

# Needs Assessment Report



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## **Background**

The year 2018 represents the 40<sup>th</sup> anniversary of the Jefferson County Developmental Disabilities Resource Board (JCDDR), now known as Developmental Disability Advocates. In August of 1978, the generous voters of Jefferson County established the Jefferson County Commission for the Handicapped (later renamed the Jefferson County Developmental Disabilities Resource Board) through the passage of “Proposition S” – “The Special Ones”. The passage of Proposition S led to a 10-cent levy on each one hundred dollars of assessed property. The funds collected from the 10-cent levy were and still are used to develop community-based supports for the numerous citizens of Jefferson County with developmental disabilities. In 1985, the 10-cent levy was rolled back to 6-cents as a result of re-assessment and, in 1988 with the Passage of Proposition H, the levy was increased by 4-cents restoring it to the original amount of 10-cents per each one hundred dollars of assessed property. In 1996, a ballot initiative, (again, Proposition H) appeared on both the August and November ballots to increase the levy from 10-cents to 15-cents. Both failed at the polls. There was not a significant marketing campaign connected to this initiative, which was determined as the key factor in its failure.

Therefore, for the last thirty years, Developmental Disability Advocates has frugally operated within this budget to carrying out the mission of **providing resources to create opportunities for individuals with developmental disabilities in Jefferson County to live full and enriched lives.** However, while the number of people served and the level of services has expanded since 1988, the levy has not been increased. Today, this tax levy only generates approximately three million dollars annually to fund this all important mission.

In June 1980, Developmental Disability Advocates established the non-profit corporation, Exceptional Ones, Inc. (now known as NextStep for Life) to provide direct, community-based services to individuals with developmental disabilities in Jefferson County. That 37 year history as essentially one entity came to a close in 2017 as federal and state mandates required conflict free case management in Missouri, resulting in two separate agencies with distinct Boards of Directors and executive leadership. This separation formally occurred on July 1, 2017. Both agencies developed strategic plans for fiscal year 2016 – 2020 (July 1, 2015 – June 30, 2020) and two goals of the Developmental Disability Advocates strategic plan are to:

***Strategic Goal #1: By July 1, 2019, Developmental Disability Advocates will be positioned to respond to the needs of individuals with developmental disabilities residing in Jefferson County.***

- Objective #1.1: By July 1, 2017, Developmental Disability Advocates will have completed a comprehensive needs assessment designed to provide information on the present and future projection of the prevalence and needs of individuals with developmental disabilities in Jefferson County.

***Strategic Goal #2: By June 30, 2020, Developmental Disability Advocates will have financial resources to meet the present and future needs of the County that are sufficient, stable and sustainable.***

- Objective #2.1: By July 1, 2019, Developmental Disability Advocates will have completed a feasibility study on the level of success for passing an increase in the tax levy by June 30, 2020.

- Objective #2.3: By July 1, 2019, Developmental Disability Advocates will be allocating its available funds based on established priorities that reflect the needs of individuals with developmental disabilities living in Jefferson County.

Furthermore, Key Performance Indicators (KPI's) were established related to these strategic goals and objectives:

**KPI #1:** As the result of a comprehensive needs assessment, Developmental Disability Advocates will have an empirically based projection of the prevalence and needs of individuals with developmental disabilities in Jefferson County.

**KPI #3:** The decision will have been made to seek or not to seek an increase in the tax levy.

In partnership with the Department of Mental Health – Division of Developmental Disabilities (DDD), 1,264 individuals with I/DD in Jefferson County were actively receiving essential resources through service coordination supports as of 6/30/17. According to the 2010 census, Jefferson County is home to more than 218,000 individuals. Applying the accepted prevalence rate of 1.58% for people with intellectual and developmental disabilities in the general population (Larson, et al., 2001), there could be approximately 3,444 individuals with I/DD in Jefferson County. However, from FY13 – FY18, 338 individuals from Developmental Disability Advocates were discharged from services for various reasons such as moving out of the county, death, unable to locate, etc. and while the number discharged from DDD for the same time period is unknown, it could be estimated around 170. This would mean approximately 500 additional people were at one time receiving formal services and supports, but were not active on 6/30/17. Therefore, Developmental Disability Advocates and DDD could be serving an additional 1,680 individuals who are living in the county and potentially have unmet needs for services.

This report will serve as summary of needs assessment data collected from July 2017 through June 2018, the various sources of data, means of collection, number and description of stakeholders represented, data findings and interpretation.

## **Methodology**

A formal needs assessment survey was developed by the TOGETHER committee, which serves as an advisory committee to Developmental Disability Advocates. TOGETHER is a 10 member, voluntary committee appointed by Developmental Disability Advocates and comprised of family members of a person with a developmental disability, self-advocates (a person with a developmental disability) and agency/community representative. 50% must be family members or self-advocates and 50% are agency/community representatives. The needs assessment survey was finalized in June 2017 and ran in the News-Leader the week of July 6 (see Exhibit A). In addition to the full page survey in the newspaper, a Survey Monkey version was made available on the agency website and Facebook page, an e-mail version was sent to the Provider Partnership group, TOGETHER committee, Developmental Disability Advocates Service Coordination

Larson, S.A., Lakin, K.C., Anderson, L.L., Kwak, N., Lee, J.H., Anderson, D. (2001). Prevalence of mental retardation and developmental disabilities: Estimates from the 1994/1995 National Health Interview Survey Disability Supplements. American Journal on Mental Retardation, 106, 231-252.

and Board, Department of Mental Health (DMH) – St. Louis Regional Office (SLRO) Jefferson County team, and paper copies were also made for distribution. There was not a formal date for submission identified, however, when only 80 surveys had been submitted as of August 28, 2018, Developmental Disability Advocates Executive Director, Stacey Ismail, wrote a letter to the editor of the News-Leader, published September 14. This effort made little impact on the overall number of surveys received. A grand total of only 87 responses were received - 58 were done manually and submitted and 29 were done electronically using the survey link. With the poor response rate from the actual needs assessment survey, other sources of information about the needs of individuals with developmental disabilities in Jefferson County were sought. The following sources were identified to assist in summarizing needs data:

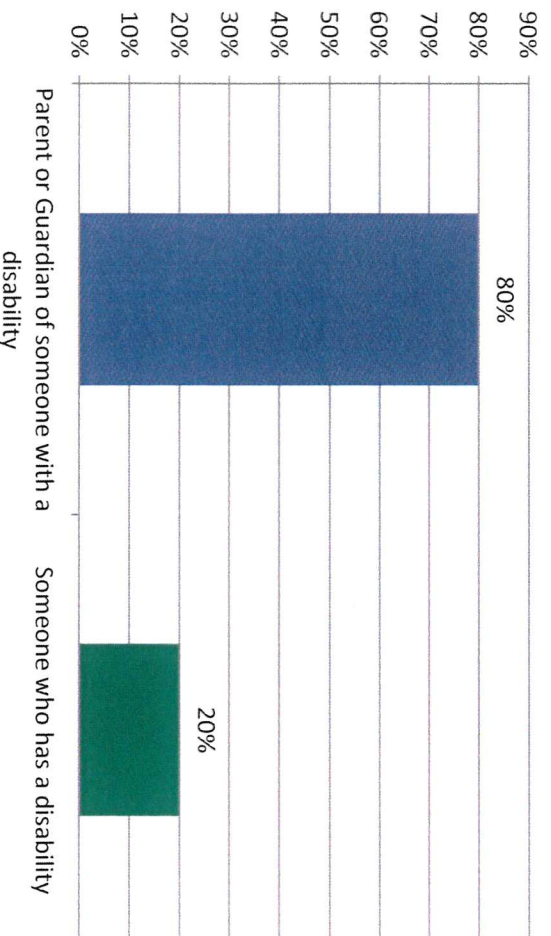
- Developmental Disability Advocates Service Coordination Satisfaction Survey & Accessibility Analysis – June 2017 (809 sent – 386 responded for a 48% return rate) & June 2018 (826 sent – 341 responded for a 41.28% return rate)
- Developmental Disability Advocates Service Coordination Wait List Report – March 2018
- Annual Reports – FY13 through FY17
- Coordinated Public Transit-Human Services Transportation Plan – Prepared for the Jefferson County Community Partnership by the LSC Transportation Consultants, Inc. – February 2018
- Anecdotal Information from Provider Partnership, TOGETHER and Developmental Disability Advocates Board meetings

### **Demographic Data**

The following data was obtained from the needs assessment survey:

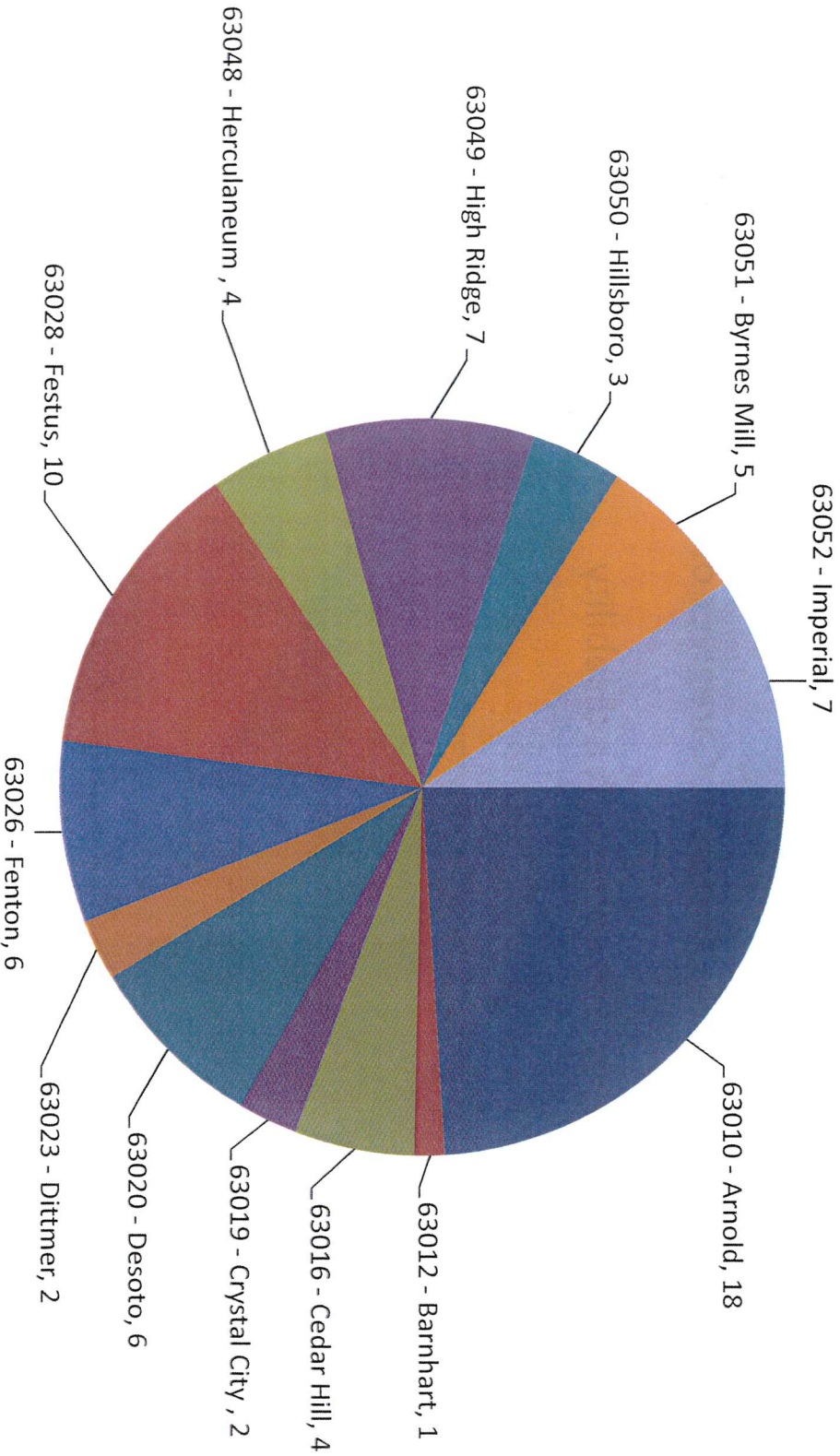
## 2017 Needs Assessment Survey Data

- Question 1 asked who they were, either someone with a disability or the parent or caregiver of someone with a disability.
- Of the 87 responses – 80 people chose to answer – 7 skipped the question
- 80 % of the responders were the Parent or Caregiver of someone with a disability
- 20% of the responders were someone with a disability



# 2017 Needs Assessment Survey Data

## Responses by Zip Code/Geographical Area



## 2017 Needs Assessment Survey Data

- Question 3 asked for the age of the person with the disability.

Responses by Age of the Individual

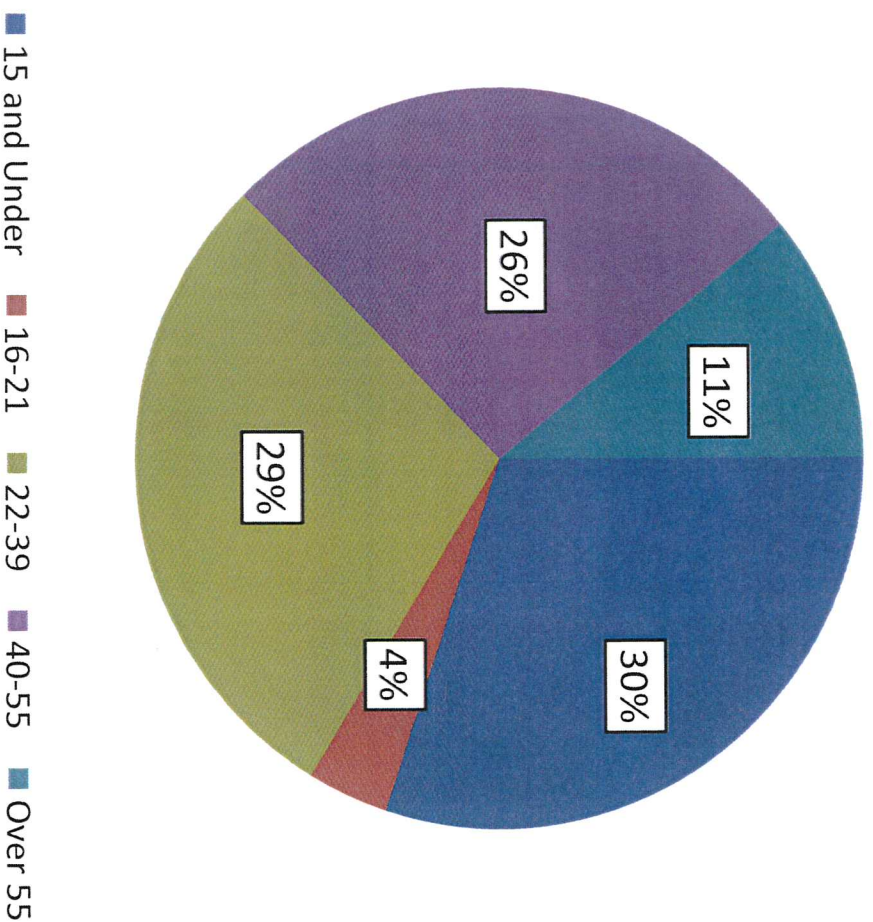


Table 1			
Ages	FY17	FY13	Cumulative % Increase
*Birth - 16	448	437	2.5%
16-20	157	109	44%
21-30	236	208	13.5%
31-40	158	130	21.5%
41-50	114	118	(3.4%)
51-60	101	97	4.1%
61-over	50	39	28.2%
Totals	1,264	1,138	11% increase

\*Served by DMH

### **Demographic Analysis:**

Not surprisingly, the majority of individuals who completed the surveys were the parent or caregiver of the person with the disability. While the majority of responses were received from the major population centers in the county – Arnold and Festus – there were responses received from throughout the county demonstrating equal access to the survey and opportunity to participate.

The number of individuals served by Service Coordination has grown by approximately 11% in the past five years as evidenced in Table 1. This table also indicates that the most growth has been in the 16-20 age range closely followed by the 61+ age range. The services needed by individuals in these two age ranges vary greatly as they are in very different stages of life.

In reaction to a decision by the Department of Mental Health – Division of Developmental Disabilities to no longer provide service coordination, effective July 1, 2018, to individuals without Medicaid, autism, or other general revenue funded services, Developmental Disability Advocates transitioned 55 individuals over the age of 3 into JCDDR service coordination during the last quarter of FY2018. The total number of individuals receiving service coordination between the Department of Mental Health and Developmental Disability Advocates is 1,313 as of July 2018.

### **Service Data Analysis**

The following service data analysis was gathered from the needs assessment survey:



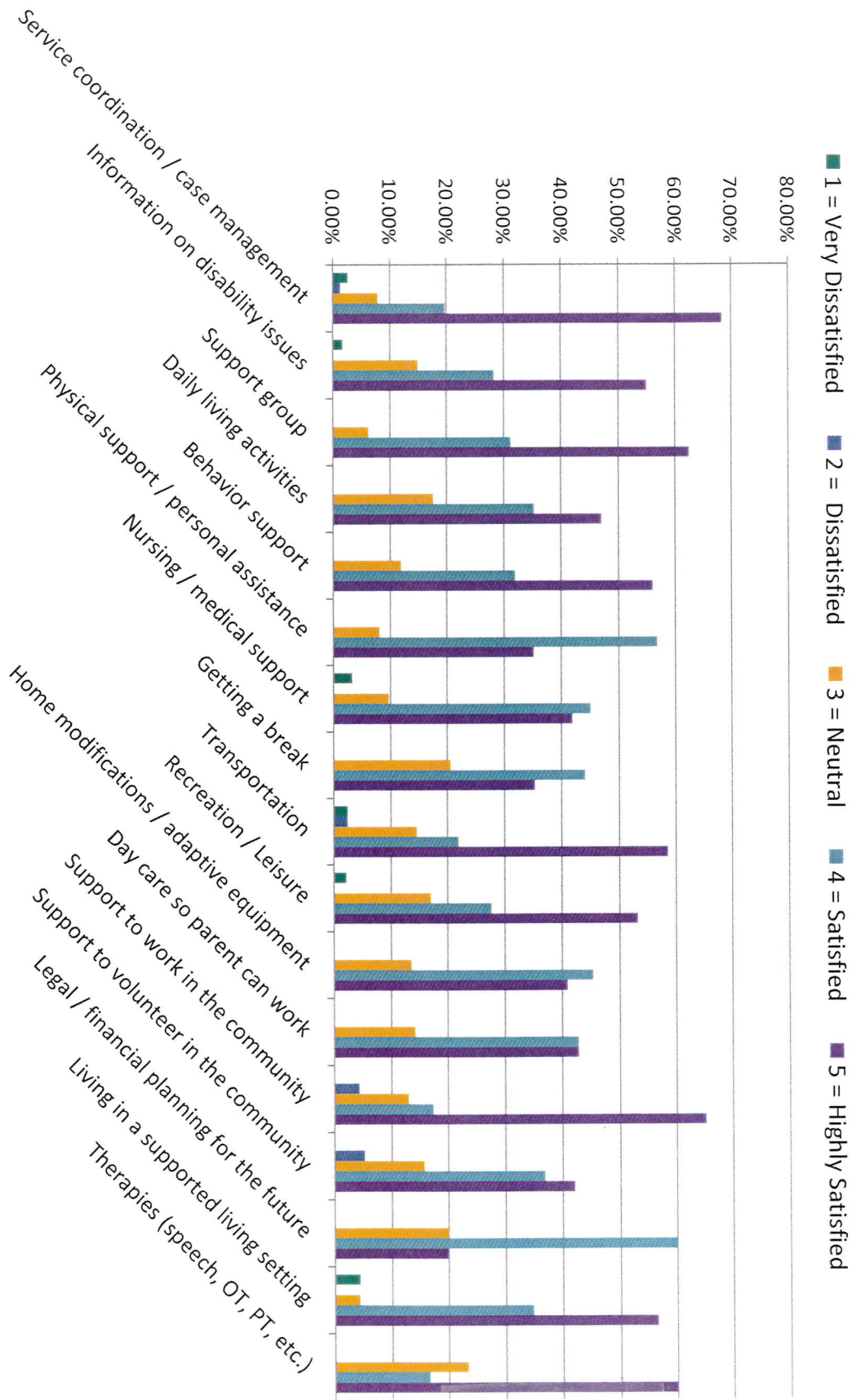
## 2017 Needs Assessment Survey Data

Question 4 - Are you or the person with a developmental disability receiving the following?

	Yes	No
Service coordination / case management	91.67%	8.33%
Information on disability issues	72.62%	27.38%
Support group	18.52%	81.48%
Daily living activities	39.76%	60.24%
Behavior support	28.57%	71.43%
Physical support / personal assistance	44.58%	55.42%
Nursing / medical support	36.14%	63.86%
Getting a break	43.37%	56.63%
Transportation	53.57%	46.43%
Recreation / Leisure	61.18%	38.82%
Home modifications / adaptive equipment	24.71%	75.29%
Day care so parent can work	17.07%	82.93%
Support to work in the community	28.92%	71.08%
Support to volunteer in the community	22.62%	77.38%
Legal / financial planning for the future	23.17%	76.83%
Living in a supported living setting	27.38%	72.62%
Therapies (speech, OT, PT, etc.)	35.37%	64.63%

# 2017 Needs Assessment Survey Data

If "yes", rate the service



## 2017 Needs Assessment Survey Data

If the respondent answered “NO” that they are not receiving those services, it was asked if the service would be needed in the next 5 years.

	Yes		No		Unsure	
Service coordination / case management	57.14%	8	7.14%	1	35.71%	5
Information on disability issues	58.33%	14	25.00%	6	16.67%	4
Support group	22.81%	13	38.60%	22	38.60%	22
Daily living activities	28.57%	12	33.33%	14	38.10%	16
Behavior support	15.69%	8	52.94%	27	31.37%	16
Physical support / personal assistance	21.95%	9	39.02%	16	39.02%	16
Nursing / medical support	11.90%	5	50.00%	21	38.10%	16
Getting a break	16.28%	7	46.51%	20	37.21%	16
Transportation	36.36%	12	33.33%	11	30.30%	10
Recreation / Leisure	48.39%	15	19.35%	6	32.26%	10
Home modifications / adaptive equipment	16.36%	9	45.45%	25	38.18%	21
Day care so parent can work	12.50%	7	73.21%	41	14.29%	8
Support to work in the community	33.33%	17	43.14%	22	23.53%	12
Support to volunteer in the community	25.00%	13	51.92%	27	23.08%	12
Legal / financial planning for the future	39.62%	21	28.30%	15	32.08%	17
Living in a supported living setting	21.15%	11	44.23%	23	34.62%	18
Therapies (speech, OT, PT, etc.)	21.28%	10	44.68%	21	34.04%	16

## **Current Service Data Analysis:**

The data from the needs assessment survey indicate a high level of satisfaction with services currently received and the top four services being most used (in order of usage):

1. Service Coordination
2. Information on Disability Issues
3. Recreation/Leisure
4. Transportation

It was not identified who the provider of these services are or other details about the frequency, intensity or duration of the services. These 4 services are all funded in full or in part by Developmental Disability Advocates and service coordination is directly provided by the agency for individuals 16 or older or approximately 70% of the respondents.

Additional data from Service Coordination in Table 4 describes how the approximately \$25 Million in authorized services are distributed based on needs and goals identified in a person's Individual Support Plan (ISP). The amounts in Table 4 reflect authorizations, not necessarily services delivered, and are not unduplicated - meaning one person could be receiving multiple services. Utilization of services is approximately 80%, so therefore around \$20 Million was utilized to provide services to approximately 816 people (Table 4 is only Developmental Disability Advocates data). These are services funded by Medicaid, the Department of Mental Health – Division of Developmental Disabilities or Eastern Missouri Autism Project (EMAP) funds. The only amount funded by Developmental Disability Advocates in Table 4 is \$150,000 in respite for FY13 and FY17 (funding through service coordination revenue).

Table 4\*

Service	FY17	# of people served	Ave. annual cost per person		FY13	# of people served	Ave. annual cost per person
Residential Services	\$16,354,278	146	\$112,016		\$10,680,835	129	\$82,797
Personal Assistance	\$2,759,470	99	\$27,873		\$1,219,205	137	\$8,899
Day Habilitation (includes ISD)	\$2,220,466	120	\$18,504		\$1,769,897	127	\$13,936
Transportation	\$1,035,055	226	\$4,580		\$832,242	153	\$5,439
Community Integration	\$777,547	89	\$8,736		\$385,766	70	\$5,511
Specialized Medical Equipment	\$417,669	164	\$2,547		\$160,102	71	\$2,255
Employment Services	\$186,002	11	\$16,909		N/A	N/A	N/A
Physical Therapy	\$169,720	138	\$1,230		\$94,811	117	\$810
Applied Behavioral Analysis	\$124,369	69	\$1,802		\$38,557	12	\$3,213
Respite	\$243,614	162	\$1,504		\$221,855	165	\$1,344
Speech Therapy	\$82,446	112	\$736		\$48,545	88	\$552
Occupational Therapy	\$69,934	142	\$492		\$68,045	114	\$597
Dental	\$20,496	2	\$10,248		\$5,575	1	\$5575
Other	\$285,241	N/A	N/A		\$45,030	N/A	N/A
<b>Total</b>	<b>\$24,746,307</b>	<b>1,328</b>			<b>\$15,570,465</b>	<b>1,184</b>	
<b>Change over 5 Years</b>	<b>59% increase in authorized costs</b>	<b>12% increase in persons served</b>					

\*Table 4 does not include authorizations from DMH service coordination.

Table 5 depicts growth in funding awards by Developmental Disability Advocates over the past five years. It can be assumed that the needs of individuals are represented in the requests of the agencies funded with county tax dollars. Developmental Disability Advocates does not fund services otherwise paid for by another funding source such Medicaid, DMH or EMAP.

Table 5			
Agency Funded	Service(s) Funded	FY17 Amount	FY13
<b>Total</b>		<b>\$4,021,180.00</b>	<b>\$2,714,947.00</b>
<b>Percent Change</b>		<b>48% increase</b>	

An almost 50% increase in funding awards to agencies over a 5 year period is significant and not sustainable without depleting agency reserves.

## Wait Lists:

At the time of this needs assessment, the following waitlist information was gathered by agency to further identify needs in Jefferson County. The challenge with these numbers is that they are likely duplicated and quickly become outdated. The TOGETHER advisory committee is discussing how the various agencies could collaborate in the future to capture more reliable, unduplicated data on needs without compromising protected personally identifiable consumer information.

### **DDAdvocates Service Coordination (individuals not waiver eligible)**

#### 11 on waitlist due to no funding:

- 3 - Personal Assistance
- 1 - Day Habilitation
- 1 – Community Integration
- 2 – Speech Therapy
- 2 – Occupational Therapy
- 3 – Specialized Medical Equipment
- 1 - Behavior Therapy
- 1 - Parent Training
- 2 - Skill Development
- 1- Hippotherapy

#### 18 on waitlist due to no provider:

- 7 – Physical Therapy
- 4 – Personal Assistance
- 2 – Individualized Supported Living
- 1 – Day Habilitation
- 1 – OT Eval
- 1 – Speech Eval
- 1 – Speech Therapy

## Anecdotal Information:

Service Coordination conducts an annual satisfaction and accessibility survey in June of each year. There is opportunity for individuals/guardians/families to write in answers to the question, “What service or support would improve the quality of your life?” Combining the answers into broad categories resulted in the following data:

Service Needed	FY17	FY18
Residential Services	4	6
Personal Assistance	8	11
Day Habilitation	2	4
Community Integration/volunteer opportunities	6	7
Employment Services	5	4
OT, PT, and/or Speech	2	3
Behavior Services	2	4
SSI/Medicaid/Health Insurance	4	1
Transportation	13	
Specialized Medical Equipment	3	
Environmental Accessibility Adaptations	4	
Social/Leisure/Recreation	6	
Access to Camp	2	
Dental Services	2	
Exercise Equipment	1	
Educational Classes – Cooking, Budgeting, Computers, etc.		5
Driving Lessons		9
Services for Individuals Graduating		3
Staff Consistency		2
Self-Directed Services		1
Help with medication		1
More providers in Jefferson County		2

There are a few service needs that have been identified that have not been common in past surveys such as driving lessons and educational/life skills classes. This information is an opportunity for Developmental Disability Advocates to present options to existing providers or recruit new providers to explore providing these types of services.

## Transportation Needs:

Transportation remains one of the most needed services, not only for people with developmental disabilities, but for many in Jefferson County. In 2017, The Jefferson County Community Partnership contracted with LSC Transportation Consultants, Inc. of Colorado Springs to develop a Coordinated Public Transit-Human Services Transportation Plan. There are specific requirements for this type of plan including an inventory of existing transportation services, identification of unmet transportation needs, identification of duplication of services and gaps in service, and development of strategies to reduce duplication and serve the unmet needs. The final plan report was released in February 2018 and includes a set of recommendations with proposed timelines.



JC Transit is the transportation system previously owned and operated by Developmental Disability Advocates to provide services to individuals with disabilities in Jefferson County. OATS, a private non-for-profit company specializing in transportation, took over ownership of JC Transit on July 1, 2017 as part of the conflict free case management changes. People who are disabled as defined by the Americans with Disabilities Act (ADA) are eligible to ride JC Transit. Eligibility is determined on an individual basis by JC Transit staff. Services are provided daily from 6:00 a.m. to 10:00 p.m. with the exception of designated holidays.

JC Transit is a curb-to-curb transit service with scheduled routes and Request-a-Ride services. Scheduled routes are provided for individuals who attend developmental training programs or are employed at JSI, Inc. (sheltered workshop). Trips for eligible riders are paid by MoDOT (MEHTAP), the Department of Mental Health (DMH), and Developmental Disability Advocates. However, a project is underway in 2018 to change the funding source for scheduled routes to JSI, Inc. to Medicaid Waiver if the person is eligible for waiver funding. This will allow Developmental Disability Advocates to allocate an estimated \$100,000 to provide additional request a ride trips. Request-a-Ride services may be scheduled for medical appointments, shopping, employment, nutrition sites, and leisure activities, and require reservations 48 hours in advance.

Five year data for JC Transit reflects that scheduled routes have slightly decreased over time, while request a ride services have increased.



JeffCo Express is a public transit service operating four deviated routes. JeffCo Express was designed to serve senior citizens, persons with disabilities, and low-income individuals in Jefferson County. The Jefferson County Community Partnership (JCCP) serves as the project coordinator of JeffCo Express and the service is operated by OATS, Inc. Ridership has grown from fewer than a thousand passenger-trips during FY 2010 to over 17,000 passenger-trips during FY 2017. 2,943 individuals with a disability benefitted from JeffCo Express in FY17. Developmental Disability Advocates typically supports JeffCo Express with \$2,500 annually to fund riders with developmental disabilities.



OATS, Inc. records and reports monthly on the number of JC Transit rides they have to deny, including person's name, date, origin zip, destination zip, date requested, reason for denial and action (which is always to put on the wait list). The number of trips on this report averaged 72 per month in FY17. They also report OATS and JeffCo Express denials monthly by many of the same categories. This is excellent data for planning purposes and needs assessment.

### **Transportation Recommendations:**

The Coordinated Public Transit-Human Services Transportation Plan included the recommendation and implementation of multiple strategies rather than a single strategy. These are outlined in Table 7 and include a recommended implementation schedule. David Weiler, Director of Administration and Bill Knittig, Director of Service Coordination continue to be involved in the Transportation Solutions Committee, which was the first recommendation of the plan – to develop a county coordinating council.

To review the full Coordinated Public Transit-Human Services Transportation Plan, copy on the link below:  
<https://static1.squarespace.com/static/59d5585af5e2319471bb7169/t/5a8f1ae0652deac02d67f278/1519328019702/JeffCo+Final.pdf>

**Table 7**

**Figure VIII-1** Recommended Implementation Schedule

	2018	2019	2020	2021	2022	2023
Form Coordinating Council	█					
Create One-Call Center	█					
Increase One-Call Center Participants			█			
Mobility Manager		█				
Develop Travel Training		█				
Create Non-Profit Transit Agency		█				
Implement Service Change for JeffCo Express	█					
Create Transit Coalition		█				
Establish County Transit Authority		█	█			
Consolidate Services			█			
Consolidate Additional Services					█	



## Direct Support Professional (DSP) Crisis:

A needs assessment report for Jefferson County would be incomplete without a discussion of the Direct Support Professional (DSP) crisis which is occurring in the county, state of Missouri, and nation. A DSP is a paid, hands-on support person who assists individuals with disabilities with activities of daily living including, but not limited to bathing, grooming, dressing, feeding, working, and engaging in the community. DSP's work in a wide range of settings, including family homes, people's own homes, supported living homes, intermediate/residential care facilities, residential group homes, community job sites, vocational and day training programs and others. DSPs also provide assistance in a wide range of activities across the lifespan. They work with children, youth, young adults, adults in mid-life, and elderly individuals. They help people make informed decisions and exercise choice by teaching, training, and supporting them in all aspects of life. They are charged with keeping people safe and healthy. They dispense medications, take people to various medical appointments, and carry out health protocols.

All of the service provider agencies serving people with developmental disabilities in Jefferson County, report significant challenges currently with recruiting and retaining DSPs. This is primarily due to low wages, complex job responsibilities, poor or no benefits, extended work days and evening/weekend work requirements. In our current economy of low unemployment, people are leaving this type of work for better pay, expanded employee benefits and low responsibility with companies such as Amazon, Wal-Mart, Target, and CVS, just to name a few.

This crisis was detailed in a 2017 Report to the President, *America's Direct Support Workforce Crisis: Effects on People with Intellectual Disabilities, Families, Communities and the U.S. Economy* by the President's Committee for People with Intellectual Disabilities and can be found here:

[https://www.acl.gov/sites/default/files/programs/2018-02/2017%20PCPID%20Full%20Report\\_0.PDF](https://www.acl.gov/sites/default/files/programs/2018-02/2017%20PCPID%20Full%20Report_0.PDF)

\*The Department of Mental Health, Division of Developmental Disabilities projects needing over \$78M in General Revenue using an hourly wage of \$12 to address the DSP crisis in Missouri. These cost projections are understated because the figures used to prepare that report are now over 2 years old. If the problem isn't addressed in another ten years it will cost over \$125M in General Revenue and results may include:

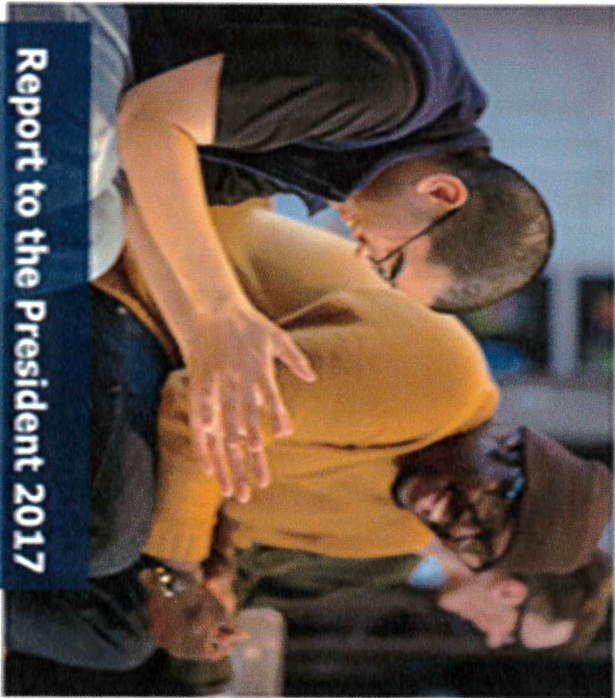
- Quality of care will continue to be impacted.
- DSP workforce will be reduced by other opportunities and providers will be forced to close their doors.
- Individuals and families currently served by DD community providers will no longer have those services available to meet their needs.
- DD community services system will implode if we continue to ignore the problem.

Addressing this issue must be a priority of the Mental Health Commission and the Department of Mental Health. MARF members are asking the Mental Health Commission to support including a new decision item in the Fiscal Year 2020 DMH budget request next October to begin addressing this crisis. This must be a top priority for 2020 DMH budget. DD Community Providers cannot continue to operate at insufficient rates. They must be able to recruit and retain qualified DSPs to continue to be successful in meeting the needs of the individuals they serve.

*(\*Source: Power Point presentation to the Mental Health Commission by the Missouri Association of Rehabilitation Facilities (MARF), April 2018)*

The role of Senate Bill 40 Boards, such as Developmental Disability Advocates, is unclear in this crisis, with the exception of one action – advocacy. It is clearly a call to action for all persons and agencies involved in the provision of services to people with developmental disabilities at a local, state and federal level.

# National News - Reports



## Report to the President 2017

America's Direct Support Workforce Crisis:

Effects on People with Intellectual Disabilities,  
Families, Communities and the U.S. Economy



### DSP Crisis

- average DSP wages of \$10.72 per hour
- average DSP wages below the federal poverty level for a family of four
- half of DSPs relying on government-funded and means-tested benefits
- most DSPs working two or three jobs
- average annual DSP turnover rates of 45 percent (range 18-76 percent)
- average vacancy rates of more than 9 percent

### Factors for Crisis

- high staff turnover;
- growing demand for services due to the growth and aging of the U.S. population in general;
- increased survival rates for people with ID;
- demographic shifts resulting in fewer people moving into the DSP workforce;
- persistently non-competitive aspects of direct support employment, including low wages, poor access to health insurance, and lack of paid time off (PTO) and other benefits;
- high stress and demands of direct support employment, including round-the-clock, seven-days-a-week work;
- insufficient training and preparation for DSP roles; and
- lack of professional recognition and status for skilled DSPs.

## Conclusions and Recommendations:

The two primary purposes for this needs assessment was to:

- Identify and quantify the empirically based projection of the prevalence and needs of individuals with developmental disabilities in Jefferson County.
- Ensure Developmental Disability Advocates is allocating its available funds based on established priorities that reflect the needs of individuals with developmental disabilities living in Jefferson County.

The ultimate goal of having financial resources to meet the present and future needs of the County that are sufficient, stable and sustainable is also directly correlated to this needs assessment. However, due to the lack of participation in the survey process and the lack of empirically-based, quantifiable data that is consistent, reliable, unduplicated and uncoordinated, it is challenging to draw firm conclusions on the financial goal for the short or long term. However, if the prevalence rate of I/DD in the community is roughly 1.58% of the population and the service coordination teams are serving roughly over 1,300 by the end of FY17, it could be estimated that approximately 2,144 individuals could be in need of services in Jefferson County.

According to the data presented, Developmental Disability Advocates and DMH experienced an 11% increase in persons receiving service coordination over the past 5 years. A similar increase of 11% over the next 5 years will put the county total at just over 1,400 people served.

The need for a consistent, comprehensive service needs collection process and reporting system is evident. An outstanding example of a data driven, empirically-based needs assessment is the Report to St. Charles County Citizens: Assessing the Need for Children's Services by the Community and Children's Resource Board (CCRB) which can be found here:

[http://www.stcharlescountykids.org/download/needs\\_assessment/2016-Needs-Assessment.pdf](http://www.stcharlescountykids.org/download/needs_assessment/2016-Needs-Assessment.pdf)

The interest in qualitative data to inform tax levy decisions and reflect upon the "fit" between what is being allocated and what is the most needed is an often stated and growing desire among Senate Bill 40 Boards and agencies providing services to people with developmental disabilities throughout the state. The ability to be accountable for the dollars being invested in services and supports that actually change lives of people with developmental disabilities is of great value in an atmosphere of competitive and shrinking funds at the state and federal level for social services programs. Outcomes based payment systems and managed care for long term supports such as those for people with developmental disabilities have changed the landscape of our industry and the need for timely, meaningful, reliable data has become a necessity.

### **Recommendation #1**

It is recommended that Developmental Disability Advocates, in partnership with the Productive Living Board (PLB) of St. Louis County, the Developmental Disabilities Resource Board (DDRB) of St. Charles County, and the St. Louis City Developmental Disability Resources (DDR) include the development of a needs assessment process into the scope of work of the Integration and Alignment Project currently underway with the Insight Partners Consulting Firm. The anticipated timeframe for this project is July 2018 – December 2019.

### **Recommendation #2**

It is recommended that Developmental Disability Advocates seek a tax levy increase to meet the growing number and needs of individuals with developmental disabilities in Jefferson County. The timing of this increase appearing on the ballot and the amount of the increase will be determined by a Levy Committee to be formed in Fall 2018.

### **Recommendation #3**

It is recommended that Developmental Disability Advocates concentrate support services in the areas of employment based upon the extremely large indicator of those between the ages of 15-40.

### **Recommendation #4**

It is recommended that Developmental Disability Advocates gather additional information about the needs of the aging population with developmental disabilities and the best practice models for supporting them as they age. Monitor the living options desired/required by families, as this may shift given the growing population of older adults.

### **Recommendation #5**

It is recommended that Developmental Disability Advocates gather current information about the needs of children with developmental disabilities, under the age of 21, and their families, with particular focus on those without access to Medicaid services. Continue to work with the Together Advisory Committee to maintain a comprehensive matrix of available community resources and make them available in a variety of formats.

### **Recommendation #6**

It is recommended that Developmental Disability Advocates continue to support the needs of individuals living in the natural home setting as this is the predominant housing type for individuals (63%). This could translate into a need of more personal assistance options based upon historical use of that service to address unmet support needs as more people enter the workforce.