 (1.5)	30 (76.9)	3.1 (1.5)	28 (71.8)	3.3 (1.6)	92 (77.3)	2.6 (1.6)	86 (72.3)	2.8 (1.7)	20 (74.1)	2.9 (1.7)	19 (70.4)	2.9 (1.7)
Social skills training	594 (89.2)	4.1 (1.2)	575 (86.3)	4.1 (1.2)	441 (84.3)	3.1 (1.5)	406 (77.6)	3.3 (1.5)	157 (74.1)	3.2 (1.5)	141 (66.5)	3.3 (1.5)	29 (74.4)	3.2 (1.6)	28 (71.8)	3.3 (1.6)	92 (77.3)	2.8 (1.6)	84 (70.6)	2.8 (1.6)	22 (81.5)	3.1 (1.7)	20 (74.1)	3.3 (1.8)
Summer recreation	570 (85.6)	3.2 (1.6)	554 (83.2)	3.3 (1.6)	431 (82.4)	2.8 (1.6)	400 (76.5)	3.0 (1.6)	152 (71.7)	2.6 (1.6)	135 (63.7)	2.7 (1.7)	30 (76.9)	2.8 (1.6)	28 (71.8)	2.8 (1.7)	89 (74.8)	3.1 (1.8)	86 (72.3)	3.3 (1.7)	22 (81.5)	3.5 (1.6)	20 (74.1)	3.3 (1.8)
Community membership in organizations or clubs	577 (86.6)	3.1 (1.5)	562 (84.4)	3.3 (1.5)	439 (83.9)	2.9 (1.5)	414 (79.2)	3.1 (1.6)	155 (73.1)	2.9 (1.5)	136 (64.2)	3.1 (1.6)	32 (82.1)	3.0 (1.5)	30 (76.9)	3.1 (1.5)	93 (78.2)	3.0 (1.6)	89 (74.8)	3.3 (1.6)	22 (81.5)	3.3 (1.4)	19 (70.4)	3.3 (1.8)
Parks and recreation activities	580 (87.1)	3.3 (1.4)	566 (85)	3.4 (1.4)	434 (83)	3.0 (1.5)	407 (77.8)	3.2 (1.5)	154 (72.6)	2.9 (1.5)	135 (63.7)	3.0 (1.5)	31 (79.5)	3.5 (1.3)	30 (76.9)	3.4 (1.4)	92 (77.3)	3.1 (1.6)	89 (74.8)	3.3 (1.6)	22 (81.5)	3.4 (1.3)	19 (70.4)	3.3 (1.6)
Fitness/wellness activities	581 (87.2)	3.5 (1.4)	561 (84.2)	3.6 (1.4)	447 (85.5)	3.3 (1.4)	416 (79.5)	3.4 (1.4)	158 (74.5)	3.3 (1.5)	139 (65.6)	3.4 (1.6)	31 (79.5)	3.7 (1.2)	30 (76.9)	3.8 (1.3)	93 (78.2)	3.3 (1.6)	89 (74.8)	3.5 (1.6)	21 (77.8)	3.2 (1.6)	19 (70.4)	3.2 (1.8)

Table 20. Responses across Disability Diagnosis

Services/Supports	Autism (n=666)				Intel. Disability (n=523)				Learning Disability (n=212)				TBI (39)				Cerebral Palsy (n=119)				Epilepsy (27)			
	Current		Future		Current		Future		Current		Future		Current		Future		Current		Future		Current		Future	
	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)	n (%)	M (SD)
Disability specific activities	563 (84.5)	2.9 (1.5)	540 (81.1)	3.1 (1.6)	421 (80.5)	3.0 (1.5)	399 (76.3)	3.1 (1.5)	153 (72.2)	2.7 (1.6)	134 (63.2)	2.8 (1.7)	32 (82.1)	3.1 (1.4)	29 (74.4)	3.1 (1.5)	96 (80.7)	3.3 (1.6)	90 (75.6)	3.5 (1.6)	21 (77.8)	3.8 (1.5)	19 (70.4)	3.5 (1.8)
Self-advocacy and self-determination	574 (86.2)	3.5 (1.5)	557 (83.6)	3.7 (1.5)	426 (81.5)	3.0 (1.5)	402 (76.9)	3.1 (1.6)	156 (73.6)	3.6 (1.5)	138 (65.1)	3.7 (1.6)	32 (82.1)	3.4 (1.5)	30 (76.9)	3.7 (1.4)	92 (77.3)	3.1 (1.6)	87 (73.1)	3.3 (1.6)	20 (74.1)	3.5 (1.6)	19 (70.4)	3.1 (1.8)

Note. Percentages were calculated excluding missing responses; Mean = average importance ratings; SD = standard deviation, indicating the extent to which the importance rating spread out from the mean.

Global Responses across Region

In addition to analyzing the data based on age and disability diagnosis, we also analyzed it with reference to where people lived in St. Louis County. As Table 21 demonstrates, we analyzed four separate regions of the county: Central, North, South, and West. Overall, the two most important needs across all regions were “Living with parents/family” and “Social skills training.” Additionally, the region with the greatest needs across all domains of the survey was the North (mean score = 3.0), closely followed by the Central region (mean score = 2.9). The South (mean score = 2.7) and the West (mean score = 2.7) did not cite as many needs. The information below describes the lessons learned about each domain of the survey.

Employment

In terms of employment, “Working with supports in the community” was the most important current and future need in each of the regions. The data indicate that it was slightly more important to people who lived in North St. Louis County. “Working in summer employment” was the second most important current and future need although it did not reach the level of moderately important in any of the regions.

Living Options

As we have seen in other portions of this report, the most important living option is “Living with parents/family.” Interestingly, in each region “Living with parents/family” is considered a very important current need. While it is still the most important future need, respondents do not rate it highly as they rated it when thinking about current needs. The least popular living option across all regions is “Living independently in the community without support.”

Life Transitions

Respondents from the four regions tended to agree on the most important services and supports in the Life Transitions domain. The two most important were “Independent living skills” and “Support with a meaningful day activity.” These were closely followed by the “Financial management” support.

Family

Regarding the supports and services listed in the family domain, the two respite items (“Occasional out-of-home support” and “Occasional in-home support”) were identified as the most important current and future needs in each of the four regions. The Family domain is one in which respondents from the North and Central regions of St. Louis County clearly identify a greater level of need than the individuals who live in the South and West regions.

Socialization/Wellness

The socialization and wellness domain is the most important for respondents in each region of the county. Very few of the current or future needs are rated below moderately important. The most important support listed in this domain is “Social skills training.” This is closely followed by “Fitness/wellness activities” and “Self-advocacy and self-determination.” This domain is another in which respondents from the North and Central regions of St. Louis County indicate a greater level of need than in the other two regions of the county.

Table 21
Responses across Regions

Services/Supports	Central (n=427)				North (n=427)				South (n=571)				West (n=485)				Overall (n=2012)			
	Current		Future		Current		Future		Current		Future		Current		Future		Current		Future	
	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)
Employment																				
Working with supports in the community	369 (86.4)	3.0 (1.6)	361 (84.5)	3.4 (1.6)	380 (89.0)	3.3 (1.5)	350 (82.0)	3.6 (1.5)	500 (87.6)	2.9 (1.6)	488 (85.5)	3.4 (1.5)	428 (88.2)	2.9 (1.7)	414 (85.4)	3.5 (1.6)	1,677 (83.3)	3.0 (1.6)	1,613 (80.2)	3.4 (1.6)
Working without supports in the community	348 (81.5)	2.1 (1.4)	330 (77.3)	2.7 (1.7)	349 (81.7)	2.4 (1.5)	320 (74.9)	2.7 (1.6)	463 (81.1)	2.2 (1.5)	447 (78.3)	2.7 (1.6)	391 (80.6)	2.0 (1.4)	373 (76.9)	2.7 (1.6)	1,551 (77.1)	2.2 (1.5)	1,470 (73.1)	2.7 (1.6)
Working in a sheltered workshop	362 (84.8)	2.1 (1.5)	344 (80.6)	2.5 (1.6)	373 (87.4)	2.5 (1.6)	343 (80.3)	2.8 (1.7)	484 (84.8)	2.1 (1.6)	462 (80.9)	2.5 (1.7)	415 (85.6)	2.2 (1.7)	399 (82.3)	2.6 (1.7)	1,634 (81.2)	2.2 (1.6)	1,548 (76.9)	2.6 (1.7)
Working in summer employment	349 (81.7)	2.2 (1.6)	333 (78.0)	2.6 (1.7)	353 (82.7)	2.5 (1.6)	330 (77.3)	2.9 (1.7)	465 (81.4)	2.1 (1.6)	443 (77.6)	2.6 (1.7)	398 (82.1)	2.1 (1.5)	379 (78.1)	2.7 (1.7)	1,565 (77.8)	2.2 (1.6)	1,485 (73.8)	2.7 (1.7)
Living Options																				
Living with parents/family	381 (89.2)	4.0 (1.5)	350 (82.0)	3.6 (1.6)	388 (90.9)	4.2 (1.3)	349 (81.7)	3.9 (1.5)	519 (90.9)	4.2 (1.4)	479 (83.9)	3.7 (1.5)	436 (89.9)	4.3 (1.2)	396 (81.6)	3.9 (1.4)	1,724 (85.7)	4.2 (1.4)	1,574 (78.2)	3.8 (1.5)
Living in a 24-hour supervised residential setting	349 (81.7)	2.3 (1.7)	334 (78.2)	2.8 (1.8)	338 (79.2)	2.1 (1.5)	314 (73.5)	2.6 (1.7)	451 (79.0)	1.8 (1.4)	441 (77.2)	2.3 (1.6)	392 (80.8)	1.8 (1.4)	392 (80.8)	2.5 (1.7)	1,530 (76.0)	2.0 (1.5)	1,481 (73.6)	2.5 (1.7)
Living independently in the community with supports 0 to 20 hours each week	335 (78.5)	2.2 (1.6)	324 (75.9)	2.7 (1.7)	324 (75.9)	2.2 (1.6)	304 (71.2)	2.6 (1.7)	442 (77.4)	2.1 (1.6)	433 (75.8)	2.5 (1.6)	372 (76.7)	1.8 (1.4)	365 (75.3)	2.4 (1.7)	1,473 (73.2)	2.1 (1.5)	1,426 (70.9)	2.6 (1.7)
Living independently in the community with supports 20 to 50 hours each week	331 (77.5)	1.9 (1.4)	320 (74.9)	2.4 (1.6)	314 (73.5)	2.0 (1.4)	309 (72.4)	2.5 (1.6)	431 (75.5)	1.8 (1.3)	421 (73.7)	2.2 (1.5)	361 (74.4)	1.6 (1.3)	356 (73.4)	2.2 (1.6)	1,437 (71.4)	1.8 (1.4)	1,406 (69.9)	2.3 (1.6)
Living independently in the community with supports over 50 hours each week	330 (77.3)	1.8 (1.4)	318 (74.5)	2.3 (1.6)	314 (73.5)	2.1 (1.5)	312 (73.1)	2.6 (1.7)	428 (75.0)	1.7 (1.3)	420 (73.6)	2.2 (1.6)	359 (74.0)	1.5 (1.2)	358 (73.8)	2.1 (1.5)	1,431 (71.1)	1.8 (1.4)	1,408 (70.0)	2.3 (1.6)
Living independently in the community without support	325 (76.1)	1.8 (1.4)	312 (73.1)	2.2 (1.6)	311 (72.8)	2.0 (1.5)	311 (72.8)	2.4 (1.7)	424 (74.3)	1.7 (1.4)	411 (72.0)	2.2 (1.6)	361 (74.4)	1.5 (1.1)	355 (73.2)	2.0 (1.5)	1,421 (70.6)	1.7 (1.4)	1,389 (69.0)	2.2 (1.6)
Life Transitions																				
Adult education	346 (81.0)	1.9 (1.5)	323 (75.6)	2.3 (1.6)	349 (81.7)	2.2 (1.6)	319 (74.7)	2.5 (1.7)	474 (83.0)	1.9 (1.4)	434 (76.0)	2.3 (1.6)	388 (80.0)	1.9 (1.4)	375 (77.3)	2.3 (1.6)	1,557 (77.4)	2.0 (1.5)	1,451 (72.1)	2.4 (1.6)
Support to volunteer in the community	344 (80.6)	2.5 (1.5)	333 (78.0)	2.8 (1.5)	353 (82.7)	2.4 (1.5)	317 (74.2)	2.6 (1.5)	476 (83.4)	2.3 (1.5)	445 (77.9)	2.6 (1.6)	387 (79.8)	2.3 (1.5)	377 (77.7)	2.6 (1.6)	1,560 (77.5)	2.4 (1.5)	1,472 (73.2)	2.7 (1.6)
Pre-employment training	341 (79.9)	2.5 (1.6)	328 (76.8)	2.9 (1.7)	341 (79.9)	2.7 (1.7)	310 (72.6)	2.9 (1.7)	468 (82.0)	2.4 (1.6)	437 (76.5)	2.8 (1.7)	387 (79.8)	2.5 (1.7)	380 (78.4)	2.9 (1.7)	1,537 (76.4)	2.5 (1.7)	1,455 (72.3)	2.9 (1.7)
Planning for transition from school to work/adult life	336 (78.7)	2.4 (1.7)	323 (75.6)	2.8 (1.8)	338 (79.2)	2.5 (1.7)	309 (72.4)	2.8 (1.8)	461 (80.7)	2.3 (1.7)	427 (74.8)	2.7 (1.8)	385 (79.4)	2.5 (1.8)	379 (78.1)	2.9 (1.8)	1,520 (75.5)	2.4 (1.7)	1,438 (71.5)	2.8 (1.8)
Support with a meaningful day activity	355 (83.1)	3.3 (1.6)	339 (79.4)	3.6 (1.6)	355 (83.1)	3.3 (1.6)	321 (75.2)	3.5 (1.5)	476 (83.4)	2.8 (1.7)	450 (78.8)	3.1 (1.7)	391 (80.6)	2.9 (1.7)	389 (80.2)	3.4 (1.7)	1,577 (78.4)	3.1 (1.7)	1,499 (74.5)	3.4 (1.6)

Table 21
Responses across Regions

Services/Supports	Central (n=427)				North (n=427)				South (n=571)				West (n=485)				Overall (n=2012)			
	Current		Future		Current		Future		Current		Future		Current		Future		Current		Future	
	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)
Planning for transition from work to retirement	324 (75.9)	1.7 (1.3)	322 (75.4)	2.2 (1.6)	337 (78.9)	2.1 (1.6)	307 (71.9)	2.4 (1.7)	454 (79.5)	1.7 (1.3)	434 (76.0)	1.9 (1.5)	370 (76.3)	1.6 (1.3)	368 (75.9)	1.8 (1.5)	1,485 (73.8)	1.8 (1.4)	1,431 (71.1)	2.1 (1.6)
Financial management	352 (82.4)	3.0 (1.7)	339 (79.4)	3.3 (1.6)	349 (81.7)	3.0 (1.6)	326 (76.3)	3.3 (1.6)	479 (83.9)	2.8 (1.7)	456 (79.9)	3.1 (1.7)	397 (81.9)	2.6 (1.7)	391 (80.6)	3.0 (1.7)	1,577 (78.4)	2.8 (1.7)	1,512 (75.1)	3.2 (1.7)
Independent living skills training	356 (83.4)	3.2 (1.6)	341 (79.9)	3.5 (1.5)	351 (82.2)	3.1 (1.7)	329 (77)	3.5 (1.6)	488 (85.5)	3.1 (1.6)	464 (81.3)	3.4 (1.6)	404 (83.3)	3.1 (1.7)	394 (81.2)	3.6 (1.6)	1,599 (79.5)	3.1 (1.6)	1,528 (75.9)	3.5 (1.6)
Retirement supports	331 (77.5)	1.8 (1.4)	323 (75.6)	2.2 (1.6)	333 (78.0)	2.1 (1.6)	314 (73.5)	2.4 (1.7)	458 (80.2)	1.8 (1.4)	439 (76.9)	2.0 (1.5)	372 (76.7)	1.7 (1.4)	367 (75.7)	2.0 (1.5)	1,494 (74.3)	1.8 (1.4)	1,443 (71.7)	2.1 (1.6)
Family																				
Occasional out-of-home support	350 (82.0)	3.1 (1.7)	321 (75.2)	3.3 (1.6)	363 (85.0)	3.2 (1.7)	333 (78.0)	3.4 (1.6)	478 (83.7)	2.8 (1.7)	454 (79.5)	3.0 (1.7)	409 (84.3)	3.0 (1.7)	397 (81.9)	3.2 (1.7)	1,600 (79.5)	3.0 (1.7)	1,505 (74.8)	3.2 (1.7)
Occasional in-home support	343 (80.3)	3.1 (1.7)	315 (73.8)	3.3 (1.7)	360 (84.3)	3.2 (1.7)	330 (77.3)	3.4 (1.7)	484 (84.8)	2.9 (1.7)	458 (80.2)	3.0 (1.7)	405 (83.5)	3.1 (1.7)	390 (80.4)	3.3 (1.7)	1,592 (79.1)	3.0 (1.7)	1,493 (74.2)	3.2 (1.7)
Personal care assistance	343 (80.3)	3.0 (1.7)	320 (74.9)	3.3 (1.7)	358 (83.8)	3.1 (1.7)	331 (77.5)	3.2 (1.7)	470 (82.3)	2.4 (1.6)	444 (77.8)	2.7 (1.7)	398 (82.1)	2.4 (1.7)	387 (79.8)	2.8 (1.7)	1,569 (78.0)	2.7 (1.7)	1,482 (73.7)	3 (1.7)
Family/individual short-term counseling	337 (78.9)	2.5 (1.5)	306 (71.7)	2.6 (1.6)	347 (81.3)	2.6 (1.6)	318 (74.5)	2.7 (1.6)	472 (82.7)	2.2 (1.4)	443 (77.6)	2.3 (1.4)	399 (82.3)	2.2 (1.5)	378 (77.9)	2.3 (1.5)	1,555 (77.3)	2.4 (1.5)	1,445 (71.8)	2.5 (1.5)
Parenting skills training	331 (77.5)	2.0 (1.4)	301 (70.5)	2.1 (1.5)	344 (80.6)	2.1 (1.5)	314 (73.5)	2.2 (1.6)	460 (80.6)	1.8 (1.3)	432 (75.7)	1.9 (1.4)	391 (80.6)	1.8 (1.3)	375 (77.3)	1.8 (1.3)	1,526 (75.8)	1.9 (1.4)	1,422 (70.7)	2.0 (1.4)
Behavioral supports	341 (79.9)	3.0 (1.6)	315 (73.8)	3.0 (1.6)	354 (82.9)	2.9 (1.6)	324 (75.9)	3.0 (1.7)	472 (82.7)	2.6 (1.6)	442 (77.4)	2.7 (1.6)	406 (83.7)	2.7 (1.6)	386 (79.6)	2.7 (1.6)	1,573 (78.2)	2.8 (1.6)	1,467 (72.9)	2.8 (1.6)
Adaptive equipment for health and safety	341 (79.9)	2.5 (1.7)	319 (74.7)	2.7 (1.7)	358 (83.8)	2.7 (1.7)	323 (75.6)	2.9 (1.7)	462 (80.9)	2.2 (1.6)	440 (77.1)	2.4 (1.7)	395 (81.4)	2.0 (1.5)	376 (77.5)	2.2 (1.6)	1,556 (77.3)	2.3 (1.6)	1,458 (72.5)	2.5 (1.7)
Before or after school care	324 (75.9)	2.2 (1.7)	298 (69.8)	2.2 (1.6)	339 (79.4)	2.3 (1.7)	312 (73.1)	2.3 (1.7)	458 (80.2)	1.9 (1.4)	431 (75.5)	2.1 (1.6)	388 (80.0)	2.0 (1.6)	364 (75.1)	2.0 (1.6)	1,509 (75.0)	2.1 (1.6)	1,405 (69.8)	2.1 (1.6)
Assistive technology	332 (77.8)	2.6 (1.7)	308 (72.1)	2.7 (1.7)	346 (81.0)	2.7 (1.7)	322 (75.4)	2.8 (1.7)	468 (82.0)	2.4 (1.6)	437 (76.5)	2.5 (1.7)	392 (80.8)	2.2 (1.6)	372 (76.7)	2.3 (1.6)	1,538 (76.4)	2.4 (1.6)	1,439 (71.5)	2.6 (1.7)
Socialization / Wellness																				
Healthy relationship training	350 (82.0)	3.3 (1.6)	327 (76.6)	3.4 (1.5)	352 (82.4)	3.4 (1.5)	332 (77.8)	3.6 (1.5)	478 (83.7)	3.2 (1.5)	454 (79.5)	3.4 (1.5)	406 (83.7)	3.2 (1.5)	391 (80.6)	3.4 (1.5)	1,586 (78.8)	3.3 (1.5)	1,504 (74.8)	3.4 (1.5)
Social skills training	351 (82.2)	3.5 (1.4)	326 (76.3)	3.6 (1.4)	359 (84.1)	3.6 (1.5)	334 (78.2)	3.7 (1.5)	492 (86.2)	3.5 (1.4)	457 (80.0)	3.6 (1.4)	409 (84.3)	3.5 (1.5)	394 (81.2)	3.6 (1.5)	1,611 (80.1)	3.5 (1.5)	1,511 (75.1)	3.6 (1.4)
Summer recreation	340 (79.6)	3.2 (1.7)	313 (73.3)	3.2 (1.6)	343 (80.3)	3.0 (1.6)	326 (76.3)	3.2 (1.6)	477 (83.5)	2.9 (1.6)	451 (79)	3.0 (1.7)	400 (82.5)	3.0 (1.7)	383 (79.0)	3.1 (1.7)	1,560 (77.5)	3.0 (1.6)	1,473 (73.2)	3.1 (1.6)
Community membership in organizations or clubs	350 (82.0)	3.1 (1.5)	325 (76.1)	3.3 (1.5)	347 (81.3)	3.0 (1.6)	328 (76.8)	3.2 (1.6)	486 (85.1)	2.9 (1.5)	456 (79.9)	3.2 (1.5)	403 (83.1)	3.1 (1.5)	392 (80.8)	3.2 (1.5)	1,586 (78.8)	3.0 (1.5)	1,501 (74.6)	3.2 (1.5)
Parks and recreation activities	351 (82.2)	3.3 (1.4)	323 (75.6)	3.4 (1.4)	353 (82.7)	3.3 (1.4)	332 (77.8)	3.4 (1.5)	474 (83.0)	3.0 (1.5)	449 (78.6)	3.2 (1.5)	402 (82.9)	3.1 (1.5)	391 (80.6)	3.2 (1.5)	1,580 (78.5)	3.2 (1.5)	1,495 (74.3)	3.3 (1.5)
Fitness/wellness activities	353 (82.7)	3.5 (1.4)	325 (76.1)	3.6 (1.4)	358 (83.8)	3.5 (1.4)	336 (78.7)	3.6 (1.4)	487 (85.3)	3.3 (1.4)	462 (80.9)	3.5 (1.4)	407 (83.9)	3.4 (1.4)	390 (80.4)	3.5 (1.4)	1,605 (79.8)	3.4 (1.4)	1,513 (75.2)	3.5 (1.4)

Table 21
Responses across Regions

Services/Supports	Central (n=427)				North (n=427)				South (n=571)				West (n=485)				Overall (n=2012)			
	Current		Future		Current		Future		Current		Future		Current		Future		Current		Future	
	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)
Disability specific activities	341 (79.9)	3.1 (1.5)	313 (73.3)	3.1 (1.5)	344 (80.6)	3.3 (1.5)	323 (75.6)	3.4 (1.6)	467 (81.8)	2.9 (1.5)	443 (77.6)	3.1 (1.6)	392 (80.8)	2.7 (1.5)	374 (77.1)	2.9 (1.6)	1,544 (76.7)	3.0 (1.5)	1,453 (72.2)	3.1 (1.6)
Self-advocacy and self-determination	344 (80.6)	3.5 (1.5)	319 (74.7)	3.6 (1.5)	347 (81.3)	3.4 (1.5)	329 (77.0)	3.5 (1.5)	483 (84.6)	3.3 (1.5)	455 (79.7)	3.5 (1.5)	399 (82.3)	3.3 (1.6)	392 (80.8)	3.4 (1.6)	1,573 (78.2)	3.4 (1.5)	1,495 (74.3)	3.5 (1.5)

Note. Percentages were calculated excluding missing responses; Mean = average importance ratings; SD = standard deviation, indicating the extent to which the importance rating spread out from the mean.

Global Responses across Organizations

The last comparison that we conducted was between the organizations that provided supports and services to the respondents to the survey. This included those who received services from: 1) PLB only, 2) Department of Mental Health (DMH) only, 3) Special School District (SSD), and 4) PLB and DMH. Table 22 below has two columns (PLB All and DMH ALL) that incorporate the responses from people who receive services from both PLB and DMH.

Employment

Respondents who receive supports and services from each of the groups agreed that “Working with supports in the community” was the most important future employment support. “Working in a sheltered workshop” was more important for those who received services from PLB only than for any other group. The respondents who received services from SSD valued “Working in summer employment” more than any of the other groups.

Living Options

“Living with parents/family” was the most important current and future support in the Living Options domain. For each group, it was more important as a current option than as a future option. Interestingly, while it was the most important living option for those who received services from DMH only, this group of respondents rated it significantly lower than any other group. The “Living with parents/family” was the only living option that received a ranking of “Moderately Important” or above. For those who received services from PLB only and DMH only, this option was “Very Important” as both a current and future need.

Life Transitions

“Planning for transition from school to work/adult life” was the most important transition support identified by the respondents from SSD. It was significantly less important for those

who received supports from PLB and DMH. Each of the groups indicated that “Support with a meaningful day activity” was an important future need. It was, however, less important to people who received services from PLB only than for the other groups. “Independent living skills training” was also an important future need for all groups. Again, those who received services from PLB only rated it slightly lower than the other groups. Finally, all of the groups agreed that “Financial management” was an important future need.

Family

Within the Family domain, the supports that provided “Occasional in-home support” and “Occasional out-of-home support” were important current and future needs for those who received supports from PLB only and SSD. For those who received support from DMH only, the most important future support was “Personal care assistance.” Lastly, “Behavior supports” were much more important for those who received supports from SSD than any of the other groups.

Socialization/Wellness

All of the services and supports included in the Socialization/Wellness domain were considered “Moderately Important” or higher future needs. This was particularly true for those who received services from SSD. This group rated every item in this domain more highly than the other groups. “Social skills training” was the most important current and future service for all of the groups. The respondents from SSD indicated that it was “Very Important” overall. “Fitness/wellness activities” and “Self-advocacy and self-determination” were the second most important services and supports for the respondents from each organization.

Table 22
Responses across Organizations

Services/Supports	PLB Only (n=171)				DMH Only (n=453)				SSD (n=438)				PLB All (n=1054)				DMH All (n=1336)				Overall (n=2012)			
	Current		Future		Current		Future		Current		Future		Current		Future		Current		Future		Current		Future	
	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)
Employment																								
Working with supports in the community	147 (86.0)	2.9 (1.5)	142 (83.0)	3.4 (1.5)	399 (88.1)	3.0 (1.6)	380 (83.9)	3.4 (1.5)	387 (88.4)	2.8 (1.7)	389 (88.8)	3.5 (1.6)	913 (86.6)	3.1 (1.6)	863 (81.9)	3.4 (1.6)	1,165 (87.2)	3.1 (1.6)	1,101 (82.4)	3.4 (1.6)	1,730 (86.0)	3.0 (1.6)	1,660 (82.5)	3.4 (1.6)
Working without supports in the community	141 (82.5)	2.3 (1.5)	136 (79.5)	2.8 (1.6)	380 (83.9)	2.4 (1.5)	345 (76.2)	2.9 (1.7)	370 (84.5)	2.1 (1.4)	364 (83.1)	2.9 (1.6)	819 (77.7)	2.1 (1.4)	775 (73.5)	2.5 (1.6)	1,058 (79.2)	2.2 (1.5)	984 (73.7)	2.6 (1.6)	1,598 (79.4)	2.2 (1.5)	1,510 (75.0)	2.7 (1.6)
Working in a sheltered workshop	145 (84.8)	2.4 (1.7)	141 (82.5)	2.8 (1.7)	384 (84.8)	2.0 (1.5)	354 (78.1)	2.3 (1.6)	368 (84.0)	1.9 (1.3)	367 (83.8)	2.5 (1.6)	901 (85.5)	2.5 (1.7)	844 (80.1)	2.7 (1.7)	1,140 (85.3)	2.3 (1.7)	1057 (79.1)	2.6 (1.7)	1,686 (83.8)	2.2 (1.6)	1,595 (79.3)	2.6 (1.7)
Working in summer employment	138 (80.7)	2.2 (1.6)	134 (78.4)	2.9 (1.7)	378 (83.4)	2.2 (1.5)	353 (77.9)	2.5 (1.7)	374 (85.4)	2.4 (1.6)	377 (86.1)	3.2 (1.6)	833 (79.0)	2.1 (1.6)	769 (73.0)	2.5 (1.7)	1,073 (80.3)	2.1 (1.6)	988 (74.0)	2.5 (1.7)	1,614 (80.2)	2.2 (1.6)	1,525 (75.8)	2.7 (1.7)
Living Options																								
Living with parents/family	152 (88.9)	4.4 (1.2)	132 (77.2)	4.0 (1.3)	405 (89.4)	3.8 (1.5)	372 (82.1)	3.5 (1.6)	408 (93.2)	4.6 (0.9)	370 (84.5)	4.2 (1.2)	941 (89.3)	4.1 (1.4)	855 (81.1)	3.7 (1.5)	1,194 (89.4)	4.0 (1.5)	1,095 (82.0)	3.6 (1.6)	1,780 (88.5)	4.2 (1.4)	1,624 (80.7)	3.8 (1.5)
Living in a 24-hour supervised residential setting	136 (79.5)	1.7 (1.3)	122 (71.3)	2.2 (1.6)	363 (80.1)	2.2 (1.7)	346 (76.4)	2.6 (1.7)	350 (79.9)	1.7 (1.3)	337 (76.9)	2.3 (1.6)	833 (79.0)	2.0 (1.5)	811 (76.9)	2.6 (1.7)	1,060 (79.3)	2.1 (1.6)	1,035 (77.5)	2.7 (1.7)	1,574 (78.2)	2.0 (1.5)	1,522 (75.6)	2.5 (1.7)
Living independently in the community with supports 0 to 20 hours each week	132 (77.2)	1.9 (1.4)	116 (67.8)	2.4 (1.6)	348 (76.8)	2.1 (1.5)	334 (73.7)	2.5 (1.7)	340 (77.6)	1.7 (1.3)	339 (77.4)	2.4 (1.5)	797 (75.6)	2.2 (1.6)	768 (72.9)	2.7 (1.7)	1,013 (75.8)	2.2 (1.6)	986 (73.8)	2.7 (1.7)	1,511 (75.1)	2.1 (1.5)	1,467 (72.9)	2.6 (1.7)
Living independently in the community with supports 20 to 50 hours each week	128 (74.9)	1.8 (1.3)	116 (67.8)	2.2 (1.5)	342 (75.5)	1.9 (1.4)	327 (72.2)	2.3 (1.6)	338 (77.2)	1.6 (1.2)	342 (78.1)	2.3 (1.6)	770 (73.1)	1.8 (1.4)	749 (71.1)	2.3 (1.6)	984 (73.7)	1.9 (1.4)	960 (71.9)	2.3 (1.6)	1,475 (73.3)	1.8 (1.4)	1,443 (71.7)	2.3 (1.6)
Living independently in the community with supports over 50 hours each week	127 (74.3)	1.7 (1.3)	114 (66.7)	2.1 (1.5)	342 (75.5)	2.0 (1.5)	330 (72.8)	2.3 (1.6)	335 (76.5)	1.7 (1.3)	343 (78.3)	2.4 (1.6)	770 (73.1)	1.7 (1.3)	751 (71.3)	2.3 (1.6)	985 (73.7)	1.8 (1.4)	967 (72.4)	2.3 (1.6)	1,472 (73.2)	1.8 (1.4)	1,449 (72.0)	2.3 (1.6)
Living independently in the community without support	129 (75.4)	1.8 (1.4)	120 (70.2)	2.3 (1.6)	342 (75.5)	2.0 (1.5)	330 (72.8)	2.5 (1.7)	335 (76.5)	1.6 (1.3)	341 (77.9)	2.3 (1.6)	757 (71.8)	1.7 (1.3)	731 (69.4)	2.1 (1.5)	970 (72.6)	1.8 (1.4)	941 (70.4)	2.2 (1.6)	1,459 (72.5)	1.7 (1.4)	1,427 (70.9)	2.2 (1.6)
Life Transitions																								
Adult education	136 (79.5)	1.9 (1.5)	119 (69.6)	2.6 (1.7)	362 (79.9)	2.1 (1.5)	344 (75.9)	2.4 (1.7)	356 (81.3)	2.1 (1.5)	338 (77.2)	2.8 (1.8)	859 (81.5)	1.9 (1.4)	788 (74.8)	2.2 (1.6)	1,085 (81.2)	2.0 (1.5)	1,013 (75.8)	2.2 (1.6)	1,604 (79.7)	2.0 (1.5)	1,495 (74.3)	2.4 (1.6)
Support to volunteer in the community	136 (79.5)	2.2 (1.5)	121 (70.8)	2.6 (1.6)	365 (80.6)	2.3 (1.4)	345 (76.2)	2.7 (1.5)	347 (79.2)	2.3 (1.5)	344 (78.5)	2.9 (1.6)	868 (82.4)	2.4 (1.5)	803 (76.2)	2.6 (1.6)	1,097 (82.1)	2.4 (1.5)	1,027 (76.9)	2.6 (1.5)	1,608 (79.9)	2.4 (1.5)	1,518 (75.4)	2.7 (1.6)
Pre-employment training	139 (81.3)	2.5 (1.7)	123 (71.9)	3.0 (1.6)	367 (81.0)	2.5 (1.6)	349 (77.0)	2.8 (1.6)	348 (79.5)	2.7 (1.7)	351 (80.1)	3.4 (1.7)	842 (79.9)	2.4 (1.7)	775 (73.5)	2.7 (1.7)	1,070 (80.1)	2.4 (1.6)	1,001 (74.9)	2.7 (1.7)	1,584 (78.7)	2.5 (1.7)	1,500 (74.6)	2.9 (1.7)

Table 22
Responses across Organizations

Services/Supports	PLB Only (n=171)				DMH Only (n=453)				SSD (n=438)				PLB All (n=1054)				DMH All (n=1336)				Overall (n=2012)			
	Current		Future		Current		Future		Current		Future		Current		Future		Current		Future		Current		Future	
	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)
Planning for transition from school to work/adult life	138 (80.7)	2.3 (1.6)	118 (69.0)	2.9 (1.8)	352 (77.7)	2.4 (1.6)	340 (75.1)	2.8 (1.8)	356 (81.3)	3.0 (1.7)	358 (81.7)	3.6 (1.7)	828 (78.6)	2.2 (1.7)	756 (71.7)	2.4 (1.7)	1,042 (78.0)	2.2 (1.7)	978 (73.2)	2.5 (1.8)	1,563 (77.7)	2.4 (1.7)	1,479 (73.5)	2.8 (1.8)
Support with a meaningful day activity	137 (80.1)	2.7 (1.7)	122 (71.3)	3.1 (1.7)	377 (83.2)	3.2 (1.6)	361 (79.7)	3.5 (1.6)	358 (81.7)	3.0 (1.7)	351 (80.1)	3.4 (1.7)	859 (81.5)	3.0 (1.7)	805 (76.4)	3.3 (1.6)	1,099 (82.3)	3.1 (1.7)	1,044 (78.1)	3.4 (1.6)	1,623 (80.7)	3.1 (1.7)	1,543 (76.7)	3.4 (1.6)
Planning for transition from work to retirement	132 (77.2)	1.9 (1.5)	123 (71.9)	2.4 (1.7)	347 (76.6)	1.8 (1.4)	336 (74.2)	2.2 (1.6)	335 (76.5)	1.6 (1.3)	341 (77.9)	2.0 (1.6)	820 (77.8)	1.8 (1.4)	773 (73.3)	2.1 (1.5)	1,035 (77.5)	1.8 (1.4)	986 (73.8)	2.1 (1.5)	1,528 (75.9)	1.8 (1.4)	1,473 (73.2)	2.1 (1.6)
Financial management	139 (81.3)	2.6 (1.6)	127 (74.3)	3.1 (1.7)	377 (83.2)	2.9 (1.7)	366 (80.8)	3.3 (1.7)	349 (79.7)	2.7 (1.7)	353 (80.6)	3.2 (1.7)	865 (82.1)	2.8 (1.6)	812 (77.0)	3.1 (1.7)	1,103 (82.6)	2.9 (1.7)	1,051 (78.7)	3.2 (1.7)	1,619 (80.5)	2.8 (1.7)	1,555 (77.3)	3.2 (1.7)
Independent living skills training	142 (83)	2.8 (1.7)	127 (74.3)	3.3 (1.7)	376 (83)	3.1 (1.6)	363 (80.1)	3.4 (1.6)	359 (82.0)	2.9 (1.7)	358 (81.7)	3.5 (1.6)	883 (83.8)	3.2 (1.6)	827 (78.5)	3.5 (1.6)	1,117 (83.6)	3.2 (1.6)	1,063 (79.6)	3.5 (1.6)	1,645 (81.8)	3.1 (1.6)	1,572 (78.1)	3.5 (1.6)
Retirement supports	132 (77.2)	1.8 (1.4)	121 (70.8)	2.2 (1.6)	353 (77.9)	2.0 (1.5)	344 (75.9)	2.2 (1.6)	336 (76.7)	1.6 (1.3)	335 (76.5)	2.0 (1.6)	821 (77.9)	1.9 (1.4)	783 (74.3)	2.1 (1.6)	1,042 (78.0)	1.9 (1.5)	1,006 (75.3)	2.2 (1.6)	1,537 (76.4)	1.8 (1.4)	1,485 (73.8)	2.1 (1.6)
Family																								
Occasional out-of-home support	139 (81.3)	3.1 (1.7)	133 (77.8)	3.3 (1.7)	379 (83.7)	2.7 (1.6)	359 (79.2)	2.9 (1.7)	370 (84.5)	3.1 (1.7)	347 (79.2)	3.3 (1.7)	878 (83.3)	3.1 (1.7)	817 (77.5)	3.3 (1.7)	1,118 (83.7)	3.0 (1.7)	1,043 (78.1)	3.2 (1.7)	1,652 (82.1)	3.0 (1.7)	1,549 (77)	3.2 (1.7)
Occasional in-home support	137 (80.1)	3.3 (1.7)	127 (74.3)	3.4 (1.7)	374 (82.6)	2.6 (1.6)	354 (78.1)	2.9 (1.7)	368 (84)	3.1 (1.7)	346 (79.0)	3.2 (1.7)	877 (83.2)	3.2 (1.7)	814 (77.2)	3.4 (1.7)	1,114 (83.4)	3.0 (1.7)	1,041 (77.9)	3.2 (1.7)	1,645 (81.8)	3.0 (1.7)	1,539 (76.5)	3.2 (1.7)
Personal care assistance	132 (77.2)	2.5 (1.7)	123 (71.9)	2.8 (1.6)	374 (82.6)	2.8 (1.7)	349 (77.0)	3.1 (1.7)	363 (82.9)	2.5 (1.7)	342 (78.1)	2.9 (1.7)	860 (81.6)	2.7 (1.7)	810 (76.9)	2.9 (1.7)	1,102 (82.5)	2.8 (1.7)	1,036 (77.5)	3.0 (1.7)	1,622 (80.6)	2.7 (1.7)	1,526 (75.8)	3 (1.7)
Family/individual short-term counseling	138 (80.7)	2.3 (1.6)	126 (73.7)	2.6 (1.6)	368 (81.2)	2.4 (1.5)	344 (75.9)	2.5 (1.5)	363 (82.9)	2.6 (1.5)	338 (77.2)	2.7 (1.5)	852 (80.8)	2.3 (1.5)	783 (74.3)	2.4 (1.5)	1,082 (81.0)	2.3 (1.5)	1,001 (74.9)	2.4 (1.5)	1,608 (79.9)	2.4 (1.5)	1,489 (74.0)	2.5 (1.5)
Parenting skills training	135 (78.9)	2.1 (1.5)	125 (73.1)	2.2 (1.6)	361 (79.7)	1.9 (1.3)	339 (74.8)	2.0 (1.4)	364 (83.1)	2.4 (1.5)	339 (77.4)	2.5 (1.5)	828 (78.6)	1.7 (1.3)	762 (72.3)	1.8 (1.4)	1,054 (78.9)	1.7 (1.3)	976 (73.1)	1.8 (1.3)	1,578 (78.4)	1.9 (1.4)	1,465 (72.8)	2.0 (1.4)
Behavioral supports	137 (80.1)	2.7 (1.6)	126 (73.7)	2.8 (1.6)	368 (81.2)	2.7 (1.6)	344 (75.9)	2.8 (1.6)	370 (84.5)	3.3 (1.6)	347 (79.2)	3.2 (1.6)	863 (81.9)	2.6 (1.6)	795 (75.4)	2.6 (1.6)	1,094 (81.9)	2.6 (1.6)	1,013 (75.8)	2.7 (1.7)	1,627 (80.9)	2.8 (1.6)	1,512 (75.1)	2.8 (1.6)
Adaptive equipment for health and safety	133 (77.8)	2.1 (1.5)	123 (71.9)	2.3 (1.6)	371 (81.9)	2.6 (1.7)	344 (75.9)	2.7 (1.7)	360 (82.2)	2.4 (1.7)	336 (76.7)	2.6 (1.7)	850 (80.6)	2.2 (1.6)	796 (75.5)	2.4 (1.7)	1,088 (81.4)	2.3 (1.6)	1,017 (76.1)	2.5 (1.7)	1,607 (79.9)	2.3 (1.6)	1,502 (74.7)	2.5 (1.7)
Before or after school care	134 (78.4)	2.3 (1.7)	124 (72.5)	2.5 (1.7)	357 (78.8)	1.9 (1.4)	333 (73.5)	1.9 (1.5)	364 (83.1)	2.7 (1.7)	338 (77.2)	2.8 (1.7)	812 (77.0)	1.9 (1.5)	751 (71.3)	2.0 (1.6)	1,035 (77.5)	1.8 (1.5)	960 (71.9)	1.9 (1.5)	1,558 (77.4)	2.1 (1.6)	1,447 (71.9)	2.1 (1.6)
Assistive technology	134 (78.4)	2.5 (1.6)	124 (72.5)	2.5 (1.7)	362 (79.9)	2.5 (1.7)	342 (75.5)	2.7 (1.7)	364 (83.1)	2.8 (1.7)	338 (77.2)	2.9 (1.7)	834 (79.1)	2.2 (1.6)	775 (73.5)	2.4 (1.7)	1,062 (79.5)	2.3 (1.6)	993 (74.3)	2.4 (1.7)	1,586 (78.8)	2.4 (1.6)	1,481 (73.6)	2.6 (1.7)
Socialization / Wellness																								
Healthy relationship training	136 (79.5)	3.1 (1.6)	128 (74.9)	3.4 (1.5)	376 (83.0)	3.2 (1.5)	360 (79.5)	3.4 (1.5)	364 (83.1)	3.5 (1.5)	346 (79.0)	3.8 (1.4)	873 (82.8)	3.1 (1.6)	819 (77.7)	3.3 (1.5)	1,113 (83.3)	3.2 (1.5)	1,051 (78.7)	3.3 (1.5)	1,639 (81.5)	3.3 (1.5)	1,551 (77.1)	3.4 (1.5)
Social skills training	139 (81.3)	3.6 (1.5)	129 (75.4)	3.7 (1.4)	377 (83.2)	3.4 (1.5)	357 (78.8)	3.5 (1.5)	374 (85.4)	4.0 (1.3)	355 (81.1)	4.1 (1.2)	884 (83.9)	3.4 (1.5)	817 (77.5)	3.5 (1.5)	1,122 (84.0)	3.3 (1.5)	1,045 (78.2)	3.5 (1.5)	1,663 (82.7)	3.5 (1.5)	1,556 (77.3)	3.6 (1.4)
Summer recreation	135 (78.9)	3.0 (1.7)	126 (73.7)	3.1 (1.6)	366 (80.8)	2.7 (1.6)	349 (77.0)	2.8 (1.6)	360 (82.2)	3.6 (1.5)	348 (79.5)	3.6 (1.5)	856 (81.2)	2.9 (1.7)	792 (75.1)	3.0 (1.7)	1,087 (81.4)	2.8 (1.7)	1,015 (76)	2.9 (1.7)	1,609 (80.0)	3.0 (1.6)	1,516 (75.3)	3.1 (1.6)

Table 22
Responses across Organizations

Services/Supports	PLB Only (n=171)				DMH Only (n=453)				SSD (n=438)				PLB All (n=1054)				DMH All (n=1336)				Overall (n=2012)			
	Current		Future		Current		Future		Current		Future		Current		Future		Current		Future		Current		Future	
	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)	n (%)	M(SD)
Community membership in organizations or clubs	138 (80.7)	2.9 (1.5)	126 (73.7)	3.2 (1.5)	373 (82.3)	2.9 (1.5)	360 (79.5)	3.0 (1.5)	366 (83.6)	3.2 (1.5)	347 (79.2)	3.5 (1.4)	873 (82.8)	3.0 (1.5)	817 (77.5)	3.2 (1.5)	1,108 (82.9)	3.0 (1.5)	1,051 (78.7)	3.1 (1.5)	1,638 (81.4)	3.0 (1.5)	1,549 (77.0)	3.2 (1.5)
Parks and recreation activities	135 (78.9)	3.0 (1.5)	127 (74.3)	3.1 (1.4)	377 (83.2)	3.1 (1.5)	357 (78.8)	3.1 (1.5)	367 (83.8)	3.5 (1.4)	349 (79.7)	3.6 (1.4)	862 (81.8)	3.1 (1.5)	808 (76.7)	3.2 (1.5)	1,104 (82.6)	3.1 (1.5)	1,038 (77.7)	3.2 (1.5)	1,633 (81.2)	3.2 (1.5)	1,541 (76.6)	3.3 (1.5)
Fitness/wellness activities	137 (80.1)	3.1 (1.5)	126 (73.7)	3.3 (1.4)	374 (82.6)	3.2 (1.4)	361 (79.7)	3.4 (1.5)	361 (82.4)	3.6 (1.4)	344 (78.5)	3.7 (1.4)	896 (85.0)	3.4 (1.4)	827 (78.5)	3.5 (1.4)	1,133 (84.8)	3.4 (1.4)	1,062 (79.5)	3.5 (1.4)	1,658 (82.4)	3.4 (1.4)	1,559 (77.5)	3.5 (1.4)
Disability specific activities	133 (77.8)	2.8 (1.6)	121 (70.8)	3.0 (1.6)	373 (82.3)	3.0 (1.5)	355 (78.4)	3.2 (1.6)	351 (80.1)	3.2 (1.5)	335 (76.5)	3.3 (1.6)	843 (80.0)	2.8 (1.5)	780 (74.0)	3.0 (1.6)	1,083 (81.1)	2.9 (1.5)	1,014 (75.9)	3.1 (1.6)	15,93 (79.2)	3.0 (1.5)	1,497 (74.4)	3.1 (1.6)
Self-advocacy and self-determination	135 (78.9)	3.2 (1.6)	125 (73.1)	3.4 (1.6)	384 (84.8)	3.4 (1.5)	363 (80.1)	3.5 (1.5)	362 (82.6)	3.7 (1.4)	349 (79.7)	3.9 (1.4)	849 (80.6)	3.2 (1.5)	801 (76.0)	3.3 (1.6)	1,098 (82.2)	3.3 (1.5)	1,039 (77.8)	3.4 (1.6)	1,621 (80.6)	3.4 (1.5)	1,539 (76.5)	3.5 (1.5)

Note. Percentages were calculated excluding missing responses; Mean = average importance ratings; SD = standard deviation, indicating the extent to which the importance rating spread out from the mean.

A Review of other Statewide Data

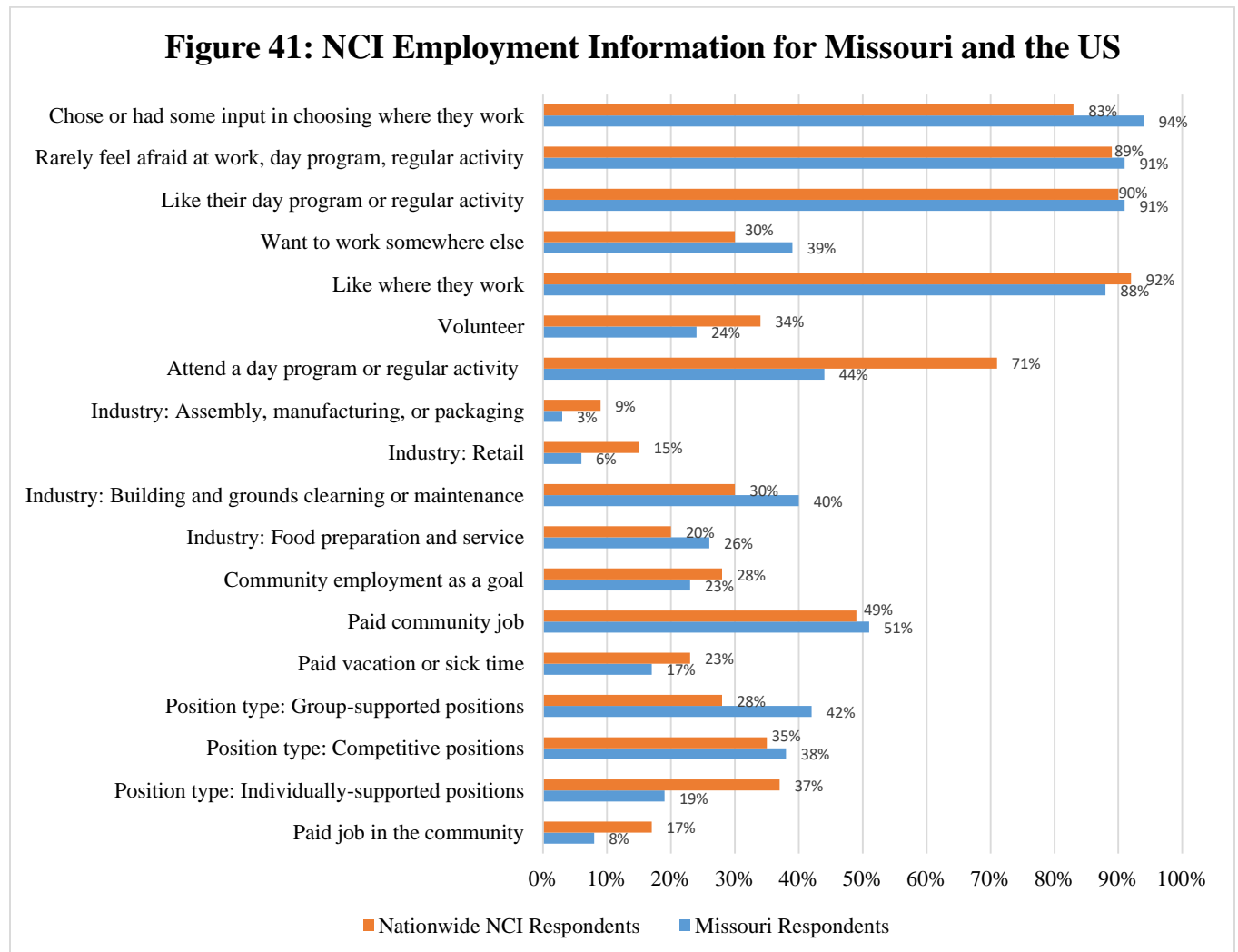
The purpose of this section is to look at other reports detailing the experience of individuals with intellectual and developmental disabilities (IDD) as they relate to the domains on the PLB survey. Information from the National Core Indicators (NCI), Missouri Partnership for Hope (PfH) evaluation, the State of the States in Intellectual and Developmental Disabilities report, and Missouri Support Coordination Capacity and Innovation Project (MOSCCIP) are presented below. We discuss information from these reports within the context of the five domains from the PLB needs assessment survey (see Appendix B).

The National Core Indicators (2016) allowed developmental disabilities agencies to assess their own performance as it relates to “employment, rights, service planning, community inclusion, choice, health, and safety” (p. 7). The Missouri Partnership for Hope evaluation focused on measuring the impact of this innovative Health and Community Based Services Waiver. (Gotto et. al, 2017). The State of the States report is an annual study of trends in spending for IDD long-term care services and supports in the United States (Braddock et. al, 2014). Lastly, the MOSCCIP study was designed to identify the most important aspects of support coordination from the perspective of professionals, family members, and individuals with IDD (Gotto et. al, 2017).

Employment

In 2013, \$6.8 million dollars were spent on supported employment for the 688 participants surveyed for the State of the States report (Braddock et. al, 2014). According to NCI data, 8% of survey respondents from Missouri and 17% across NCI states reported having a paid job in their community (NCI, 2016). With regards to working with or without supports in the community, 19% of respondents from Missouri work in individually-supported positions, 38% in

competitive positions, and 42% in group-supported positions (NCI, 2016). As Figure 41 below demonstrates, Missouri compares favorably to the other states that participate in the annual NCI study.



Data from NCI Adult Consumer Survey Outcomes Missouri Report 2014-2015

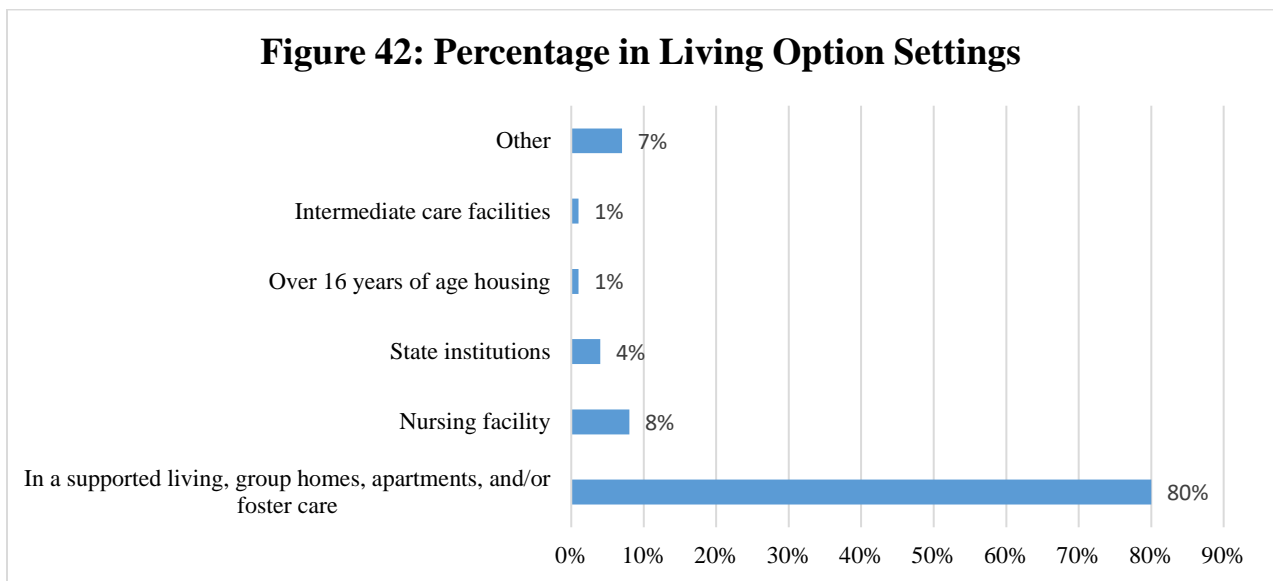
According to the NCI data, the most common job settings for individuals with IDD in Missouri are in food preparation and service oriented positions (26%). The plurality of these positions (40%) are in building and grounds cleaning or maintenance, 6% in retail, and 3% are employed in assembly, manufacturing, or packaging jobs (NCI, 2016). A majority of Missouri respondents (94%) stated they had input regarding where they worked and enjoyed their current

place of employment (NCI, 2016). Over a third (39%) of Missouri respondents reported a desire to work somewhere other than their current place of employment (NCI, 2016).

Regarding attending a day program or regular activity, 44% of respondents from Missouri and 71% across all NCI states reported attending (NCI, 2016). A majority of those polled (91% from Missouri) reported that they like their current day program or regular activity (NCI, 2016). With regards to safety, 91% of respondents from Missouri and 89% across NCI states reported that they never or rarely feel afraid or scared at their work, day program, or regular activity (NCI, 2016).

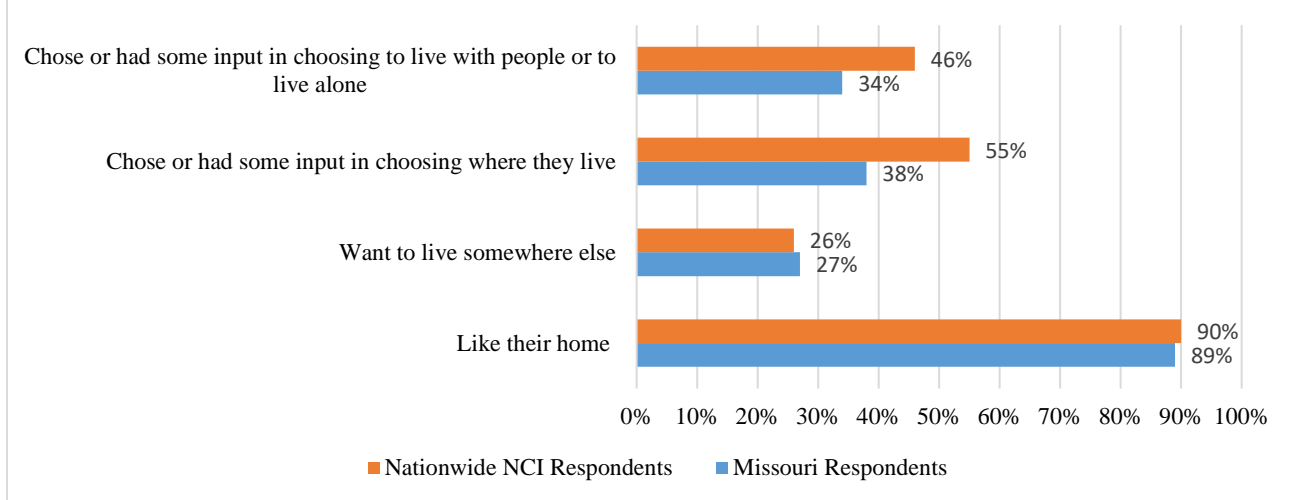
Living Options

The fiscal profile of Missouri shows that in 2013, \$378.9 million were spent on supported living for 7,563 participants (Braddock et. al, 2014). Most of the funding went to supported living, group home, apartment, and/or foster care settings (Braddock et. al, 2014). The rest was split between nursing facilities (8%), state institutions (4%), over 16 years of age housing (1%), intermediate care facilities (<1%), and other locations (7%) (Braddock et. al, 2014).



Data from NCI Adult Consumer Survey Outcomes Missouri Report 2014-2015

Figure 43: Living Options



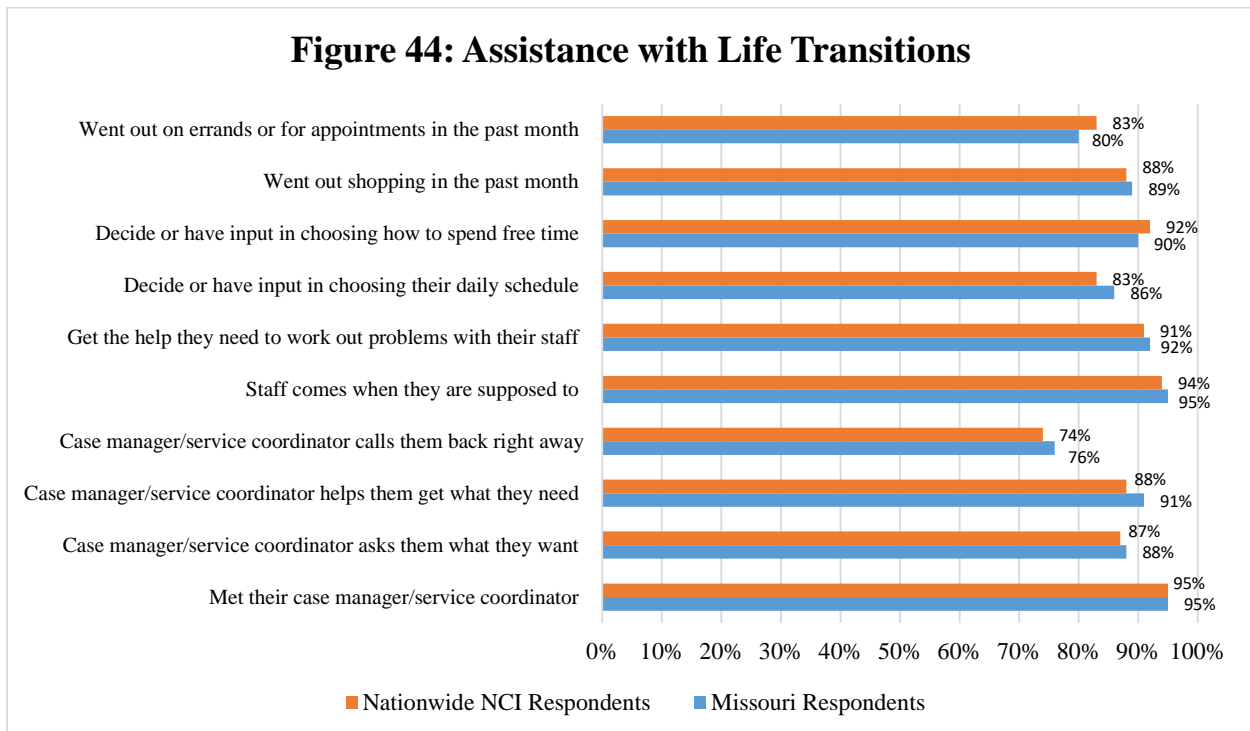
Data from NCI Adult Consumer Survey Outcomes Missouri Report 2014-2015

Per NCI data, 38% of respondents from Missouri and 55% across NCI states reported that they chose or had some input in choosing where they live (NCI, 2016). In Missouri 34% of respondents and 46% across NCI states reported that they chose or had some input in choosing the people with whom they live, or that they chose to live alone (NCI, 2016). The majority of Missouri respondents (89%) and NCI states (90%) reported that they like their home (NCI, 2016). In Missouri, the Partnership for Hope HCBS waiver is one example of a program that helps participants stay in their own home or the family home (Gotto, 2017). The NCI data indicate that 27% of respondents from Missouri and 26% across NCI states reported that they would rather live somewhere other than where they currently live (NCI, 2016).

Life Transitions

The reports summarized in this section do not directly address “Life Transitions.” However, they do touch on policies that can have a positive impact on life transitions. For example, the Partnership for Hope evaluation found that the waiver program provided individuals with IDD and their family support that allowed them to make progress in all areas of their lives. For example, family participants in the evaluation felt the PfH program allowed the

participant to make progress at school or work (Gotto et. al, 2017). This was largely because they were able to access good support coordination. According to NCI data, 95% of respondents from Missouri and 95% across NCI states reported that they met their case manager/service coordinator (NCI, 2016). The majority (88%) of respondents from Missouri reported that their case manager/service coordinator asks them what they want (NCI, 2016). Additionally, 91% of respondents from Missouri reported their case manager/service coordinator helps them get what they need (NCI, 2016). In terms of regular communication, 76 percent of respondents from Missouri reported that if they leave a message, their case manager/service coordinator calls them back right away (NCI, 2016). Respondents from Missouri (95%) reported their direct support staff come when they are supposed to (NCI, 2016). Furthermore, 92% of respondents from Missouri reported that they get the help they need to work out problems with their staff.

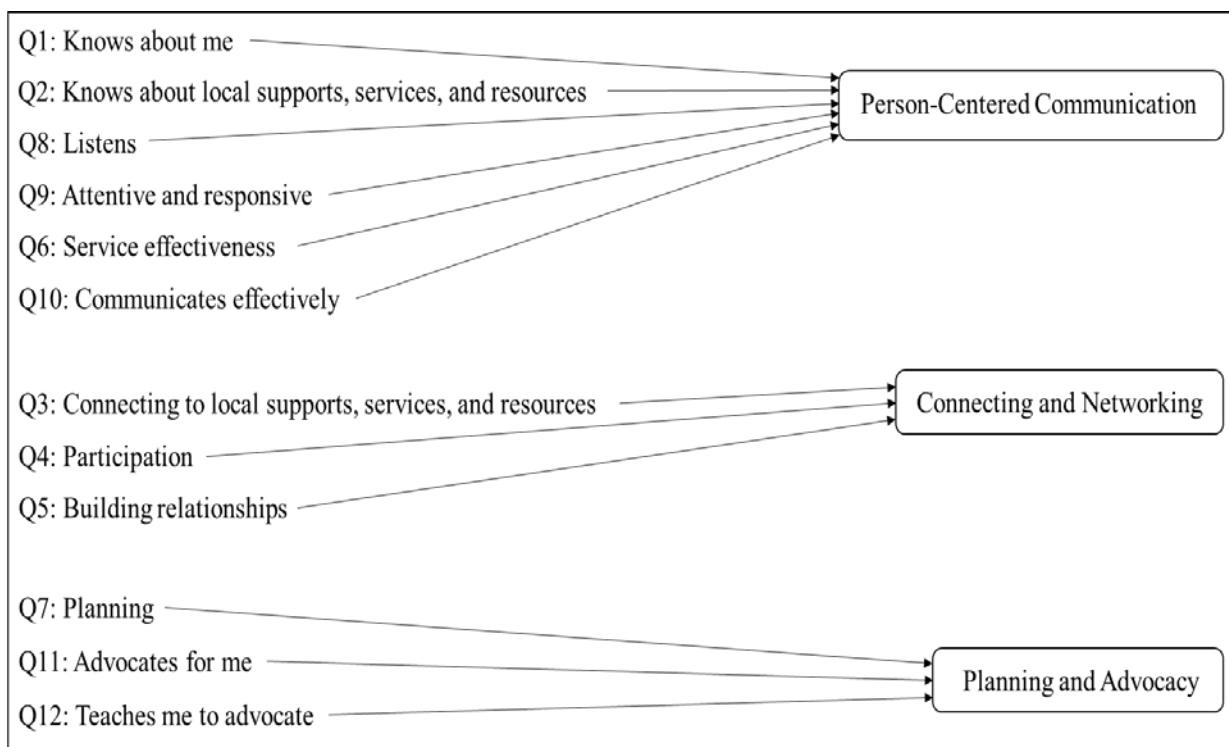


Data from NCI Adult Consumer Survey Outcomes Missouri Report 2014-2015

As Figure 44 above indicates, a majority of the Missouri NCI respondents to the NCI report that they get the services and attention they need in order to transition successfully from

one life stage to the next. The Community Services team at UMKC-IHD recently conducted a statewide survey with families about the most important characteristics in a support coordinator. They identified 12 items which fall into three broad domains (see Figure 45): Person-Centered Communication, Connecting and Networking, and Planning and Advocacy, respectively. Each of these domains and items echo the findings from the PLB needs assessment activities discussed above.

Figure 45. Item level structure



Family

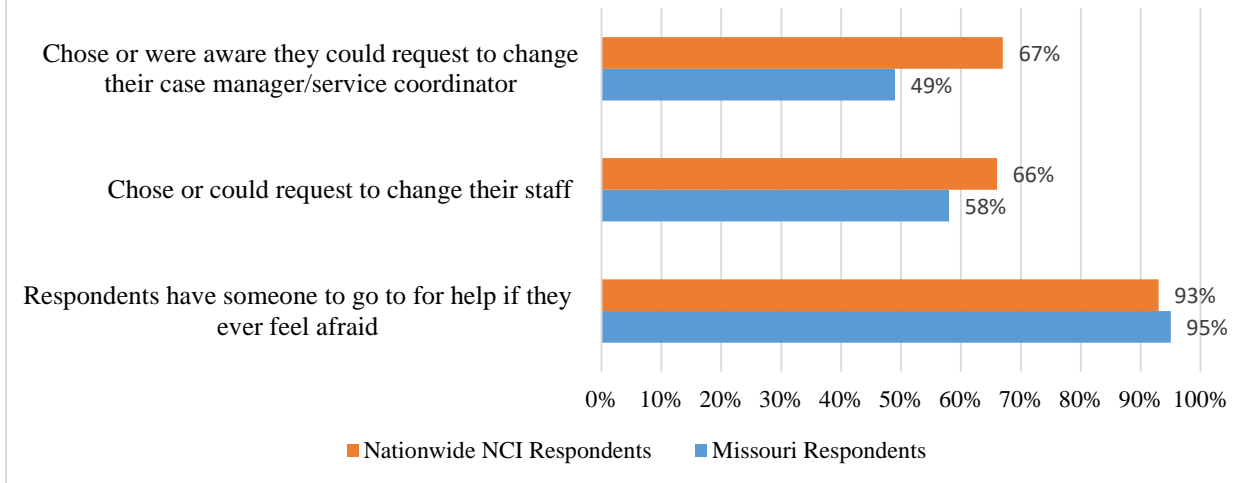
The Missouri PfH waiver program is designed to provide services and supports to individuals with IDD who are approaching a crisis but who, with minimal support, can continue living in their own home or with their families. This is an important outcome given that researchers have found that individuals receiving HCBS waiver services who lived with family members had significantly more positive results in terms of liking where they lived, feeling safer

at home, and experiencing fewer feelings of loneliness than those not living with family members (Stancliffe, et al., 2009). This aligns very well with the results from the PLB needs assessment in which we consistently see how important living in the family home is to individuals with IDD and their family members. Overall, research has consistently shown that living in the community is better for people with IDD than living in institutions (Francis, et al. 2014).

The PfH waiver program supports families and is an example of a policy that helps maintain the family as a system of support, while at the same time promoting community integration and the pursuit of independence for people with DD. Policies such as this are especially important “as the demands for services that support individuals with IDD are increasing, while at the same time both state and federal funds are diminishing” (Hecht, et al., 2011, p. 2). For a small amount of money (\$12,000 annual cap per person) compared to other HCBS waiver options in Missouri, the PfH waiver is helping to relieve the emotional, social, physical, and economic demands experienced by families that include a person with DD. According to the NCI data, in 2013, Missouri paid \$43.1 million for family support for 4,621 participants (Braddock et. al, 2014).

With regards to service providers targeting family based needs, 58 %of the NCI respondents from Missouri and 66% across NCI states reported that they chose to or could request to change their direct support staff (NCI, 2016). In Missouri, 49% of the NCI respondents and 67% across NCI states reported that they chose or were aware they could

Figure 46: Family Supports



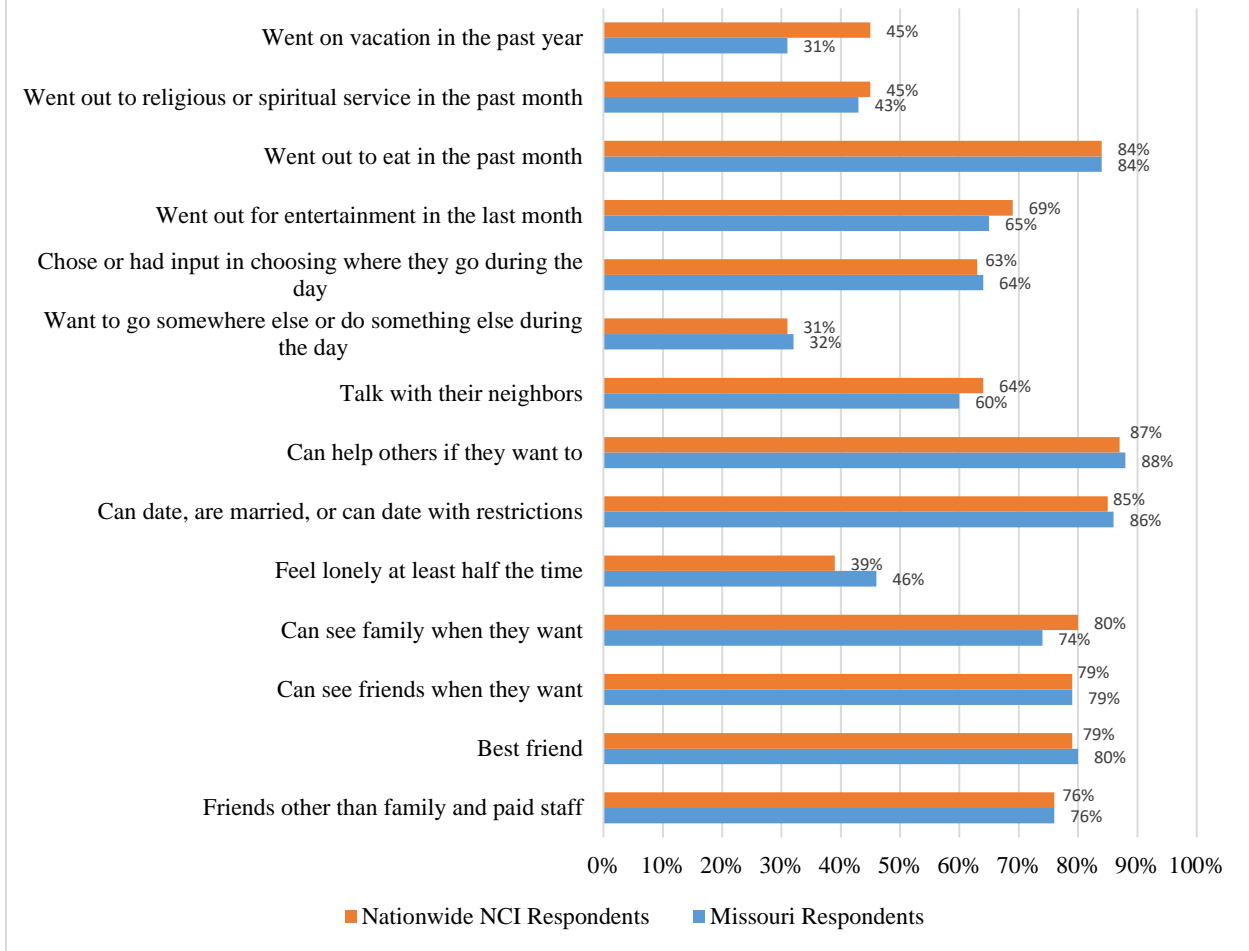
Data from NCI Adult Consumer Survey Outcomes Missouri Report 2014-2015

request to change their case manager/service coordinator (NCI, 2016). The majority of NCI respondents from Missouri (95%) and 93% across NCI states reported that they have someone to go to for help if they ever feel afraid (NCI, 2016).

Socialization

The NCI data demonstrate that 76% of respondents from Missouri reported that they have friends other than family or paid staff (NCI, 2016). Furthermore, 80% of respondents from Missouri reported that they have a best friend (who may be family or paid staff) (NCI, 2016). Over three quarters (79%) of the NCI respondents from Missouri reported that they can see their friends when they want (NCI, 2016). In terms of socializing with their family members, 74% of respondents from Missouri and 80% across NCI states reported that they can see their family when they want (NCI, 2016). With that said, almost half (46%) of respondents from Missouri and 39% across NCI states reported that they feel lonely at least half the time (NCI, 2016).

Figure 47: NCI Socialization Indicators



Data from NCI Adult Consumer Survey Outcomes Missouri Report 2014-2015

The majority of respondents from Missouri (64%) reported that they chose or had some input in choosing where they go during the day (NCI, 2016). During the non-working hours, 65% of respondents from Missouri and 69% across NCI states reported that they went out for entertainment in the past month (NCI, 2016). Respondents from Missouri went out for entertainment an average of 3.2 times in the past month, and respondents across NCI states went an average of 3.7 times (NCI, 2016). A large majority of respondents from Missouri (84%) and other NCI states (84%) respondents reported that they went out to eat in the past month (NCI,

2016). Respondents from Missouri went out to eat an average of 4.1 times in the past month, and respondents across NCI states went an average of 4.5 times (NCI, 2016).

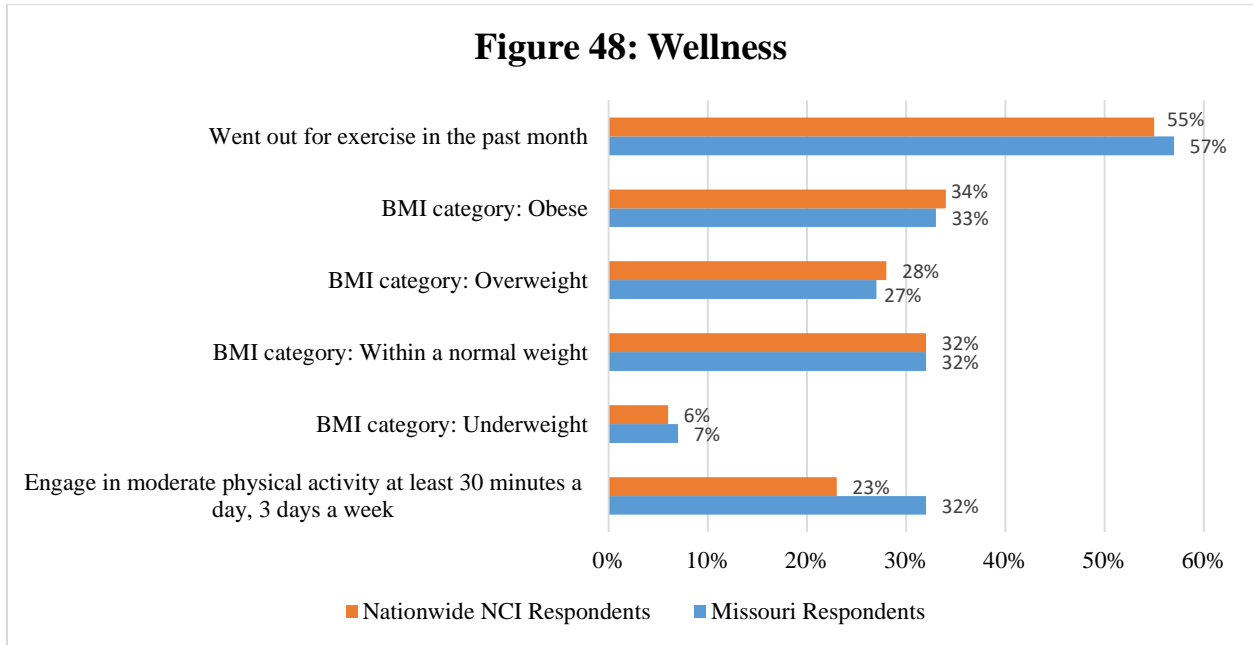
Fewer than half of the NCI respondents from Missouri (43%) and NCI states (45%) reported that they went out to a religious service or spiritual practice in the past month (NCI, 2016). On the other hand respondents from Missouri went out to a religious service or spiritual practice an average of 3.9 times in the past month, and respondents across NCI states went an average of 3.7 times (NCI, 2016). Lastly, in terms of vacation, only 31% of respondents from Missouri and 45% across NCI states reported that they had a vacation in the past year (NCI, 2016). Respondents from Missouri went on vacation an average of 1.5 times in the past year, and respondents across NCI states went an average of 1.8 times (NCI, 2016).

Wellness

Funds associated with the PfH waiver program had an effect on the well-being of the families a few impactful ways. It provide enough stability to allow families to gain access to transportation. The waiver provided additional help toward everyday expenses. This stability has a positive effect on the emotional well-being of the family as a whole. Additional funding alleviates the stress that comes to the financial situation of the family.

When analyzing NCI data regarding the physical well-being of respondents from Missouri and across NCI states, people with IDD polled fall into the following BMI categories, respectively: 7% and 6% underweight, 32% and 32% within a normal weight, 27% and 28% overweight, and 33% and 34% obese (NCI, 2016). 32% of respondents from Missouri, in comparison to an average of 23% across NCI states, reported to engaging in moderate physical activity at least 30 minutes a day three days a week (NCI, 2016). 57% of respondents from Missouri and 55% across NCI states reported that they went out for exercise in the past month

(NCI, 2016). Respondents from Missouri went out for exercise an average of 9.9 times in the past month. Respondents across NCI states went out for exercise an average of 10.5 times in the past month (NCI, 2016)



Data from NCI Adult Consumer Survey Outcomes Missouri Report 2014-2015

Appendix A

CHARTING the life course Life Trajectory Worksheet

Needs for Achieving My Vision



VISION for Next Five Years
Living Options... Accommodations and Access... Transportation

Barriers to Achieving my Visions

What I DON'T Want

Developed by Missouri Family to Family at the UMKC Institute for Human Development, UCEDD

August 2016



Appendix B

A

2017 Consumer Needs Assessment Survey

Thank you for participating in the Productive Living Board's (PLB) 2017 Needs Assessment Survey. This survey provides you with an opportunity to advise the PLB on your current and future need for supports.

Instructions

- 1) Please answer all of the questions on this survey about the individual who receives supports and services. When you have completed the survey, please return it in the enclosed postage paid envelope.
- 2) If you have any questions about this survey, including how to complete the survey, please contact George Gotto at (816)235-5334 or gottog@umkc.edu.
- 3) If you would like to complete the survey online the web address is: <http://bit.ly/plbneeds>

Introductory Questions (Please note: your responses to these questions will only be used for statistical reporting related to this Needs Assessment Survey)

1. Who is completing this survey? (check one box below)
 - I am an individual who receives supports and services.
 - I am completing this survey on behalf of an individual with a disability. My relationship to the individual: _____
2. Race/Ethnicity
 - American Indian or Alaska Native
 - Asian or Pacific Islander
 - Black, not of Hispanic origin
 - Hispanic/Latino
 - White, not of Hispanic origin
 - Other
3. Gender
 - Female
 - Male

4. Primary disability

- Autism
- Intellectual Disability/Metal Retardation
- Learning Disability
- Traumatic Brain Injury (TBI)
- Cerebral Palsy
- Epilepsy
- Other _____

5. Zip code _____

6. Age _____

7. Primary day activity

- Pre-school
- School
- Employed without supports
- Employed with supports
- Employed in a sheltered workshop
- Not employed
- Volunteering in the community
- Day program
- Retired

8. Living arrangement

- With parents/family
- In a group home/supervised residential setting
- Living in an apartment or home with supports
- Independently without supports
- Other: _____

9. Receives Department of Mental Health (DMH) service coordination / case management

- Yes
- No
- I don't know

Current Needs and Future Needs

Using the **Current Needs Table** below, please tell us about your current need for supports.

Using the **Future Needs Table** below, please tell us about your changing need for supports over the next five (5) years.

- Please check the box below the category that indicates how important each support is to you:
- Check the box below either Yes or No to indicate if your need is currently met.

This **example** shows how to complete this form.

How important are the following?	CURRENT NEEDS					Is this need met now?	FUTURE NEEDS (next 5 years)						
	Not Important	Slightly Important	Moderately Important	Very Important	Extremely Important		Not Important	Slightly Important	Moderately Important	Very Important	Extremely Important		
	1	2	3	4	5	<u>Yes</u>	<u>No</u>	<u>NA</u>	1	2	3	4	5
1. Support A	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
2. Support B	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

How important are the following?	CURRENT NEEDS					Is this need met now?			FUTURE NEEDS (next 5 years)				
	Not Important	Slightly Important	Moderately Important	Very Important	Extremely Important				Not Important	Slightly Important	Moderately Important	Very Important	Extremely Important
	1	2	3	4	5	Yes	No	NA	1	2	3	4	5
Employment													
10. Working with supports in the community	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Working without supports in the community	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Working in a sheltered workshop	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Working in summer employment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

14. What are the challenges to getting and keeping employment? (check all that apply)

- Not knowing what I need
- Not knowing what is available
- Service I need is not available
The service I need is: _____
- Service is available, but level of support is insufficient
- Location of service providers

- Cost of service
- Not knowing who to ask about resources
- Quality of service (reliability, consistency)
- Transportation
- Other: _____
- Does not apply

How important are the following?	CURRENT NEEDS					Is this need met now?	FUTURE NEEDS (next 5 years)						
	Not Important	Slightly Important	Moderately Important	Very Important	Extremely Important		Not Important	Slightly Important	Moderately Important	Very Important	Extremely Important		
<u>Living Options</u>	1	2	3	4	5	Yes	No	NA	1	2	3	4	5
15. Living with parents/family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Living in a 24-hour supervised residential setting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Living <i>independently</i> in the community with supports <i>0 to 20 hours</i> each week	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Living <i>independently</i> in the community with supports <i>20 to 50 hours</i> each week	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Living <i>independently</i> in the community with supports <i>over 50 hours</i> each week	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Living <i>independently</i> in the community <i>without</i> support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

21. What are the challenges to obtaining the living options that you need? (check all that apply)

- | | |
|---|--|
| <input type="checkbox"/> Not knowing what I need | <input type="checkbox"/> Cost of service |
| <input type="checkbox"/> Not knowing what is available | <input type="checkbox"/> Not knowing who to ask about resources |
| <input type="checkbox"/> Service I need is not available | <input type="checkbox"/> Quality of service (reliability, consistency) |
| The service I need is: _____ | <input type="checkbox"/> Transportation |
| <input type="checkbox"/> Service is available, but level of support is insufficient | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Location of service providers | <input type="checkbox"/> Does not apply |

How important are the following?	CURRENT NEEDS					Is this need met now?			FUTURE NEEDS (next 5 years)				
	Not Important	Slightly Important	Moderately Important	Very Important	Extremely Important				Not Important	Slightly Important	Moderately Important	Very Important	Extremely Important
<u>Life Transitions</u>	1	2	3	4	5	<u>Yes</u>	<u>No</u>	<u>NA</u>	1	2	3	4	5
22. Adult education (GED/continuing education)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. Support to volunteer in the community	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. Pre-employment training	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. Planning for transition from school to work/adult life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. Support with a meaningful day activity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. Planning for transition from work to retirement	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. Financial management	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. Independent living skills training (grocery shopping, cooking, home management)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. Retirement supports	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

31. What are the challenges to obtaining the life transitions that you need? (check all that apply)

- Not knowing what I need
- Not knowing what is available
- Service I need is not available
The service I need is: _____
- Service is available, but level of support is insufficient
- Location of service providers
- Cost of service
- Not knowing who to ask about resources
- Quality of service (reliability, consistency)
- Transportation
- Other: _____
- Does not apply

How important are the following?	CURRENT NEEDS					Is this need met now?			FUTURE NEEDS (next 5 years)				
	Not Important	Slightly Important	Moderately Important	Very Important	Extremely Important				Not Important	Slightly Important	Moderately Important	Very Important	Extremely Important
Family	1	2	3	4	5	Yes	No	NA	1	2	3	4	5
32. Occasional out-of-home support (respite)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. Occasional in-home support (respite)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. Personal care assistance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. Family/individual short-term counseling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36. Parenting skills training	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. Behavioral supports	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. Adaptive equipment for health and safety	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39. Before or after school care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. Assistive technology	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

41. What are the challenges to obtaining the family supports that you need? (check all that apply)

- | | |
|---|--|
| <input type="checkbox"/> Not knowing what I need | <input type="checkbox"/> Cost of service |
| <input type="checkbox"/> Not knowing what is available | <input type="checkbox"/> Not knowing who to ask about resources |
| <input type="checkbox"/> Service I need is not available | <input type="checkbox"/> Quality of service (reliability, consistency) |
| The service I need is: _____ | <input type="checkbox"/> Transportation |
| <input type="checkbox"/> Service is available, but level of support is insufficient | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Location of service providers | <input type="checkbox"/> Does not apply |

How important are the following?	CURRENT NEEDS					Is this need met now?			FUTURE NEEDS (next 5 years)				
	Not Important	Slightly Important	Moderately Important	Very Important	Extremely Important				Not Important	Slightly Important	Moderately Important	Very Important	Extremely Important
	1	2	3	4	5	Yes	No	NA	1	2	3	4	5
<u>Socialization/Wellness</u>													
42. Healthy relationship training	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
43. Social skills training	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
44. Summer recreation (day/residential camping)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
45. Community membership in organizations or clubs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
46. Parks and recreation activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
47. Fitness/wellness activities or programs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
48. Disability specific activities (eg. People First)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
49. Self-advocacy and self-determination	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

50. What are the challenges to obtaining the socialization/wellness supports that you need? (check all that apply)

- | | |
|---|--|
| <input type="checkbox"/> Not knowing what I need | <input type="checkbox"/> Cost of service |
| <input type="checkbox"/> Not knowing what is available | <input type="checkbox"/> Not knowing who to ask about resources |
| <input type="checkbox"/> Service I need is not available | <input type="checkbox"/> Quality of service (reliability, consistency) |
| The service I need is: _____ | <input type="checkbox"/> Transportation |
| <input type="checkbox"/> Service is available, but level of support is insufficient | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Location of service providers | <input type="checkbox"/> Does not apply |

How important are the following?	CURRENT NEEDS					Is this need met now?			FUTURE NEEDS (next 5 years)				
	Not Important	Slightly Important	Moderately Important	Very Important	Extremely Important				Not Important	Slightly Important	Moderately Important	Very Important	Extremely Important
Please list any other support needs you may have below:	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>	<u>Yes</u>	<u>No</u>	<u>NA</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>
51. _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
52. _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
53. _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

54. What are the challenges to obtaining the other needs that you listed above? (check all that apply)

- Not knowing what I need
- Not knowing what is available
- Service I need is not available
The service I need is: _____
- Service is available, but level of support is insufficient
- Location of service providers
- Cost of service
- Not knowing who to ask about resources
- Quality of service (reliability, consistency)
- Transportation
- Other: _____
- Does not apply

Additional Questions

55. Previously, lack of transportation has been identified as a barrier. What suggestions do you have to address this issue?

56. What other comments do you have about your current or future need for supports?