

Needs Assessment

Prepared For

EITAS

**(Empowering Individuals through Advocacy and Support)
Developmental Disability Services of Jackson County**

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By

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- Amanda George-Executive Director, Metropolitan Council for Developmental Disabilities
- Kathy Marlatt-Service Provider-Kansas City Regional Center (KCRC)
- Richard Enfield-Parent and Community Consultant
- Terry Bigby-Consultant, Kansas City Regional Professional Development Center
- Dynetta Banks-Member of the Disabilities Community
- Bill Anderson-Member of the Disabilities Community
- Jim Johnson-Executive Director, Center for the Developmentally Disabled
- Bill Anderson-EITAS Board Member and Parent
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TABLE OF CONTENTS

	<i>Page</i>
EXECUTIVE SUMMARY	S-1
INTRODUCTION	1
Goals and guiding questions	1
APPROACH	3
Needs assessment advisory board	3
Focus groups	4
Prevalence data	6
Resource inventory	6
Surveys	6
Key informants	7
FINDINGS	10
Prevalence of developmental disabilities in Jackson County	10
Coordination of services	13
Case management	13
Waiver funding	15
Consumer control of services	16
Provider training	16
Employment	17
Housing	20
Transition to adulthood	22
Transition planning	23
Continuing education	25
Other areas of need	27
MRDD services received and waiting lists	29
Respite	30
Transportation	30
Life skills training	31
Information dissemination	31
Services for aging individuals with disabilities	32
Community resources	34
Mapping community agencies and organizations	34
Availability of services	35
Priority areas for improvement	37
RECOMMENDATIONS	38

TABLE OF TABLES

	<i>Page</i>
Table 1. Needs assessment advisory board members	3
Table 2. Schedule and content of advisory board meetings	3
Table 3. Focus group schedule, location, and attendance	5
Table 4. Number of surveys received	7
Table 5. Survey of individuals with disabilities: Demographic information	7
Table 6. Survey of family members of adults with disabilities: Demographic information	8
Table 7. Survey of service providers: Demographic information	8
Table 8. Survey of parents of children with disabilities: Demographic information	9
Table 9. Survey of secondary teachers: Demographic information	9
Table 10. Number of individuals with developmental disabilities in Jackson County, rostered by DMH/MRDD, by diagnosis and by age	12
Table 11. Number and percent of students with developmental disabilities in Jackson County schools during the past decade	12
Table 12. Service coordination provided by the Kansas City Regional Center	13
Table 13. Numbers of Jackson County individuals receiving DMH/MRDD service coordination by diagnosis	15
Table 14. Percent of service providers reporting to be highly or somewhat knowledgeable	16
Table 15. Number of students, ages 15-21 years old, with developmental disabilities in Jackson County Schools in 2007	24
Table 16. Number of students, ages 17-21 years old, with developmental disabilities in Jackson County Schools in 2006	24
Table 17. Number of students, ages 17-21 years old, with developmental disabilities in Jackson County Schools in 2005	24
Table 18. Community agencies/ organizations involved in transition planning	26
Table 19. Key areas of greatest unmet personal needs as reported on surveys	28
Table 20. DMH/MRDD services received by disability diagnosis	29
Table 21. Percent of service providers reporting services and supports need to be more available	35
Table 22. Priority services and supports for improvement (percentage of survey respondents)	37

TABLE OF FIGURES

Figure 1. How many students participate in community based instruction	26
Figure 2. Count of service category by region	35

EXECUTIVE SUMMARY

In November 2006, EITAS contracted with the UMKC Institute for Human Development to conduct a needs assessment. The purpose of this needs assessment was to provide EITAS with information about the current needs of individuals with developmental disabilities, as well as anticipated needs of individuals with developmental disabilities as they age or transition into adult services.

Goals

There were five goals for this needs assessment.

1. Determination of the current and anticipated numbers of adults with developmental disabilities in Jackson County.
2. Identification of current and future service needs of adults with developmental disabilities in Jackson County.
3. Identification of direct support workers' and case managers' professional viewpoints of the status of services in Jackson County for individuals with developmental disabilities.
4. Identification of current and anticipated administrative and management considerations affecting services for individuals with developmental disabilities in Jackson County.
5. Identification and prioritization of needed services and supports for adults with developmental disabilities in Jackson County.

Approach

This needs assessment was conducted in three stages. In the first stage, an advisory board was appointed and convened, initial rounds of focus groups were conducted, an inventory of county resources and services for individuals with disabilities was compiled, and statewide prevalence data was attained. In the second stage, surveys were then developed and distributed. Third, follow-up focus groups designed to (a) hone in on particular themes that emerged from the first round of focus groups and survey responses and (b) increase the opportunity for county individuals to voice their perspectives were conducted. At the conclusion of these three stages, all of these qualitative and quantitative data sources were analyzed and compiled into this report.

Findings

The number of individuals with developmental disabilities in Jackson County approximates 2% of the county population. This prevalence rate has remained consistent in past years and therefore is the estimated rate for the immediate future. The needs of these individuals with developmental disabilities are discussed and summarized by key service areas. The following are the highlights of the findings.

Coordination of Services

- Approximately 24-27% of the individuals with developmental disabilities in Jackson County are currently served by DMH/MRDD.
- Families want service coordination to be more relationship-based as characterized by service coordinators actively listening to and working with families to connect individuals with disabilities to needed services, supports, and opportunities. However, the current system makes this challenging.
- 21% of surveyed families of adults with developmental disabilities reported that the individual with a disability receives waiver funding.

Provider Training

- Adult service providers and special educators alike reported being knowledgeable about person-centered planning, state policies and regulations, community employment opportunities, and independent living opportunities.
- However, consensus in the focus groups was that further training and professional development is needed in order to most effectively implement these practices.

Employment

- While sheltered workshops are the primary places of employment for individuals with developmental disabilities in Jackson County and families are comforted by the safety and social acceptance offered, there is a desire for additional employment options for individuals with varying abilities.
- 80% of family members surveyed would prefer that their loved one with a disability remain working in their current situation and 8% want their loved one to work in a different job in the community.
- Of the people with disabilities responding to the survey, 23% want a different job working in the community and 7% were unemployed and looking for work.
- Families of children with disabilities reported wanting their child to either continue schooling (college or trade school) after graduating from high school (46%) or get a job in the community (33%).

Housing

- On the survey, 38% of the adults with disabilities reported that they live in their own home or apartment, 33% reported that they live with their parents or family, and 27% live in group homes. The majority of these individuals are happy and do not want to change residences.
- On the survey of family members, 64% of the adults with disabilities live with their family and the majority prefers to maintain current housing arrangements.
- Providers report there has been an increased number of people with disabilities living in a natural home setting and a trend of aging parents caring for aging adults with disabilities as a result.
- The majority of surveyed parents of children with disabilities (65%) wants their child to live in his/her own home or apartment, either with or without paid support

and 26% of these parents wants their child to live at home with them after high school graduation.

Transition to Adulthood

- Increased opportunities for community-based instruction during high school would be beneficial in preparing students for adult life after graduation.
- Parents are unaware of the adult service options for their graduated child.
- Parents believe that with continued education after graduation, their child with a disability would be successful in supported employment and/or independent living.

Key Areas of Unmet Needs

- Of the 3,222 individuals with developmental disabilities in Jackson County reported by DMH/MRDD to receiving services, 26% are on a waiting list for services. In regard to the estimated 13,294 Jackson County residents with developmental disabilities, 6% are on a waiting list for services.
- Individuals with disabilities reported needing more support with social relationships, employment, and housing.
- Caregivers reported needing assistance with finding information, connecting their son/daughter with social and recreation activities, monitoring the quality of services, and finding family support groups.
- Educators and caregivers of students reported a need for continued education after graduation and more supported employment opportunities.
- The need for respite care was shared through focus groups and the surveys as a high priority for families of children as well as families of adults with more significant disabilities and/or health concerns.
- Accessible, flexible, and affordable transportation is needed.
- Life skills training for young adults with developmental disabilities transitioning out of high school is needed.
- Families reported needing more information about available services, supports, resources, and opportunities in Jackson County for individuals with developmental disabilities.
- Families and service providers shared there is a growing need for services with people with disabilities as they reach retirement age.

Availability of Community Resources

- Considering three regions of Jackson County (eastern, western, and southern), the array of services is more available in the western region.
- Service providers reported priority needs for increased availability of the following services: public transportation, help finding social clubs, therapy for individuals with disabilities that have been abused, family support groups, responsive health professionals, and getting information about trusts and guardianships.

Community Priorities

- Employment, housing, continuing education, information dissemination, transportation, services for aging individuals, and family support were reported priority areas for improvement across stakeholders.

Recommendations

While numerous areas of need arose in this study, a few overarching needs were identified across stakeholders. These targeted areas for improvement are:

- Expansion and enhancement of the array of housing and employment options;
- Provide relationship-based service coordination in which service coordinators, families, and individuals with disabilities partner to identify needs, services, and opportunities;
- Increase availability of continuing education, particular for young adults after graduation from high school;
- Increase availability of accessible and flexible transportation;
- Increase support and services for aging individuals with disabilities; and
- Improve dissemination of information.

INTRODUCTION

In their 2006-2008 Strategic Plan, EITAS articulates a commitment to supporting vocational, residential, and transportation services in a manner that is responsive to the individualized needs of Jackson County residents with developmental disabilities. EITAS also states a desire to stimulate new services and programs thus expanding opportunities for individuals with developmental disabilities. In order to make well-informed decisions regarding EITAS's role in supporting individuals with developmental disabilities in Jackson County, EITAS contracted with the UMKC Institute for Human Development to conduct a needs assessment in November 2006. The results of this needs assessment provides EITAS with information about the current needs of individuals with developmental disabilities, as well as anticipated needs of individuals with developmental disabilities as they age or transition into adult services.

The method used to assess the current and anticipated service needs for persons with developmental disabilities residing in Jackson County included multiple sources of information. Consumers, families, services providers, and teachers were involved as key informants through focus groups, surveys, and in an advisory capacity. Population data was gathered from statewide sources. Relevant documents describing available programs and services were reviewed. All of this information gathered across multiple sources results in this rich description of current and anticipated needs of individuals with developmental disabilities in Jackson County.

Goals and Guiding Questions

Five goals and guiding questions provided the framework for this needs assessment.

Goal 1: Determination of the current and anticipated numbers of adults with developmental disabilities in Jackson County.

Data was gathered from multiple sources in order to analyze population trends of people with developmental disabilities in Jackson County. Sources of data included existing statewide databases from the Missouri Department of Mental Health, Division of Mental Retardation and Developmental Disabilities and the Department of Elementary and Secondary Special Education, Division of Special Education. From these data sources, a trend analysis was conducted using the number of individuals with developmental disabilities served in the recent past years, the current number of individuals with developmental disabilities served or on waiting lists, and the students with developmental disabilities anticipating services upon graduation from high school.

Goal 2: Identification of current and future service needs of adults with developmental disabilities in Jackson County.

Goal 2 focused on the consumers that (a) are currently receiving services, (b) are on waiting lists for services, or (c) are anticipating a need for services in the upcoming years.

For individuals with developmental disabilities: Are the needs of individuals with developmental disabilities being met? Do the services align with their personal priorities? What are their perceptions of availability and access to needed community services and supports? Are they on a waiting list? If so, for what types of services are they waiting and how long have they been waiting?

For students with developmental disabilities anticipating a need for services after high school graduation: What types of services will they likely need in the beginning years of this transition? In what ways is it anticipated that the students' needs for services will change in the early years of adulthood? Are students and their families knowledgeable about the range of services currently available?

Goal 3: Identification of direct support workers' and case managers' professional viewpoints of the status of services in Jackson County for individuals with developmental disabilities.

The perceptions of individuals who provide direct supports and coordinate services targeted such questions as: What services are currently provided? What do you perceive as consumer needs? What are the barriers and challenges to providing services for individuals with developmental disabilities in Jackson County?

Goal 4: Identification of current and anticipated administrative and management considerations affecting services for individuals with developmental disabilities in Jackson County.

Goal 4 focused on the management/ administrative perspectives of currently available services for individuals with developmental disabilities in Jackson County. How are administrative systems and resources supporting or deterring the availability and quality of services available for individuals with developmental disabilities? What are the gaps in available services and what are priority areas for improvement?

Goal 5: Identification and prioritization of needed services and supports for adults with developmental disabilities in Jackson County.

The question of what are the priority services and supports needing improvement was posed to all key stakeholders. The results across stakeholder were cross-analyzed and resulted in recommendations for EITAS.

APPROACH

This needs assessment occurred in three stages. The first stage involved the appointment of an advisory board, initial round of focus groups, compiling an inventory of county resources for individuals with disabilities, and attaining statewide prevalence data. Second, building on the information learned in the focus groups, surveys were then developed and distributed. Third, follow-up focus groups designed to (a) hone in on particular themes that emerged from the first round of focus groups and survey responses and (b) increase the opportunity for county individuals to voice their perspectives were conducted. Finally, all of these qualitative and quantitative data sources were analyzed and compiled into this report. This section describes each step of the needs assessment.

Needs Assessment Advisory Board

An advisory board for the EITAS Needs Assessment was formed to provide guidance and direction during the process. The needs assessment advisory board consisted of service providers, individuals with disabilities, and family members of individuals with disabilities. Key IHD staff also served in a supportive capacity on the advisory board. Table 1 lists the members of the advisory board and their role.

Table 1. Needs assessment advisory board members

Community Stakeholders	Community Role
Amanda George	Service Provider, Director of Metropolitan Council on Developmental Disabilities (MCDD)
Kathy Marlatt	Service Provider, Kansas City Regional Center (KCRC)
Richard Enfield	Consultant and parent of an individual with a disability
Jake Jacobs	Executive Director, EITAS (Developmental Disability Services of Jackson County)
Terry Bigby	Consultant, Kansas City Regional Professional Development Center
Dynetta Banks	Member of the disabilities community
Bill Anderson	EITAS Board Member and parent of a child with a disability
Jim Johnson	Executive Director, Center for the Developmentally Disabled
Bill Anderson	Member of the disabilities community
Joan LaBelle	Director, Independent Living Program, The Whole Person, also a member of the disabilities community
IHD Staff	
Ronda Jensen, PhD	Project Director and Lead Researcher
Vim Horn	Senior Policy Analyst
Tracy Graybill	Research Associate
Mike McCarthy	Facilitator

During the course of the needs assessment, the advisory board met four times. See Table 2 for the meeting dates and the topics discussed.

Table 2. Schedule and content of advisory board meetings

Date	Issues Addressed
Monday, November 21 st	- Introductions and explanation of needs assessment project.
Wednesday, December 20 th	- Discussion of focus group activities

Date	Issues Addressed
Thursday, March 1st	<ul style="list-style-type: none"> - Strategies for focus group information dissemination and recruitment - Presentation of focus group data - Survey development
Wednesday, May 16 th	<ul style="list-style-type: none"> - Strategies for survey dissemination - Feedback on recurring thoughts and comments shared in the focus groups

Focus Groups

In order to get a representative sampling of individuals residing across regions of the county, recruitment for and the location of the focus groups occurred with respect to county divided into three regions: eastern, western, and southern. Eastern Jackson County was defined by the boundaries of highway 435 on the west, highways 435/471 to the south, Jackson County line to the east, and the Missouri river on the north. Southern Jackson County was defined by the boundaries of highways 435/471 to the north, Jackson County line to the east, State Line Road to the west, and Jackson County line to the south. Western Jackson County was defined as the Missouri River to the north, highway 435 to the east, highways 435/471 to the south, and State Line Road to the west.

Focus group locations with the three regions were chosen based on their proximity to amenities (ie. bus stops), accessibility, and neutrality of the location. Primarily, libraries, hotel meeting rooms, and meeting rooms located on a community college site were used for the focus groups. In addition, times and dates were carefully chosen to provide an opportunity for everyone to participate in the focus groups. Because many families have members that work during the day, family focus groups were timed in the early evening and in the mornings so that families would have a chance to participate. Consumer focus groups were conducted during a wide range of times in the late afternoon and morning. See Table 3 for the schedule of when focus groups were held and attendance.

Focus Group Recruitment

Recruitment for the focus groups involved distribution of flyers through multiple communication routes including mailings, listservs, distributing by hand, emails, and website postings. With the assistance of the Kansas City Regional Center, approximately 500 flyers were mailed to service providers, families, and individuals with disabilities. Notification of the focus groups was distributed through the MPACT¹ and EFECT² listservs. EITAS passed out flyers at their annual banquet. The Center for Developmental Disabilities included an announcement of the focus groups in their monthly newsletter. Announcement of the focus groups was made at the People First monthly meetings and disseminated through emails to People First members. The Kansas City Regional Professional Development Center announced to secondary teachers that the needs assessment was taking place and when focus groups were occurring. Finally, ACED³ staff

¹ Missouri Parents ACT
² Encouraging Families with Exceptional Children Together
³ Adult Continuing Education for Persons with Developmental Disabilities

helped with distributing information about the focus groups to their course participants and their families.

Initial focus groups were conducted in January and February of 2007 and follow-up focus groups were held in June 2007. The following table lists the schedule, location, and number of attendees for both the initial and follow-up rounds of focus groups.

Table 3. Focus group schedule, location, and attendance

Date	Location	#Attendees
Consumer Focus Groups Total Attendees: 14		
1/12/2007*(cancelled due to inclement weather)	Longview Community College	- *cancelled due to inclement weather
1/19/2007	Independence Hilton Garden Inn	2
1/26/2007	KC Public Library-Plaza Branch	4
2/2/2007**(Rescheduled from 1/12/2007)	Longview Community College	2
5/19/2007	People First Meeting-Kansas City Regional Center	6
Families of Adult Consumers Total Attendees: 33		
1/08/2007	Longview Community College	6
1/09/2007	KC Public Library-Plaza Branch	3
1/10/2007	Independence Hilton Garden Inn	8
6/18/2007	KC Public Library-Plaza Branch	16
Families of Consumers on Waiting Lists Total Attendees: 9		
1/16/2007	Longview Community College	1
1/17/2007	Independence Hilton Garden Inn	1
1/22/2007	KC Public Library-Plaza Branch	1
2/07/2007	KC Public Library-Plaza Branch	6
6/13/2007	KC Public Library-Plaza Branch	0
Teachers of Transition Age High School Students Total Attendees: 10		
2/12/2007	KC Public Library-Plaza Branch	10
Parents of Transition Age High School Students Total Attendees: 3		
2/20/2007	KC Public Library-Plaza Branch	1
6/11/2007	KC Public Library-Waldo Branch	2
Families Falling Through the Cracks Total Attendees: 4		
2/21/2007	KC Public Library-SE Branch	3
6/05/2007	Metropolitan Lutheran Ministries	1
Service Providers Total Attendees: 16		
2/01/2007	KC Public Library-Plaza Branch	16

Focus Group Procedure

At each focus group, a representative from UMKC-IHD was the focus group facilitator and convened each session using a script that explained that participation in the focus group was voluntary and anonymous. Participants can leave at any time. The focus groups were audio taped, but if any participant objected, the audio tape was stopped. The focus group facilitator used prepared protocols for guiding the focus groups. The protocols for each focus group included a list of overarching questions to guide discussion. At the end of each focus group, participants received an honorarium.

Prevalence Data

Data was received from the Missouri Department of Elementary and Secondary Education (DESE) and the Missouri Department of Mental Health (DMH). The DESE data provided a ten-year representation of the number of youth with disabilities served in Jackson County schools. This data was used to predict the prevalence of adults with developmental disabilities in the years to come. The DMH data was used to quantify the number of individuals with developmental disabilities accounted for by the Division of MRDD and served to give indication of population trends of adults with developmental disabilities in Jackson County.

Resource inventory

An inventory of available services and supports in Jackson County was compiled. This list of resources was mapped according to zip code and subsequently layered with the need for services as indicated on the surveys. The resource inventory includes the following information for 184 services agencies:

- Agency Name & Address
- Contact Person
- Phone, Fax, & TTY Number
- Web & Email Address
- Types of Disabilities Served
- Age Group Served
- Regions Served
- Services Provided
- Fees or Financial Eligibility
- On Bus Line?
- Wheelchair Accessible?

Surveys

Surveys for each target audience were developed based on the information gathered in the focus groups, and through existing data. Five surveys were developed for the key stakeholders in the project, and included: a) consumer survey; b) survey for families of adults with disabilities; c) survey for parents of children/minors with disabilities; d) survey for teachers and transition coordinators; and e) survey for providers of disabilities related services. The surveys were developed and disseminated throughout the months of April, May, and June.

Administration of Surveys

Surveys were available in both web based and print versions. Print copies of the surveys were (a) distributed in packets mailed by cooperating agencies and organizations to service providers and family members, (b) mailed as packets to provider agencies identified for the resource inventory, (c) available at the EITAS annual meeting, and (d) hand delivered to community agencies. The web based version of the surveys were posted on Survey Monkey and assigned unique URL addresses. The availability of and links to the online

surveys were disseminated via listservs (EFFECT, MPACT, People First), emails, newsletters (CDD), and website postings (MODDRC, The Whole Person, and Network of Care). Finally, for individuals wanting assistance with completing the surveys, IHD staff administered the survey as an interview. Table 4 displays the total numbers of surveys received.

Table 4. Number of surveys received

Target Respondent	# of Surveys Received
Secondary special educators	63
Service Providers	99
Parents of Children with Disabilities	36
Families of Adults with Disabilities	101
Consumers	101
Total	400

Key Informants

As mentioned, determination of the status, current needs, and anticipated needs of individuals with disabilities in Jackson County involved various key Jackson County stakeholders including adults with disabilities and their family members, parents of children with disabilities, service providers, and teachers of secondary students with disabilities. These stakeholders participated in focus groups and in completing a survey.

Overall, the survey respondents represented a close distribution across regions of the county with 28% residing in the southern region, 20% in the eastern region, and 41% in the western region. The extent and type of disability reflected in the survey responses was varied. The average age of the adult with a disability included in the survey (either by completing the consumer survey or included in the survey of family members) was 37-39 years old; however, the range was 19-77 years old. The average age of the service provider and teachers was 43 years old and they were predominantly white Caucasian; however, there was more diversity represented in the responding service providers than the teachers. The following section describes in detail the demographic characteristics for the individuals that completed surveys.

Individuals with Disabilities

As mentioned, the highest rate of return for the surveys was among individuals with disabilities. On the survey, they were asked to indicate their gender, age, race/ethnicity, and zip code of residence (see Table 5).

Table 5. Survey of individuals with disabilities: Demographic information

Gender	Age	Race/Ethnicity	Region of Residence
57% Female	Mean= 39 years	74% White	15% Southern
43% Male	Mode= 28 years	20% Black	39% Eastern
	Range= 19-62 years	4% Hispanic	45% Western

Family Members of Adults with Disabilities

On the survey for family members, respondents predominantly indicated they were the parent of an adult with a disability (77%). The remaining 23% were siblings, other relatives, or non-related guardians. Family members were also asked to provide information about their family member’s disability, gender, and age. The following table displays the demographic information for both the adult with a disability and his/her family member.

Table 6. Survey of family members of adults with disabilities: Demographic information

Family Members of Adults			
Gender	Age	Race/Ethnicity	Region of Residence
86% Female	Mean= 60 years	85% White	39% Southern
14% Male	Mode= 50 years	13% Black	20% Eastern
	Range= 29-81 years	2% Hispanic	39% Western
			2% Outside*

Adults with Disabilities			
Gender	Age	Level of Intellectual Disability	Other Conditions (in rank order of incidence)
61% Female	Mean= 37 years old	27% Mild	29% Physical Disability
39% Male	Mode= 23 years	33% Moderate	25% Cerebral Palsy
	Range= 18-77 years	23% Severe	23% Seizure Disorder
		10% Profound	22% Communication Disorder
		7% Doesn't have an intellectual disability	21% Down Syndrome
			21% Vision or Hearing Disability
			15% Brain Injury
			14% Autism
			8.3% Mental Illness

*Survey respondents resided outside the Jackson County area while their family member with a disability lived in Jackson County.

Service Providers

As shown in Table 7, service providers with various roles completed the surveys. Also, service providers were predominantly Caucasian, female, and had worked at their current job for more than 2 years.

Table 7. Survey of service providers: Demographic information

Role	Length of Current Employment	Gender	Age	Race/Ethnicity
10% Case Manager	6% < 6 months	85% Female	Mean= 43 years	76% White
4% Therapist	12% 6-12 months	15% Male	Mode= 25 years	20% Black
27% Direct Support Provider	20% 1-2 years		Range= 22-65	2% Asian
14% Administrator	62% > 2 years		years	2% American Indian
11% QMRP				
17% Supervisor				
4% Teacher				
13% Other				

Parents of Children with Disabilities

In order to hypothesize about the anticipated needs of future adults with disabilities, parents of children with disabilities were surveyed. Similar to the survey of family members of adults, the parents were asked to provide information about themselves as well as their child with a disability (see Table 8).

Table 8. Survey of parents of children with disabilities: Demographic information

Parents			
Gender	Age	Race/Ethnicity	Region of Residence
75% Female	Mean= 41 years	97% White	37% Southern
3% Male	Mode= 37 years	3% Black	29% Eastern
	Range= 23-59 years		34% Western
Children with Disabilities			
Gender	Age	Level of Intellectual Disability	Other Conditions* (in rank order of incidence)
28% Female	Mean= 12 years	9% Mild	53% Autism
72% Male	Mode= 14 years	9% Moderate	17% Seizure Disorder
	Range= 4-20 years	21% Severe	14% Physical Disability
		3% Profound	14% Communication Disorder
		58% Doesn't have an intellectual disability	11% Cerebral Palsy
			11% Down Syndrome
			8% Vision or Hearing Disability

*Less than 3% in other categories such as brain injury, mental illness, etc.

Secondary Special Educators

The distribution of the districts represented by the responding secondary teachers was primarily in the southern (57%) and western (33%) regions of the county. As shown in Table 9 various educator roles were sampled through the surveys; however, the majority of the responses reflect the perspectives of the special education teachers.

Table 9. Survey of secondary teachers: Demographic information

Role	District	Gender	Age	Race/Ethnicity
76% Special Education Teacher	26% Lee's Summit	76% Female	Mean= 43 years	90% White
	26% Raytown	24% Male	Mode= 30 years	5% Black
10% Special Education Coordinator	29% Grandview		Range= 25-65 years	5% Hispanic
	8% KCMO			
3% Therapist	4% Oak Grove			
3% Administrator	4% Independence			
8% Other	3% Blue Springs			

FINDINGS

The following discussion of the needs assessment findings begins with an outline of the current and anticipated prevalence rate of developmental disabilities in Jackson County. Data was pulled from multiple sources to give an estimate of how many individuals with developmental disabilities are currently residing in Jackson County and what percent of these individuals are currently served by the Department of Mental Health, Division of Mental Retardation and Developmental Disabilities (DMH/MRDD). After that section is a discussion of the current status of services and areas of need by service area. For each service area, the results of both the surveys and focus groups are synthesized. Finally, the conclusion of the Findings section shares the results of mapping the community resources. This availability of community resources, in light of the services received and needed, provide a rich description of the strengths and gaps in service delivery and options for people with developmental disabilities.

Prevalence of Developmental Disabilities in Jackson County

Determination of the current and anticipated numbers of adults with disabilities developmental disabilities in Jackson County involved analysis of data from two sources. The Missouri Department of Mental Health (DMH), Division of Mental Retardation and Development Disabilities collects data on the number of individuals with disabilities served across Missouri. This data includes the number of individuals served by age, disability diagnosis, and services received. Table 10 displays the numbers of individuals by diagnosis by ten year age span. The second data source was the Missouri Department of Elementary and Secondary Education (DESE), Division of Special Education. This division collects data on the children receiving special education services through the public schools. The data for students with developmental disabilities attending Jackson County schools is displayed in Table 11.

How many individuals with developmental disabilities reside in Jackson County?

- *What percent of these individuals are currently served?*

What is the estimated number of individuals with developmental disabilities in the future?

DMH data collects data on an individual's primary diagnosis only, coded according to the Diagnostic and Statistical Manual of Mental Disorders (DSM). Because only the primary diagnosis is reported and it is common that individuals with developmental disabilities experience co-occurring disorders, this analysis includes mental health disorders. 'Mental Health Disorders' include schizophrenia, bi-polar disorders, and the range of behavioral disorders such as oppositional deviant disorder and obsessive-compulsive disorder. Included within the category of 'Other Developmental Disorders' are such diagnoses as Down syndrome, brain injury, and cerebral palsy. The remaining category of 'Other' accounts for individuals for whom the diagnosis has been deferred.

The rationale for including data representative of children/ youth (less than 21 years old) is to project the number of future adults with developmental disabilities that will be needing services. Under the regulation of the Individuals with Disabilities Education Act (IDEA), special education data is referenced according to specific disability types, of which developmental disabilities is not included. Therefore, the disability diagnoses closely matching the criteria for developmental disabilities were selected and reported in Table 11.

Overall, according to the decade of data from DESE, a prevalence rate of 2% of the total school age population has been consistent for the past decade. Note, the totals of children by diagnosis differ from the count provided by DMH because a child may receive special education services through the school and not be part of the DMH/MRDD system of services. Using the 2% prevalence rate that has been consistent among school age children for the past decade and the 2006 census count of individuals with disabilities in Jackson County, an estimate of the percent served by DMH/MRDD was calculated. Specifically, the Jackson County census total for 2006 was 664,073⁴ and 2% of that number equals 13,294 Jackson County residents with developmental disabilities. DMH/MRDD reported 3,222 Jackson County residents with developmental disabilities receiving their services, which equates to approximately 24% of the population of individuals with developmental disabilities residing in Jackson County. In the year 2010, the project population of Jackson County is expected to decrease slightly to 660,763⁵, which results in approximately the same number of Jackson County residents with developmental disabilities in the next four years.

Summary

- *Individuals with developmental disabilities comprise approximately 2% of the Jackson County population.*
- *Given a decade of consistent data reflecting a prevalence rate of 2%, it is estimated that this rate will be valid into the immediate future.*
- *Approximately 24% of the individuals with developmental disabilities in Jackson County are currently served by DMH/MRDD.*

⁴ Source U.S. Census Bureau: State and County QuickFacts (2006).

⁵ Missouri Census Data Center

EITAS (Empowering Individuals through Advocacy and Support)
 Developmental Disability Services of Jackson County
 Needs Assessment 2007

Table 10. Number of individuals with developmental disabilities in Jackson County, rostered by DMH/MRDD, by diagnosis and by age

	Age of Consumers by Groups of 10 Years										Total	%
	0-10	11-20	21-30	31-40	41-50	51-60	61-70	71-80	81-90	91-100		
Mental Retardation	42	357	431	320	362	203	62	17	3	1	1798	55.8%
Screened Mental Retardation	233	3	1	1	-	-	-	-	-	-	238	7.4%
Autism/Aspergers	265	216	62	10	4	2	-	-	-	-	559	17.3%
Other Developmental Disabilities	44	62	69	56	48	9	7	3	-	-	298	9.2%
Mental Health Disorders	72	137	57	6	12	-	3	-	-	-	287	9%
Other	21	3	16	-	1	1	-	-	-	-	42	1.35%
Total	677	778	636	393	427	215	72	20	3	1	3222	100%

Source: Department of Mental Health, Division of Mental Retardation and Developmental Disabilities, February 2007.

Table 11. Number and percent of students with developmental disabilities in Jackson County schools during the past decade

School Year	Total Enrollment	Total # of Children With Dev. Disabilities	Total % of Children With Dev. Disabilities	Mental Retardation		Deaf and Blind		Multiple Disabilities		Autism		Traumatic Brain Injury	
				#	%	#	%	#	%	#	%	#	%
1998	104730	2258	2%	1496	66%	4	0%	120	5%	579	26%	59	3%
1999	104817	1742	2%	1404	81%	34	2%	107	6%	170	10%	27	2%
2000	104882	1718	2%	1310	76%	31	2%	119	7%	224	13%	34	2%
2001	104377	1778	2%	1339	75%	31	2%	109	6%	240	13%	59	3%
2002	104077	1894	2%	1401	74%	24	1%	118	6%	292	15%	59	3%
2003	104725	1941	2%	1439	74%	12	1%	114	6%	318	16%	58	3%
2004	105177	1930	2%	1408	73%	8	0%	94	5%	367	19%	53	3%
2005	104846	2067	2%	1451	70%	7	0%	110	5%	445	22%	54	3%
2006	105159	2175	2%	1478	68%	7	0%	113	5%	520	24%	57	3%
2007	103922	2258	2%	1496	66%	4	0%	120	5%	579	26%	59	3%
Total	1046712	19761	2%	14222	72%	162	1%	1124	6%	3734	19%	519	3%
Average	104671	1976	2%										

Source: Department of Elementary and Secondary Education, Division of Special Education, February 2007.

Coordination of Services

The array of services needed by individuals with developmental disabilities is individualized and can be complex due to various funding sources, eligibility requirements, and/or programmatic policies and regulations. The purpose of service coordination, or case management, is to assist individuals with disabilities in navigating the array of needed services and supports. The focus groups and surveys included opportunities for stakeholders to comment on service coordination, funding received, and the provision of innovative strategies for increasing opportunities for individuals with disabilities to be more self-determined in coordinating their own services.

Is the current state of case management working?

- *Are case managers addressing the needs of individuals with disabilities?*
- *Are consumer-directed models of service coordination occurring?*

Case Management

On the surveys, the majority of respondents reported that they currently receive service coordination through the Kansas City Regional Center (KCRC). Additionally, survey respondents generally reported that they know their service coordinator’s name and believe that she/he is helpful and understands their personal needs (see Table 12). However, for parents of children with disabilities, the extent of understanding and helpfulness provided by the case manager was comparatively less than reported by consumers and their families. A possible explanation is that while children with disabilities are receiving services through the public schools the KCRC case manager is less involved, but that is not always the parent’s preference. Repeatedly on the survey, parents of children added comments stating they would like to receive more support from their child’s case manager.

“I have had to find information on my own with no help from my case manager”

“I would like to get services for my child, and I would sure like to hear and see her case manager on more than a yearly basis”

Table 12. Service coordination provided by the Kansas City Regional Center

		Consumers with disabilities	Families members of adults with disabilities	Parents of children with disabilities
Do you have a case manager?	Yes	77%	87%	69%
	No	21%	11%	29%
	Don't Know	2%	2%	2%
If so...Do you know his/her name?	Yes	98%	96%	88%
	No	2%	4%	12%
Is he/she helpful?	Yes	79%	72%	38%
	Sometimes	18%	17%	42%
	No	3%	11%	20%

		Consumers with disabilities	Families members of adults with disabilities	Parents of children with disabilities
Does he/she understand your needs?	Yes	77%	73%	50%
	Sometimes	18%	25%	29%
	No	5%	2%	21%

In the focus groups, consumers and family members agreed that service coordination, when it is provided by someone that is engaged and active in the lives of the individuals they serve, can be greatly beneficial. The stories told by individuals with disabilities and family members articulate that it is essential for the service coordinator to be both available and responsive.

Several focus group participants provided positive experiences they had with service coordinators. One individual with a disability described her service coordinator as someone they turn to for help, *“I feel like if I needed any help I can call my case worker and he is willing to help. He takes his time, but he gets the job done.”* A family member of an adult with disabilities talked about the level of engagement he receives from his service coordinator *“Our case manager is very good, and she calls me all the time with ideas.”* Another family member added,

“I feel very fortunate. Our case manager is wonderful. Originally, the one that we had for probably 12 years was not. I mean, she was non-existent except for once a year and that was it. But since then, when I found out I could request somebody new, I have to say we have a good connection. I don’t talk to her constantly at all, but if I have a question, I e-mail her and she shoots me back an answer within the day. She calls the house sometimes to ask a question and she talks with my son. I know they have a relationship and I am personally very impressed with her.”

Some families have found their case managers to be caring, engaged individuals that they have built relationships with over time, or truly feel they can look to for help. Other focus group participants related that their relationships with service coordinators were more perfunctory and less personal as one participant noted,

“My daughter has a case manager and it seems like all that happens is they come and take the information then you don’t hear anymore until it is time to do it again.”

It was commonly shared in the focus groups that service coordinators should spend more time with individuals getting to know their needs in order to provide information and resources.

“I kind of wish my case manager was a little bit more proactive in helping us find different benefits for us. What else is out there that I am not aware of... that I don’t know to ask for? ... just someone to kind of hold my hand and say, here’s something available for you.”

Relationship-based service coordination, as characterized by a partnership between the individual with a disability, his/her family, and a responsive service coordinator for the

common goal of helping the individual achieve life goals and desires⁶, can be hindered by large caseloads. On the survey of service providers, 17% of the respondents indicated their agency/organization provides case management. Of those, the reported size of caseloads ranged from 5-100 with the average being 36 persons. Service providers shared in focus groups their perception that caseloads are often well over 50 individuals. As reported by the Kansas City Regional Center (KCRC), the current average caseload of a KCRC service coordinator is 61 consumers. However, in FY 2008 the average caseload is expected to reduce to below 50 with additional service coordinator positions funded through the SB40 boards by DMH and Medicaid⁷. In addition to the numbers of individuals needing service coordination, service providers also shared that caseloads are often reassigned, thus leading to more confusion on the part of the family and the individual with disabilities. Finally, service providers shared on the survey that they are often juggling multiple roles and responsibilities, which also limits the time available for developing a relationship with individuals and their families.

For approximately 47% of Jackson County residents with developmental disabilities, service coordination is the only services they receive from DMH/MRDD. The remaining 53% receive service coordination in addition to other services such as community supports and residential services. Table 13 displays the number of individuals receiving service coordination only by diagnosis category. (See the section discussing the prevalence rate on page 10 for a description of the categories.)

Table 13. Numbers of Jackson County individuals receiving DMH/MRDD service coordination by diagnosis

Diagnosis Category	Number
Mental Retardation	791
Screened Mental Retardation	8
Autism/Aspergers	307
Other Developmental Disabilities	175
Mental Health Disorders	191
Other	28
Total	1500

Source: Department of Mental Health, Division of Mental Retardation and Developmental Disabilities, February 2007.

Waiver Funding

The surveys asked families of adults with disabilities, as well as parents of children with disabilities, to report if they currently receive waiver funding. Twenty-one percent of the families of adults indicated that the individual with a disability receives waiver funding; however, most of them did not know which type of funding. Of the families that did know which type of waiver they received, few families reported to receive the community support waiver (4%), comprehensive waiver (2%), or the EITAS waiver (5%). Among the parents of children with disabilities, only four parents reported to be receiving a waiver and for all of them it is Sarah Lopez waiver.

⁶ Maronne, J. (2002) *Emerging practices for service coordination/ case management: Transition to what?* National Capacity Building Institute, Center on Disability Studies, University of Hawaii.

⁷ Source: Department of Mental Health, Division of Mental Retardation and Developmental Disabilities, August 2007.

Consumer Control of Services

“Over the past decade, greater control of long-term services and supports has shifted toward individuals with disabilities and their families.”⁸ Evidence of consumer control in the coordination of services was measured by asking families if their family member with a disability has a/n (a) individualized negotiated budget, (b) person centered plan, (c) microboard, and/or (d) support broker. Approximately half of the responding families shared that their family member with a disabilities does have an individualized negotiated budget (58%) and/or a person centered plan (50%). While more than half of the surveyed families reported that an individualized negotiated budget and a person-centered plan were in place, it is still uncertain as to the degree the budget is negotiated and the extent to which the person centered plan is individualized. These percentages indicate a familiarity with the terminology, but do not measure the quality or extent of the individual’s control of services.

A microboard is an incorporated agency established by people who care about the individual with a disability for the purpose of planning and obtaining needed services.⁹ Only 4% of the responding families had established a microboard. A support broker is someone hired directly by the individual with a disability to support him/her in navigating service systems and obtaining desired services. Only one responding family member reported their family member with a disability has a support broker.

Summary

- *Approximately 24-27% of the individuals with developmental disabilities in Jackson County are currently served by DMH/MRDD.*
- *Families want service coordination to be more relationship-based as characterized by service coordinators actively listening to and working with families to connect individuals with disabilities to needed services, supports, and opportunities. However, the current system makes this challenging.*
- *21% of surveyed families of adults with developmental disabilities reported that the individual with a disability receives caregiver funding*

Provider Training

Adult service providers, as well as secondary special educators, were asked how knowledgeable they believed they were about numerous practices pertaining to services for adults with disabilities. Educators were asked to report their general level of knowledge regarding the given practice. Adult service providers were asked to report their

Are service providers knowledgeable about best practices in serving adults with developmental disabilities?

Are secondary special educators knowledgeable about these same practices?

⁸ Caldwell, J. & Heller, T. (2007). Longitudinal outcomes of a consumer-directed program supporting adults with developmental disabilities and their families. *Intellectual and Developmental Disabilities*, 45(3), 161-173.

⁹ Horn, V. (2001). *Missouri’s Microboard Development Workbook*. Institute for Human Development. University of Missouri-Kansas City.

perception of their knowledge of how to facilitate the given practice. Table 14 lists the responses of educators of students with disabilities and adult service providers.

Table 14. Percent of service providers reporting to be highly or somewhat knowledgeable

Practice	Adult Service Providers	Special Educators
Person-centered planning	80%	49%
State policies and regulations	68%	54%
Community employment opportunities	53%	54%
Independent living opportunities	48%	38%
Research-based best practices	27%	43%
Individually negotiated budget	61%	34%
Support brokering	20%	9%
Culturally competent services	56%	25%
Microboard	16%	4%

Overall, service providers reported on the survey to be very knowledgeable. However, in focus groups there was consensus that professional development is needed and concern for EITAS’s reduced role in providing training opportunities.

“EITAS used to have a documentation class that really helped our consumers. They decreased a lot of the training. They used to have some really good training for direct care staff that they no longer provide.”

Summary

- *Adult service providers and special educators alike reported being knowledgeable about person-centered planning, state policies and regulations, community employment opportunities, and independent living opportunities.*
- *However, consensus in the focus groups was that further training and professional development is needed in order to most effectively implement these practices*

Employment

On the survey of individuals with disabilities were asked (a) where they worked or spent their day, (b) who chose where they worked or spent their day, (c) were they paid and if so was it enough money, (d) were they happy with their current employment arrangement, and (e) where would they prefer to work or spend their day. Sixty-one percent of the individuals with disabilities reported to work at a sheltered workshop, 10% attended a day program, 8% had a job in the community, 7% were unemployed and looking for a job, and the remaining 15% stayed at home, volunteered, or were in school full time. When asked who chose where they worked or spent their day, 49% reported to have made the choice themselves, of which 23% reported they had help in making the choice. For 29% of the adults with disabilities, their family and/or friends chose and for another 16% of the individuals, professionals made the choice of where they would be employed or spend their day. The amount of pay was reportedly nothing (28%) or not enough (28%). Thirty-

eight percent of the individuals reported to be paid enough and 6% reported they were paid more than enough. When asked if they were happy with their current employment arrangement, 70% of the individuals with disabilities reported they were happy, 20% were somewhat happy, and 10% were not happy. Lastly, when posed the question of where would prefer to work or spend their day, 65% wanted to stay where they are now, 23% wanted a different job in the community, 6% wanted to work at a sheltered workshop or move to a different sheltered workshop, and the remaining 6% wanted to spend more time during the day in social activities, stay at home, or be a teaching assistant with the ACED program. For the individuals with disabilities, there was not a relationship between being happy with the current employment arrangement and the employment setting, income, or distinction of who chose.

Where are individuals with disabilities working or spending their day?

- *Who chose where they work or spend their day?*
- *Are they paid?*
- *Are they happy?*
- *Where would they prefer to work or spend their day?*

Looking ahead....Where do parents of children with disabilities want their child to do after he/she graduates from high

The same questions were posed on the survey of family members of adults with disabilities. Similarly, the results showed that sheltered workshops were the most frequently reported places of employment (46%) followed by day programs (26%). Ten percent of their family members with disabilities spent the day at home, 4% had a job in the community, and the remaining 14% were unemployed, volunteered, or were full time students. As reported by family members, the amount of input the individual with a disability had in choosing where he/she worked or spent the day varied from none to a lot of input. Twenty-nine percent reported their family member with a disability had a lot of input in choosing how he/she spent his/her day, 24% had some input, 22% had a little input, and 25% had no input. Fifty-three percent of the individuals with disabilities do get paid and less than half of them (43%) report it is enough or more than enough. When asked where they would prefer their family member with a disability worked or spent the day, the predominant response was “where he/she is now” (80%). Eight percent would prefer a different job in the community and the remaining 12% would prefer a different sheltered workshop or were unsure what they wanted.

On the survey, service providers were asked, “Where do most of your clients work?” Forty-nine percent of the service providers reported that most their clients work at a sheltered workshop. Thirty-six percent of service providers reported that their clients were unemployed, 9% reported their clients had jobs in the community either with or without paid support, and the remaining 6% of the service providers reported that most of their clients were full time students.

Where do parents want their child with a disability to work or spend their day after graduating from high school? The responses differed from the family members of adults with 46% wanting their child to attend a college or trade school and 33% wanting their child with a disability to have a job in the community. Less frequently, parents indicated a preference for adult day programs (18%) and sheltered workshops (3%).

As is evident in the surveys, the sheltered workshops are often the place of employment. Family members shared in the focus groups that the sheltered workshops provide a place where the individual can feel they are accepted, and safe. One mom summed up her opinions of the sheltered workshops when she says,

“As far as the workshop situation, we want that to continue. When my son was younger, we had no clue he would end up in a workshop because we thought he was a bright person, there are a lot of places he could work. But as he has grown, we see that it is not all about what he can do. It is all about feeling loved and having friends and being safe. You just aren’t safe at McDonald’s with other people who could steal your paycheck.”

However, while parents and family members of individuals with disabilities rest assured in the safety and companionship availed in the sheltered workshops, some individuals with disabilities shared their dissatisfaction. As one individual with a disability stated *“workshops are boring and they aren’t challenging. I don’t want to work in one.”* Individuals with disabilities repeatedly shared in focus groups and survey comments that they need help finding competitive employment. Almost one-quarter of the individuals with disabilities surveyed wanted a job in the community but did not currently have one.

Family members also recognize that different opportunities are needed. Sheltered workshops are not for everyone. One family member commented that although their daughter currently works in a sheltered workshop, *“I think she could be in competitive employment, too but we just haven’t been successful in getting her in the right position.”* Other family members as well as service providers agreed that employment, like other life aspects, should be individualized for the person with a disability,

“I know there is a place for workshops but I have also gone in and seen many of the things on a daily basis. They are warehouses to a certain degree. They [workshop employees] aren’t working. There are people putting together the same puzzle day after day at the workshop. It is a place to dump them for the day.”

Services helping individuals to find the right job for them are in need of improvements as far as job choices and opportunities are concerned. One parent who is currently not using any services in Jackson County noted,

“I know people who have gone down the Vocational Rehabilitation Evaluation route only to come back with either they could do a volunteer job, or a sheltered workshop. I hope I am not being naïve but I really think my son has the ability to do more than that.”

In summary, survey and focus group respondents indicated that choices for employment should include all three options-sheltered workshops, volunteering, and competitive employment.

Family members also emphasized the importance of job coaches and mentoring to the success of people with disabilities and employment. As a family member of an individual with a disability noted,

“I know funding is a problem, but especially with employment there is more that could be done to help these kids. They are good workers once they get out and get placed the right positions. I think one of the keys is getting a job coach that is effective.”

Families feel there is a gap in available supports for recent high school graduates. In a focus group for families and individuals not receiving service in Jackson County, one participant shared,

“I think Jackson County could provide a sort of buffer zone. What my son is going to need is somebody to kind of finesse him with employers so they understand this guy has autism. He needs a job coach that can go in when he first starts working and can help him with behavior in the lunch room, this is the routine, etc. those sorts of things are really where I think there is a void. It saddens me because I think everybody is potentially employable.”

Summary

- *While sheltered workshops are the primary places of employment for individuals with developmental disabilities in Jackson County and families are comforted by the safety and social acceptance offered, there is a desire for additional employment options for individuals with varying abilities.*
- *Of the people with disabilities responding to the survey, 23% want a different job working in the community.*
- *80% of family members surveyed would prefer that their loved one with a disability remain working in their current situation and 8% want their loved one to work in a different job in the community.*
- *Of the people with disabilities responding to the survey, 23% want a different job working in the community and 7% were unemployed and looking for work.*
- *Families of children with disabilities reported wanting their child to either continue schooling (college or trade school) after graduating from high school (46%) or get a job in the community (33%).*

Housing

Similar to the questions pertaining to employment, individuals with disabilities and family members of adults with disabilities were both surveyed about their current housing, satisfaction with their current residence, and extent of choice in selecting their current residence. Thirty-eight percent of the surveyed individuals with disabilities reported to live in their own home or apartment, 33% reported they lived with their parents or other

family members, 27% lived in group homes, and 2 % lived in a large nursing or care facility. Forty-seven percent of the individuals with disability chose where they lived either by themselves or with help. For 39% of the individuals with disabilities, their family and/or friends chose where they lived, for 8% of them professionals chose, and for the remaining 5% their residence was court ordered. Predominantly, the individuals with disabilities are happy with where they live (80%). Twelve percent reported feeling just OK about their place of residence and 8% were not happy. When asked where they would prefer to live, most individuals with disabilities (70%) did not want to change their residence. Within the 30% that would prefer to live somewhere else, 20% reported a preference for their own home or apartment with or without paid staff, 7% wanted to live with their family, and 3% would prefer to live in group home.

Where are individuals with disabilities residing?

- *Who chose where they live?*
- *Are they happy?*
- *Where would they prefer to live*

Looking ahead... Where do parents of children with disabilities want their child to live when they become adults?

On the survey distributed to family members of adults with disabilities, it was most frequently reported that the family member with a disability lived with family (64%). Additional places of residence were group homes (16%), own home or apartment with or without paid staff (17%), or large nursing or care facility (3%). Similar to the choice of employment, the amount of choice in selecting where to live varied from none to a lot. According to family members, 31% of the individuals with a disability had a lot of input in choosing their current residence, 20% had some input, 11% had a little input, and 37% had no input. When asked where they prefer their family member with a disability lived, most reply “where he/she is now” (85%). Five percent would prefer their family member live in his/her own home or apartment, 8% would prefer a group home and the remaining 2% would prefer the individual with a disability lived with them.

In summary, the majority of adults with disabilities are residing with family members and this is the preferred arrangement. However, as the caregivers and the individual with a disability age, this living arrangement becomes a concern. In the focus groups, many family members were concerned about what would happen to their family member with a disability when they can no longer care for him/her. Service providers shared this concern stating that the aging population is a reality that is not being proactively addressed.

Quoted from a service provider,

“The majority of families I work with having an individual living in the natural home or with a sibling. We have a real problem in providing the supports for the caregivers. This is a real concern of mine. We are not addressing the fact that many are continuing to live in their home with parents over the age of 65 and up.”

Another service provided added,

“What we are seeing is that a lot of our parents are elderly, and we are trying to encourage them and making sure that they have a plan in place,

but they are very concerned about how many group homes are out there. Our parents have communicated to us that there is a need for more group homes. Also, what I am seeing is there is a wait list for those services

On the survey, parents of children were asked where they want their child to live after graduating from high school. The majority (65%) of parents responded that they wanted their child to live in his/her own home or apartment, either with or without paid support. Twenty-six percent shared they wanted their child to live with them and 9% preferred a group home. In contrast to the family members of adults, the majority of the parents want their child to live in their own home or apartment and fewer desired a group home.

Summary

- *On the survey, 38% of the adults with disabilities reported that they live in their own home or apartment, 33% reported that they live with their parents or family, and 27% live in group homes. The majority of these individuals are happy and do not want to change residences.*
- *On the survey of family members, 64% of the adults with disabilities live with their family and the majority prefers to maintain current housing arrangements.*
- *Providers report there has been an increased number of people with disabilities living in a natural home setting and a trend of aging parents caring for aging adults with disabilities as a result.*
- *The majority of surveyed parents of children with disabilities (65%) wants their child to live in his/her own home or apartment, either with or without paid support and 26% of these parents wants their child to live at home with*

Transition to adulthood

In both the focus groups and the surveys, experiences with transition services were a recurring theme. In the focus groups, parents of adults with disabilities described their past and current experiences with transition and how those experiences have affected services, supports, and ultimately success for the individual with a disability. Additionally, service providers and secondary educators spoke to the importance of transition preparation and offered suggestions of how it could be improved.

Are high school students with developmental disabilities prepared for adult life after graduation?

Are adult service providers involved in transition planning?

What are the needs of young adults with developmental disabilities?

Parents of recently transitioned adults with disabilities shared that community work experiences provided while in school is essential. One family member of an adult with a disability provided an example of how this system worked for her daughter as she transitioned from high school to adulthood.

“During her last year in high school she had a teacher that was very active and tried to find outside employment while she was still in school to try to help her ease into a job situation after graduation. So she worked for H&R invitations in Lenexa part-time during her senior year. She did real well in that position.”

Another parent of a graduating senior shared that her son’s transition plan has helped him know what to expect after graduation from high school.

“My son is currently in high school as a senior. This is probably the last year and so what they have been doing this last year is two mornings a week he takes a bus to [sheltered workshop] to try it out for two hours at a time. It has been a very good thing for him because he has always been slow to adapt. Going from school to work is a big thing, and I have to say now that he has done it for almost a year he loves going. So we are looking at graduation in May and possibly going to work in the summer. We feel he is as ready as he can be.”

While some parents shared stories of success and hope, other parents spoke of less effective or no transition planning. One mother and daughter both shared that a lack of transition planning has resulted in a lack of current opportunities.

“When my daughter graduated last year from school that was it and there was no transition. That had really been my fear that once she graduated she would be sitting at home doing absolutely nothing.” Her daughter added *“I am not doing anything at this point, it is really boring.”*

Another parent spoke of how her daughter has ‘fallen through the cracks’ in terms of employment opportunities due to lack of transition planning.

“My daughter is 20, and she is of average intelligence so she graduated from her high school because there wasn’t anything left for her to take. But my daughter has fallen through some cracks in terms of the service provision by other agencies that provide job mentoring. She is not able to use her hands completely so she doesn’t qualify for the IBS type of sheltered workshop industries. We are finding it really frustrating. We have been told we don’t qualify for paid employment until our daughter has some experience, but they do not provide job coaches for volunteer experiences.”

Transition coordinators and teachers also expressed numerous frustrations with transition. They spoke of needing more information about available resources, solutions for connecting students with higher level skills with continuing education or employment, and providing parents with the information and resources they will need after graduation.

Transition Planning

In accordance with the Individuals with Disabilities Education Act (2004), schools are required to provide services that prepare students with disabilities to transition to adult life after high school, beginning no later than at age 16. Data from Missouri’s Department of

Elementary and Secondary Education¹⁰ identifying the numbers of transition-age students with developmental disabilities are displayed in Tables 15-17. Table 15 lists the most current numbers of students with developmental disabilities in Jackson County public schools, ages 15 years to 21 years old, for the academic year ending May 2007. Tables 16 and 17 show the enrollment trends and the number of students that have recently graduated from high school in the past 2 years. Because the enrollment of 19-21 year olds with developmental disabilities is considerably lower than the other age ranges, this data suggests that the majority of the students leaves high school at age 18. Overall, this data gives an estimate of the number individuals with developmental disabilities that may need continued transition and vocational support upon graduation from high school.

Table 15. Number of students, ages 15-21 years old, with developmental disabilities in Jackson County Schools in 2007

Age	Mental Retardation	Deaf and Blind	Multiple Disabilities	Autism	Traumatic Brain Injury	Total
15	137	0	13	42	6	198
16	167	0	5	30	8	210
17	153	0	7	20	4	184
18	86	1	4	14	6	111
19	31	0	6	6	0	43
20	13	0	4	2	0	19
21	1	0	1	0	0	2

Source: Department of Elementary and Secondary Education, Division of Special Education, February 2007.

Table 16. Number of students, ages 17-21 years old, with developmental disabilities in Jackson County Schools in 2006

Age	Mental Retardation	Deaf and Blind	Multiple Disabilities	Autism	Traumatic Brain Injury	Total
17	139	1	4	28	5	177
18	89	0	8	12	2	111
19	25	0	4	3	0	32
20	11	1	4	3	0	19
21	0	0	1	0	0	1

Source: Department of Elementary and Secondary Education, Division of Special Education, February 2007.

Table 17. Number of students, ages 17-21 years old, with developmental disabilities in Jackson County Schools in 2005

Age	Mental Retardation	Deaf and Blind	Multiple Disabilities	Autism	Traumatic Brain Injury	Total
17	123	1	9	15	3	151
18	69	0	4	7	2	82
19	24	2	5	3	0	34

¹⁰ Student enrollment data is collected December 1 of each academic year.

Age	Mental Retardation	Deaf and Blind	Multiple Disabilities	Autism	Traumatic Brain Injury	Total
20	13	0	3	4	0	20
21	0	0	0	0	0	0

Source: Department of Elementary and Secondary Education, Division of Special Education, February 2007.

In the focus group, educators commented that the involvement of the community in transition planning is inconsistent. Often, teachers do not know who to invite to transition planning meetings or how to facilitate the student receiving services upon graduation. One transition coordinator sums up with this sentiment,

“Knowing that there are agencies out there to plug into-it would be great if I had a list as to which agencies provide which services. We have some of that, but not enough. We don’t hook into VR and KCRC and there is no coordinated effort. It seems to be very disjointed. What about independent living or supported living for some of the kids afterwards?”

Another teacher suggested looking beyond the traditional resources.

“...some of the organizations that are not for profit agencies, that don’t fit into the realm of Vocational Rehabilitation or KCRC, there are a lot of other types of agencies out there that we don’t know about because they are not hooked through Vocational Rehabilitation or KCRC.”

This recurring feeling of not knowing about available services and resources affects the ability of teachers to subsequently share information about resources for parents. When asked how well informed parents were about resources, one teacher replied, *“If we don’t know, then they really don’t know.* Parents echoed this sentiment. One father said,

“I think for our son in particular, the biggest concern is life services or life skills after school. Employment opportunities, what do we do for that transition after he is out of high school. We are working on it, but we don’t know all that is available. I think there are a lot of people out there that have no idea.”

A teacher offered the solution of a parent support group that could share information about transition planning and life after high school. She believed a parent support group would be a more effective way to share information as compared to information flyers and brochures.

“I think there needs to be some type of community parent organization that helps them with awareness rather than the school just kind of feeding it to them. We had a parent group at one time. They were more successful in passing along a lot of that information than the school was simply because they were parents passing the information.”

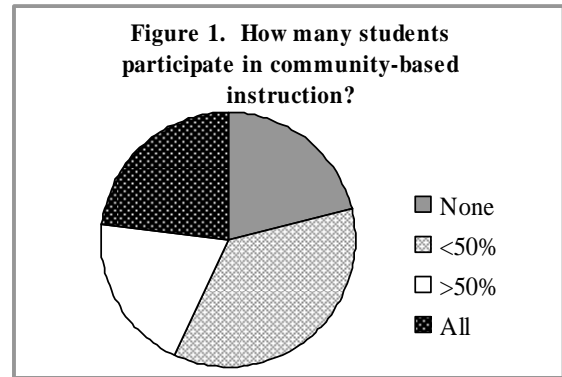
The survey of secondary special educators sought to get a broader picture of the range of community agencies involved in transition planning and the extent to which high school students with disabilities are provided community-based instruction. In an open-ended survey question, educators were asked to indicate which community agencies were often included in the transition planning process for students with disabilities. Almost three-

quarters of the time, vocational rehabilitation is involved in transition planning (71%). Other agencies and organizations identified as being involved in transition planning for a student with a disability are listed in Table 18.

Table 18. Community agencies/ organizations involved in transition planning

Agency/ Organization	% of Educators Reporting Agency Participation
Missouri Division of Vocational Rehabilitation	71%
The Helping Hands of Goodwill Industries	38%
Jewish Vocational Services	29%
Sheltered Workshops	26%
Rehabilitation Institute	26%
Kansas City Regional Center	26%
Herndon Career Center	18%
Truman Medical Center Employment Services	15%
Salvation Army	15%
Longview Community College Counseling Services	6%
No agencies or organizations	12%

Community-based instruction is an opportunity for students to learn job skills in the natural workplace environment. When educators were asked on the survey how many of their students with disabilities participate in community-based instruction, the responses were almost equally distributed (see Figure 1). More than half (57%) of educators reported that none or less than 50% of their students participate in community-based instruction.



The focus group participants shared that opportunities for work in the community during high school led to successful transitions. However, the survey findings indicate that this is not happening for most students. A possible explanation was provided by the teachers when they talked about not knowing what services and resources are available and/or not fully including the services/agencies about which they know.

Continuing Education

Teachers and transition coordinators experience some gaps between services provided for students with disabilities and student ability and skills. A transition coordinator noted, *“The real gaps are the kids that don’t qualify for the Kansas City Regional Center and are not ready to be independent. That is the gap right there. There are no services for them.”*

Not every student is a good fit for the services provided, most of which focus on those students that are lower functioning. A life skills teacher commented,

“I think that there [needs to be] a place that is aimed at continuing education for those mid range life skills students. Developing Potential and some other places...I think these are nice and well run services that take care of needy kids... but it is those higher level kids that wouldn’t be appropriate in those locations. So what I am hoping to be able to see is a little bit more services for mid range life skills-higher functioning life skills student, maybe lower level LD students that kind of thing. They just need a little more continuing education.”

As another transition coordinator reiterated, *“The gap is in the kids that don’t qualify for KCRC and are not really ready to be independent. That is the gap right there. There are no services for them.”* One teacher offered a suggestion of how EITAS could support continuing education.

“I think it would be a really good idea if the Jackson County Board of Services [EITAS] had a transition program that was kind of like a college for the graduates, for like one or two years after, that they could go and it is continuing education and job training and career.”

Summary

- *Increased opportunities for community-based instruction during high school would be beneficial in preparing students for adult life after graduation.*
- *Parents are unaware of the adult service options for their graduated child.*
- *Parents believe that with continued education after graduation, their child with a disability would be successful in supported employment and/or independent living.*

Other Areas of Needs

In addition to the description of needs woven into the prior discussion of housing, employment, and transition, other areas of need were identified through the surveys and focus groups. On the surveys of family members of adults with disabilities, individuals with disabilities, and parents of children with disabilities, each stakeholder was asked if they, or their family member, received the help they need within key areas. Additionally, secondary special educators were asked to speculate on the anticipated needs of their students upon graduation from high school. The following table highlights the areas in which the survey

Are adults with developmental disabilities receiving the help they need?

Are caregivers receiving the help they need?

In which areas is more help needed?

Looking ahead... What are the anticipated needs of adults with developmental disabilities as reported

results indicated the greatest unmet need¹¹. [Note: The service provider survey targeted their perceptions of the current availability of services and the need for increased availability. These results are discussed on page 35 and displays in Table 21.]

Table 19. Key areas of greatest unmet personal needs as reported on surveys

Consumers (current needs)	Families of Adults (current needs)	Parents of Children (current needs)	Secondary Special Education Educators (anticipated needs)
1. Finding social groups	1. Finding information about available services	1. Helping son/daughter with building friendships	1. Information about available services
2. Finding a job	2. Finding recreation activities	2. Finding social clubs for son/daughter	2. Job skills training
3. Finding friends	son/daughter/family member	3. Finding respite care	3. Continuing education (college or trade school) support
4. Finding a place to live	3. Finding social clubs for son/ daughter/family member	4. Finding recreation activities for son/daughter	4. Person centered planning
	4. Monitoring the quality of services provided	5. Monitoring the quality of services provided	5. Help getting supported employment
	5. Helping son/ daughter/family member	6. Finding family support groups	6. Help finding recreation activities
	6. Help with building friendships	7. Getting community-based instruction for son/daughter	7. Help finding clubs or other social groups to be part of
	7. Finding family support groups		
	8. Finding respite care		

Overall, the majority of the individuals with disabilities reported their current needs were being met; however, there were four areas in which they indicated needing more help than they currently received. These areas are related to relationships, employment, and housing. Comparatively, the lists of needs as reported by family members of adults and parents of children are closely matched, although with different priorities. The educators echoed much of the same needs (albeit ‘anticipated needs’) but also articulated a need for continuing education and supported employment options. The consumers were the only stakeholders to identify housing as a need. Overall, statistical analysis of the survey results did not reveal any relationship between cumulative needs for services and region of residence or age of the individual with a disability.

The focus group discussions gave descriptive insight into unmet needs. In particular, needs in the areas of respite, transportation, life-skills training, information dissemination,

¹¹ The areas of greatest unmet need, as reported by family members and parents, were determined by first calculating the extent to which needs within the given areas were being met. Then this calculation was weighted by the number of survey respondents that indicated this area was applicable to them. For example, help finding information was reported by a large number of respondents to be of moderate need and respite care was reported to be of a high need by fewer respondents. The weighted calculations take into consideration this range of responses to give a valid list of primary areas of need. The areas of greatest unmet need, as reported by consumers with disabilities, were determined by calculating the mean rank (Wilcoxon Sign-Rank statistic) of areas in which consumers reported to currently need more help than they receive. The anticipated needs, as reported by the educators, were calculated in the same manner as the needs reported by family members and parents.

and care for elderly individuals with developmental disabilities were frequently shared. Additionally, data from DMH/MRDD quantifying the numbers of individuals receiving services and the number of individuals on waiting lists further illuminates the unmet needs.

MRDD Services Received and Waiting Lists

The following table displays the number of Jackson County residents with developmental disabilities receiving services through DMH/MRDD. In addition to these services, individuals would also be receiving case management. See Table 13 on page 15 for the numbers of individuals receiving case management only. Of the individuals receiving MRDD services (including the 1500 individuals receiving case management) 24% are receiving residential services and 15% are receiving community supports.

Table 20. DMH/MRDD services received by disability diagnosis

Program Description							
	Autism Program	Community Supports	First Steps	Habilitation Center (Off Campus)	Intake & Assessment	Residential	Total Number
Mental Retardation	16	316	-	14	5	656	1007
Screened Mental Retardation	-	-	216	-	14	-	230
Autism/Aspergers	145	55	11	-	8	33	252
Other Developmental Disabilities	-	63	5	-	2	53	123
Mental Health Disorders	6	45	4	-	3	38	96
Other	1	9		1		3	14
Total	168	488	236	15	32	783	1722

Source: Department of Mental Health, Division of Mental Retardation and Developmental Disabilities, February 2007.

Data provided by DMH/MRDD also identified the number of individuals on waiting lists for services through MRDD. This data is delineated by individuals on in-home wait lists and individuals on residential wait lists. According to DMH/MRDD, 737 Jackson County individuals with disabilities are currently on a waiting list for in-home services and 98 individuals are on a waiting list for residential services¹². The combined total of the residential and in-home wait list represents approximately 26% of the individuals with developmental disabilities in Jackson County. This percentage of individuals on the wait list was consistent with the survey findings. On the surveys, families of adults, parents of children, and consumers were asked if they were on any waiting lists for services. Twenty percent of families of adults, 28% of parents of children, and 13% of consumers with disabilities reported to be on a waiting list. These waiting lists are for such services as autism services, group homes, respite, and independent supported living.

¹² Source: Department of Mental Health, Division of Mental Retardation and Developmental Disabilities, February 2007

Respite

In focus groups, parents discussed their frustrations with and needs for respite service. According to a number of family members of adults with disabilities, balancing a work schedule and care for their family member is often challenging. One mother shares her story of being a single parent and working full time.

“I am a single parent, my daughter’s father lives out of state, so I have no help. I work full time. The respite is my big issue. Evening and weekend respite. I have a baby sitter that she sees through where I work. Thank God I have family leave whenever I need it. I guess my big issue is having somebody available for some time off. Nobody wants to do it”

Additionally, when the individual with a disability is sick or requires specialized care, the challenge of finding qualified respite is magnified. Another mother shares her story and worries.

“A while back I know he [family member with disability] got sick and we had to have a catheter and surgery and so forth. During that time he couldn’t go to the workshop, so I was panicking because I had no idea what to do. I got a name of a place that did respite, but they were only open from 9 to 5, I mean it kind of scares me if something like that ever happens again. What if you needed something for 24 hours? Is it out there?”

Part of the reason for the lack of respite service may be due to cost. A family member of an adult with a disability reported, “Respite care funds are not anything anymore. They are like \$500 a year now. They used to be several thousand a year.” Service providers agreed with families that respite care is needed,

“... the reductions are hurtful to families. I think probably all of us see an ongoing need there. We hear it from the parents. We see the need because of the stress on the parents. It has been reduced, cut out, eliminated, whatever you want to call it.”

Transportation

Transportation is a recurring need. Both the cost and availability of transportation are of concern. Providers, families and consumers reported during the focus groups that the cost of transportation is often a barrier;

“I know Jackson County provides transportation for a lot of people. I know they are looking at other ways to provide support, but we have issues. Some of it is income based where we have people who can’t pay their utility bill, or dental services. Just anything that is basic living-let alone transportation.”

Another service provider echoed the need for more affordable transportation,

“We need transportation. We do pay for taxi cabs for people to go places. Transportation is a horribly expensive part of what we do, but I think it is a very, very essential service.”

For individuals with disabilities, the lack of flexibility in transportation often interferes with their independence and opportunities for social outings. As one individual with a disability sums it up, “I would like more flexibility in transportation so I can go where ever

I want, when I want to go.” Family members agreed that flexibility and availability of transportation is important. When transportation is not available, it can be very disappointing. A family member gives an example,

“Don’t give the group home tickets to Starlight if there is nobody there to take them. It is wonderful to give out 20 tickets to the Shriner’s Rodeo or the circus but if there isn’t a bus to get them there, then they can’t go. That is another part of the social/emotional interaction and a sense of independence is going on at these outings or going to the dances each month [and it is such a let down].”

Life Skills Training

The secondary special educators commented on the ongoing need for life skills training beyond high school. Parents of transition age children and family members of adults reiterated this need. A parent of a transition age student is thinking about her son’s future and his need for life-skills training, *“I think for our son, the biggest concern-or the area of need or help is life skills. Our ultimate goal for him is that some day he could live in a supervised group home.”* In a chorus of opinions, family members shared their testimonies of the value of life skills training and the ongoing need.

“We have talked about life skills-going out and taking her shopping so that she knows how to use money. She is not good with money. We have told our case managers time and again that that is what we are interested in. They agree with us, but we have been told the money has been cut so the funds aren’t there for that.”

Another family member added,

“What we need are social skills, which they [service providers] refuse to pay for social skills. We really need life skills. We have a safety issue. He [family member] runs in front of 5,000 pound trucks and doesn’t have a clue that he could be killed.”

An individual with disabilities described the importance of learning life skills on all aspects of their life.

“The place where I work has all kinds of classes. People don’t think that eating breakfast and grocery shopping has anything to do with having a job, but it does. And so you learn to go to the store and select healthy foods, and you learn how to make a doctor’s appointment and stuff. They teach you to shop, budget, every kind of life skill that they think you need to work on and it has made life better.”

Information Dissemination

Several family members discussed the lack of information about services and organizations that provide help for people with disabilities. In the focus groups, parents and family members shared their impression that service providers were sometimes reluctant to relay information about available options for possible reasons of further overextending workloads. A family member observed that *“in fact the system is almost secretive. And everybody who knows something is holding their cards tight. That is just how it is. If you*

don't ask then they are not going to tell you." Other parents and family members echoed this same statement,

"The service coordinator-they aren't calling you up and going, 'Hey, I learned about this. Put your kid in this.' They are taught not to do that. They are working the front line. They are in the ditches. They are looking you in the face and saying there is no money."

This impression was confirmed in the focus group of service providers. Service providers explained that it is indeed true. Sometimes service providers withhold information about available services because they feel they would do an injustice to the individual because they would be unable to follow through with the referral and support of the individual in attaining additional services. Other times, there seems to be a disconnect in the relay of service options and this is disconcerting to service providers. Service providers are often surprised to hear that families have not received information. For example, a service provider shared,

"A lot of the inequality is knowledge based because as we said before, they [families, people with disabilities] are not given the information. I know we have all encountered families who will tell us they have never been told any of the information we are giving them. It is like, wait a minute, this is basic information. Somebody, either in the transitioning from school into adulthood or through their case manager if they have such a thing should have told them about it. Maybe they didn't follow through, but they at least know about it. This is across the board whether it is a head injury, mental illness. I don't know how to solve it, but there is something wrong."

Some options to help improve the flow of information included *"a once a month kind of coffee group kind of like this [focus group] where on a regular basis, we can go and meet people and talk about issues,"* as shared by a family member of an adult with disabilities. Another family member added, *"It would be great if information was centrally located and you could go there and know what is available or where you need to go."* Another central idea was that of a *"universal directory of all the programs in Jackson County,"* commented a family member of adult with disability.

Services for Aging Individuals with Disabilities

In the discussion of housing status and needs, comments from service providers described their concern for the future of aging adults with developmental disabilities was shared. Adding to that discussion were additional providers, as well as family members, sharing their concerns about options for day time activities for elderly individuals with developmental disabilities. One elderly mother, whose daughter has been placed in a group home for elderly women observed,

"The big problem lies in funding, and that comes out of Jefferson City. Jackson County Board of Services gets a lot of money and they spend their money wisely. But we have all of these people that were cut from Medicaid. We have abuses going on in the system. All of your children are still young [the focus group attendees] but we have disabled people in their 70's and

80' that are still in the workshop because there is no place for them to go. There is no place for them to retire."

Day programs in particular were noted as an important option for people with disabilities that may want to retire. One suggestion was a drop in, or part time day program, would be a helpful option. A family member of an adult with disabilities described this concept,

"You know the daytime program for retired people, it could work in another way too and that is people who are still taking care of their own relatives, child or whatever, and have been for two decades, may want a day off once a week or once a month or something. It would be nice to have a day program."

Providers agreed there is a growing need for services for people with disabilities as they age. However, their concerns are that there are limited options for individuals with disabilities that are somewhat self-sufficient and that the residential or workshop settings are not as appropriate. This dilemma was explained by a service provider,

"We have got to figure out how take our older individuals who have a disability into their mature years. I have five right now that I am really concerned about because they are over 62. We don't have options. We really don't have options particularly if they are self-sufficient to a great degree. If they are self-sufficient and they need other kinds of support, we really don't have that. They are just not fitting into other niches, and we haven't addressed it."

Summary

- *Of the 3,222 individuals with developmental disabilities in Jackson County reported by DMH/MRDD to receiving services, 26% are on a waiting list for services. In regard to the estimated 13,294 Jackson County residents with developmental disabilities, 6% are on a waiting list for services.*
- *Individuals with disabilities reported needing more support with social relationships, employment, and housing.*
- *Caregivers reported needing assistance with finding information, connecting their son/daughter with social and recreation activities, monitoring the quality of services, and finding family support groups.*
- *Educators and caregivers of students reported a need for continued education after graduation on life skills and more supported employment opportunities.*
- *The need for respite care was shared through focus groups and the surveys as a high priority for families of children as well as families of adults with more significant disabilities and/or health concerns.*
- *Accessible, flexible, and affordable transportation is needed.*
- *Life skills training for young adults with developmental disabilities*

Summary (continued)

- *Families reported needing more information about available services, supports, resources, and opportunities in Jackson County for individuals with developmental disabilities.*
- *Families and service providers shared there is a growing need for services with people with disabilities as they reach retirement age.*

Community Resources

One aspect of this needs assessment is the analysis of where the resources or services are located. Additionally, service providers were asked to indicate the availability of services and their opinion if the availability needs to be increased or not. Combined these sources give insight into gaps in the availability of services.

Mapping Community Agencies and Organizations

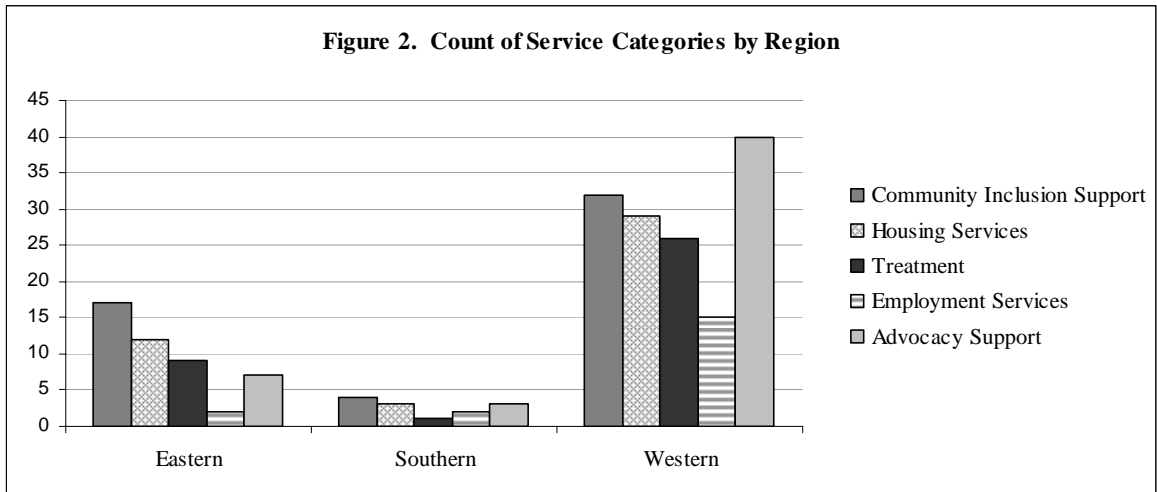
A resource inventory comprised of the range of services and resources available in Jackson County was compiled. This inventory includes 184 agencies and organizations providing services to Jackson County residents. This comprehensive list includes both agencies and organization located within and outside Jackson County. In mapping the location of the resources located within Jackson County, the list was narrowed to 119 agencies and organization. These agencies and organizations offer an array of services, which were categorized into five service types: community inclusion support, housing services, treatment, employment services, and advocacy and support. The following lists the specific services within each category.

Where are services in Jackson County located?

From the perspective of service providers, which services and supports need to be more available?

- **Community inclusion support:** personal assistance, case management, community integration and daily learning skills/activities.
- **Housing services:** residential services, respite services (in home and out of home), and daily living skills, individualize supported living
- **Treatment:** rehabilitation, habilitation (on-site and offsite), assessments, behavioral management, infant/toddler screening, therapeutic interventions/services, evaluation and specialized treatment, and counseling.
- **Employment services:** supported employment, vocational training, sheltered workshops, career awareness, and job placements.
- **Advocacy and support:** advocacy, classes/workshops, education consultants, library access, assistive technology/equipment, support groups, referrals, disability community activities, GED classes, awareness programs, group activities, services, information, and parent/caregiver training.

Figure 2 displays the density of services by region. It is important to note that many agencies and organizations provided services across multiple categories; thus, they may be counted more than once. As shown in Figure 2, the array of services is more present in the western region of the county compared to the other regions (see page 4 for a description of the regional boundaries). A limitation of this mapping is that it is based on the address(es) of the agency and does not account for services provided in homes across the county.



Availability of Services

On the survey, service providers were asked to indicate (a) how available they believed services and supports were for Jackson County residents with disabilities¹³ and (b) if the service/ support needed to more available. The survey results showed that some services/ supports such as person-centered planning and group homes were believed to be sufficiently available. Other services such as support brokers and microboards were noted as being less available; however, there was not a perceived need to increase their availability. Table 21 lists the services and supports that over 85% of the service providers believed need to be more available for Jackson County residents with disabilities.

Table 21. Percent of service providers reporting services and supports need to be more available

Service & Support for Individuals with Disabilities	% of Adult Service Providers
Public transportation*	96%
Help finding social clubs*	96%
Therapy for individuals that have been physically, sexually, or emotionally abused*	94%
Health professionals who listen to client needs*	90%
Family support groups*	90%
Help with building friendships	88%

¹³ Ranked on a scale of widely available, somewhat available, or not available.

Service & Support for Individuals with Disabilities	% of Adult Service Providers
Counseling or mental health services	88%
Getting information about trusts and guardianships*	86%
Job skills training	86%
Resources and information about available services	86%
Help finding recreation activities	86%

*Current low availability and highly important to increase

The services and supports asterisked in Table 21 were identified as areas of the greatest unmet need. In other words, service providers indicated these services were not widely available and it was important to increase their availability. The services of transportation, help finding social clubs, and family support groups have already been discussed in this report. Accessible, reliable, and flexible transportation is an ongoing challenge for individuals with disabilities and their families. Furthermore, the challenge of transportation impedes participation in community and social activities. Family support is also an ongoing need. Families remarked on the value of sharing information with each other and some commented on the therapeutic qualities of the focus groups suggesting similar discussions occur more frequently.

Service providers also introduced the perceived need for (a) therapy for individuals that have been physically, sexually, or emotionally abused, (b) health professionals who listen to client needs, and (c) getting information about trusts and guardianships. Unique to service providers was the mention of a need for more responsive health professionals. This was not a concern raised by the individuals with disabilities, family members of adults, or parents of children. Likewise, the reported need for therapy for individuals with disabilities in response to abuse was unique to service providers. These results suggest service providers witness a pervasive need for improved responsiveness to the health and well-being of individuals with developmental disabilities. Review of the literature reveals staggering rates of maltreatment of individuals with disabilities. While research results vary, the lifetime prevalence rate of maltreatment of individuals with disabilities approximates 40%.¹⁴

Summary

- *Considering three regions of Jackson County (eastern, western, and southern), the array of services is more available in the western region.*
- *Service providers reported priority needs for increased availability of the following services: public transportation, help finding social clubs, therapy for individuals with disabilities that have been abused, family support groups, responsive health professionals, and getting information about trusts and guardianships.*

¹⁴ Horner-Johnson, W. & Drum, C. E. (2006). Prevalence of maltreatment of individuals with intellectual disabilities: A review of recently published literature. *Mental Retardation and Developmental Disabilities Research Review*, 12, 57-69.

Priority Areas for Improvement

From an array of services and supports, survey respondents were asked, “What do you believe to be the top 5 priority areas for improvement of services in Jackson County for all people with developmental disabilities?” The importance of this question was to give stakeholders the opportunity to share their opinion about the priority service areas for all persons with developmental disabilities, not just themselves, family member, client, or student. Table 22 comparatively displays the ranked top five responses and percentage of survey respondents indicating the service area as a priority. Commonalities across stakeholder groups are the priorities in the areas of employment, awareness of available services, family support, services for aging persons with disabilities, and continuing education. These results reiterate the focus group discussions and other survey findings.

For all Jackson County residents with developmental disabilities, what are the priority areas for improvement?

Table 22. Priority services and supports for improvement (percentage of survey respondents)

Consumers	Families of Adults	Parents of Children	Service Providers	Secondary Special Educators
48% Sheltered workshops	41% Aging 41% Group homes	24% Family support	42% Aging 35% Employment Services	35% Employment Services 26% Transition
42% Transportation	32% Sheltered workshops	22% Respite services	29% Public awareness of services	24% Continuing education 21% Family support
39% Help getting a job	29% Public awareness of available services	18% Inclusive education	29% Early intervention	21% Transportation
34% Classes to keep track of money	27% Day programs	17% Case management	26% Case management	
32% Supported independent living		15% Transition		

Summary

- *Employment, housing, continuing education, information dissemination, transportation, services for aging individuals, and family support were reported priority areas for improvement across stakeholders.*

RECOMMENDATIONS

The following recommendations are based on all the needs assessment findings. While numerous areas of need arose in this study, a few overarching needs were identified across stakeholders.

Expand and Enhance the Array of Housing and Employment Options

Across all areas of need and as reported by all stakeholders, there is a belief that the current array of services should be strengthened such that supported employment and independent living options are available for more adults with developmental disabilities. Many family members of adults with developmental disabilities remarked on their comfort in the safety and social acceptance that sheltered workshops provide. In contrast, there were family members and individuals with disabilities, in addition to most parents of children, which desired other employment options. This scenario is similar with regard to housing. Many adults with developmental disabilities live either with their family or shared residential settings and generally, these stakeholders are satisfied with this arrangement. However, individuals with disabilities and certainly parents of children with disabilities, would like to have more opportunities for independent living, with or without paid support. In summary, stakeholders commented on providing needed support to help individuals with disabilities recognize their fullest potential, which includes opportunities for supported employment and independent living.

Provide Relationship-Based Service Coordination

Service coordination is most effective when it is a partnership between the individual with a disability, his/her family or support network, and the service coordinator for the purpose of achieving life goals and desires. It is most ideal when service coordinators are able to develop a relationship with the individual, learn his/her needs, respond to his/her choices, and support connections to needed services and supports. However, the current system of service coordination is burdened with high case loads and multiple responsibilities.

Improving service coordination will likely involve reducing caseloads and finding ways to enhance service coordination such to encourage and facilitate opportunities for building meaningful relationships leading to effective partnerships.

Increase Availability of Continuing Education

The need for life skills training and continuing education was repeated across stakeholder groups. After graduation, there are many young adults with developmental disabilities needing continuing education, either life skills training or college-like experience. Service providers and caregivers believed the potential of many individuals with developmental disabilities is unrealized due to lack of continued education. Additionally, individuals with disabilities shared their desire for continuing education. Increased opportunities for continuing education, particularly in the immediate years after high school, would be beneficial.

Increase Availability of Accessible and Flexible Transportation

A lack of transportation hinders access to the community, resulting in isolation and missed opportunities. Individuals with disabilities identified help finding social groups, friends, and a new job as a key unmet needs. Families told stories of disappointment when free tickets to an event are donated to a group home, but lack of transportation prevents the residents from participating. All of these are dependent upon transportation being available. Current public transportation options for individuals with disabilities, especially for those requiring an accessible vehicle, are limited. Accessible transportation that is readily available and accommodates varying schedules and destinations would be ideal.

Increase Support and Services for Aging Individuals with Disabilities

The needs of aging individuals with disabilities is clearly a worry for aging family members currently caring for their loved one with a disability and for service providers recognizing the future needs of these individuals. There appears to be much uncertainty as to what should be in place for elderly individuals with disabilities. There is a question as to what options need to be provided for individuals with disabilities as they get older. The data indicates a large percentage of individuals with disabilities living with their family members. However, when a caregiver dies or is no longer able to be independent, care for the individual with a disability becomes in question.

Improve Dissemination of Information

Information about available resources, services, and supports is an ongoing need for all stakeholders. The challenge is in sharing this information in a timely and comprehensive manner. Often, the status of agencies/organizations can change causing information to be inaccurate. There is a need to increase awareness of existing information resources (i.e. Network of Care and Missouri Developmental Disabilities Resource Center) and support less formal approaches to sharing information such as parent support groups.