HIMA

HEALTH MANAGEMENT ASSOCIATES HMA COMMUNITY STRATEGIES

Needs Assessment for Residents with Intellectual and Developmental Disabilities

PREPARED FOR THE
CITY AND COUNTY OF DENVER
DEPARTMENT OF HUMAN SERVICES

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Table of Contents

Contents

Acknowledgements	
Executive Summary	6
Service Inventory Service Delivery Challenges	θ
Gaps in Service	
Governance Model Recommendations	
Conclusion	10
Introduction and Purpose	11
Approach to the Health Needs Assessment	
History of the Mill Levy Denver Residents with IDD Being Served through Metro-Area CCBs	
Prevalence of Individuals with IDD in Denver	
Methodology for the Needs Assessment	15
Document Review	15
Key Informant Interviews	
Survey of Needs of People with IDD in Denver	15
Focus Groups	
Public Meeting	19
Services Inventory	19
IDD Definition	20
Entry Point	
What services are currently available for Denver's IDD population?	21
Developmental Disabilities Waiver	21
Supported Living Services Waiver	
Children's Extensive Support Waiver	
Children's Habilitation Residential Program Waiver (CHRP) Elderly Blind Disabled Waiver (EBD)	
Non-Waiver Services	
Services for Children and Adolescents Services for Adults	
Service Delivery Challenges	25
Overall Understanding of the Mill Levy	26
Experience Applying for Milly Levy Funding	
Assessment of Individual Service Delivery and Challenges	32
Gaps in Service: Top 10 "Big Problems"	35

Independent and Affordable Housing	38
Lack of Affordable Housing	
Safety	
Isolation Life Skills	
Americans with Disabilities Act (ADA) Standards for Accessibilit	
Resources and Supports	
Obtaining Employment	39
Employment Opportunities	39
Employment Support	
Case Management and Waitlist Coordination	40
Communication, Empowerment, and Support	40
Case Management and Coordination of Services	40
Mental Health Services	41
Inadequate Provider Capacity	41
Transition to Adulthood	42
Information, Awareness, and Navigation	42
Lack of Services	42
Systems Coordination	
Continued Education	
Transitional Support	
Underlying Reasons for Service Delivery Challenges	43
Stigma	43
Rights and Advocacy	44
Training and Education of the Public	
IDD Provider Capacity	
System Coordination	45
Governance Models	46
Douglas County, Colorado	47
Broomfield County, Colorado	47
Franklin County, Ohio	
Dane County, Wisconsin	
Recommendations	50
Recommendations for Governance Models	50
Recommendation 1	
Recommendation 2	
Recommendation 3	52
Recommendations for Mill Levy Spending	
First Tier	53

Affordable Housing	53
Obtaining Employment	53
Waiting Lists for Services and Supports	54
Transition to Adulthood - Transition Planning and Services	54
Adequate Mental Health Services	54
Second Tier	55
Increase Provider Capacity for IDD Services	55
Case Management	
Create Additional Infrastructure for Consumer Directed Supports	56
Address Overarching Themes Around Stigma and Service	57
Understanding of the Mill Levy	57
Cultural Competence and Sensitivity	57
Conclusion	
Appendix A: Key Informant Interview Guide	59
Appendix B: Survey Instrument	
Appendix C: Survey Dissemination Partners	
Appendix D: Survey Flyer	
Appendix E: Survey Outreach Email	87
Appendix H: Public Meeting Flyer	
Appendix I: Public Meeting Agenda	
Appendix J: Ratings for 23 Services included in the assessment	96

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A Steering Committee was identified and selected by the City and County of Denver's Department of Human Services in conjunction with the Mayor's Commission for People with Disabilities. The Steering Committee advised on the process of gathering community input to inform the needs assessment.

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Executive Summary

The City and County of Denver's Department of Human Services (DHS) contracted with Health Management Associates (HMA), between March and August 2018, to conduct a needs assessment of services and supports for individuals with intellectual and/or developmental disabilities (IDD). Denver will use findings from this assessment to inform decisions regarding the governance and distribution of mill levy funds dedicated to supporting services for Denver residents with IDD.

For this project, HMA received advice and oversight from both DHS staff and a project Steering Committee comprised of stakeholders identified by DHS in conjunction with the Mayor's Commission for People with Disabilities. The assessment was designed to incorporate a multi-pronged approach to maximize the ways in which people could participate and information could be gathered. Specifically, interviews with IDD community leaders, a city- wide online survey, several focus groups with Denver residents with IDD and IDD service providers, and a public meeting were conducted to inform the needs assessment.

Anyone interested could also provide open-ended feedback throughout the needs assessment and still can on DHS' website: https://fs7.formsite.com/CCDenver/form333/index.html.

Below is a summary of findings from the needs assessment:

Service Inventory

➤ Mill levy funding is allocated to the Denver Community Center Board (CCB), Rocky Mountain Human Services (RMHS). Of the internal enhanced services being offered by RMHS, early intervention, children's clinical assessment and consultation, and service coordination are the services being funded by the mill levy in the highest amount. The largest allocations of mill levy funds to community providers and individuals are for client education with a focus on increasing independence and to address system gaps and program service limitations of other funding sources, such as Medicaid and the state. Services to support behavioral and physical health for people with IDD and make the public aware of available services make up a much smaller proportion of the mill levy allocation.

Service Delivery Challenges

There currently is a low level of understanding from both within and outside Denver's IDD community about mill levy funding and services. Needs assessment participants reported that there should be clearer communication of what services the mill levy funds, the mechanism through which to obtain funding, and eligibility criteria.

About the Mill Levy

Since 2003, the City and County of Denver has imposed a property tax (mill levy) dedicated to funding services for residents with IDD. In 2018, the levy is projected to generate approximately \$17.5 million.

Unspent mill levy funds from 2016/2017 total \$9.2 million. The projected amount of funding not committed to Denver's Community Center Board and available between 2018 and 2020 is \$18.5 million, including unspent funds from prior years. The needs assessment will help inform how the uncommitted funds are allocated.

- Among those who are aware of mill levy funding, there is a high level of support for current mill levy services. The experience of those community members who applied for mill levy funding has been positive and the vast majority of those who applied for mill levy dollars felt that the funding met their expectations nearly half reported that it exceeded their expectations.
- ➤ Despite these findings, there is a small number of needs assessment participants within the IDD community (roughly one in 20) who had applied for mill levy funding and reported negative experiences.
- The top five services that "work well" include vision services, medical services, early intervention (services for students ages 0-3 years), durable medical equipment, and in-home respite (temporary support to relieve primary caregiver). While these services were the most frequently reported to be working well, this still represents only the experience of approximately one in five survey respondents.
- Approximately 95 percent of respondents felt that something was not working well with nonemergency medical transportation, transportation provided by Medicaid, pre-vocational services, crisis/emergency supports, and out-of-home respite (temporary support to relieve primary caregiver).
- ➤ Approximately one third of respondents felt that there are insufficient home and communitybased supports, clinical services (Occupational Therapy, Physical Therapy, Speech Language Pathology), recreational activities, transportation provided by Medicaid, and mental health services
- > Approximately 1 in 10 respondents reported not having access to residential services, in-home respite, mental health services, out-of-home respite, and transportation provided by Medicaid.
- > The least common services used by survey respondents included infant services, pre-school special education (services for students 3-5 years), early intervention, home modifications, and adult day services.

Gaps in Service

- There was a difference in the perception of what are "big problems" for people with IDD living in Denver between providers and service recipients. Overall, recipients of services identified just two issues that they felt were big problems affordable housing and obtaining employment. Meanwhile, providers in aggregate rated five things as big problems: affordable housing, waiting lists, obtaining employment, adequate mental health services, and transition to adulthood. This suggests that the priority problems common
 - across both populations affordable housing and obtaining employment are two that deserve immediate attention as ways to consider using mill levy dollars. A second tier of issues may be waiting lists, adequate mental health services, and transition to adulthood.
- The needs assessment revealed a general lack of public understanding, awareness and support for those with IDD due to stigma and lack of training and education.

Underlying Reasons for Service Delivery Challenges

- ➤ Stigma
- > Training and Education of the Public
- Rights and Advocacy
- > IDD Provider Capacity
- Systems Coordination

- > Family members and caregivers reported often feeling their voices were marginalized or ignored, and some reported a lack of knowledge on rights for those waiting or enrolled in IDD services.
- ➤ IDD provider capacity throughout Denver is limited, in part due to lack of training and knowledge on the needs of patients with IDD as well as the limited number of providers offering IDD services.
- The assessment identified a need for more coordinated services to provide support entering and transitioning through the system of care for individuals with IDD.

Recommendations

The needs assessment found that there are many key areas where additional funding could make a significant difference for persons with IDD; however, the funding is not enough to make significant changes in all the areas of need. Therefore, the needs assessment offers insights into how Denver can consider prioritizing mill levy spending. Identified priorities include improving the delivery of specific services to meet basic needs of daily living, and addressing overarching systemic barriers to the IDD community feeling heard and respected. Research findings on different governance models for local tax dollars were used to inform recommendations for methods by which to allocate mill levy revenue.

Governance Model Recommendations

- 1. DHS should establish a formal structure to disperse mill levy funding including consideration of an advisory board that consists of members (e.g. IDD providers, DHS, IDD advocates, persons with IDD, etc.) identified via an application process or an official appointment.
- 2. DHS should create a transparent funding formula that makes it easy for the residents of Denver to understand how the money is supposed to be spent. DHS should first determine a percentage of funding to be committed to RMHS. The disbursement of remaining funds should be allocated based on categories determined by the advisory board. This formula should not dictate specific providers or guarantee contracts, but should clarify the focus of mill levy funding based on identified needs and input from key stakeholders through the process of this needs assessment and other feedback mechanisms.
- 3. DHS should include reporting requirements for future contractors who are recipients of mill levy funds. DHS has a strong reporting requirement for the latest RMHS contract that includes an annual report and monthly metrics. This accountability in reporting should be replicated across contracts with providers who receive any mill levy funds.

Mill Levy Spending Recommendations

Affordable Housing

- 1. Explore purchasing housing for Denver residents with IDD.
- 2. Support incentives for landlords to accept vouchers and/or take part in implementing strategies to integrate those with IDD with other community members in their housing units.

Obtaining Employment

3. Identify ways to work with local businesses to create meaningful employment opportunities available to persons with IDD. Mill levy funds could be used to incentivize businesses, to provide employment opportunities to individuals with IDD, and to train employers on interacting and managing persons with IDD.

Waiting Lists for Services and Supports

- 4. Use mill levy funding to ensure case managers are proactively reaching out to their clients. Outreach should include: relaying waitlist information, waitlist movement or changes, critical policy updates, and opportunities for Denver residents to participate in informing policy.
- 5. Use mill levy funding to provide additional services to persons with IDD on the waitlist for comprehensive services (including residential services).

Transition Services

6. Further evaluate and study transition services in Denver to identify specific areas where the mill levy dollars could enhance transition services, including an assessment of best practices in self-directed planning and family involvement. The needs assessment identified an opportunity for mill levy funding to enhance transition services through the development of resources for families, case managers, providers, and school personnel. Resources may include a database of available adult services, trainings or information sessions for parents and case managers, and materials on best practices that incorporate self-directed planning and family involvement.

Adequate Mental Health Services

7. Contract with mental health provider(s) trained to serve people with IDD and create partnerships between these mental health providers and community IDD service providers to better integrate mental health services.

Increase Provider Capacity for IDD Services

- 8. Explore offering discounted housing for IDD providers to incentivize them to live and work in Denver. According to the job-finder website Indeed.com, the average salary for all positions in Denver that reference IDD is \$35,038 (general for all levels of expertise). Further research should be done to consider other similar housing models for a targeted workforce and the plausibility of doing something like this under the current City Code, which states mill levy funds must be used for the purpose of purchasing services and supports for persons with IDD.
- 9. Create a campaign to inform new and potential providers about persons with IDD in Denver. The marketing campaign would inform potential providers about the need for service providers, and the benefits to working in Denver.

Case Management

10. Evaluate the need for additional case managers to serve persons with IDD in Denver, the training needs for case managers, and the ability to use evidence-based practices to evaluate outcomes. Based on the determined need, mill levy funding could be used to support the appropriate number of case managers for persons with IDD in Denver, and specifically consider the case loads for persons with extremely complex cases. This may be a challenge to implement while the shift to conflict-free case management is in process and final details are unknown.

Consumer-Directed Spending

11. Implement a voucher or flexible spending account (FSA) program supported by mill levy dollars to supplement existing housing, transportation, technology, or other targeted needs for persons with IDD. To implement a program such as this, careful consideration must be given to oversight enforcement, eligibility determination, and equitable distribution of funding. DHS could engage external stakeholders or an advisory committee to work through these difficult questions.

Understanding of the Mill Levy

- 12. Develop communication materials that clearly articulate the services provided by the mill levy, and the ways in which individuals and families can access those services.
- 13. Provide funding to an external contractor to design and implement a multi-pronged communications plan.
- 14. Develop policies and procedures for case managers to follow regarding how they explain the mill levy funds to clients and how clients may use them.

Cultural Competence and Sensitivity

15. Offer public information and awareness to Denver residents to reduce stigma and increase inclusivity within the community for persons with IDD.

Conclusion

The needs assessment was designed to inform decisions regarding the governance and distribution of mill levy funds dedicated to services for Denver residents with IDD. The findings begin to uncover important complexities. Each individual with IDD has a unique set of needs and circumstances that inform the resources available to him or her to meet those needs – including awareness of services, capacity to use services, and access to those services. There are also significant barriers that underlie service access and delivery that call for increased awareness and competency for providers and the public to better serve, understand, and respect those individuals with IDD. These are not simple barriers to overcome with easy solutions, as they often involve multiple systems of care. However, the information gleaned from this needs assessment begins to inform how DHS should approach its prioritization and decision-making to support and enhance services funded by the mill levy funds for people in Denver with IDD.

Introduction and Purpose

The City and County of Denver's Department of Human Services (DHS) contracted with Health Management Associates (HMA), between March and August 2018, to conduct a needs assessment of services and supports for individuals with intellectual and/or developmental disabilities (IDD). Denver will use findings from this assessment to inform decisions regarding the governance and distribution of a Denver property tax (mill levy) dedicated to funding services for residents with IDD.

The primary goals of the needs assessment were:

- 1. Inventory current services for Denver County residents with IDD and the existing capacity in and around Denver to provide these services.
- Identify service gaps and potential ways to address these gaps by engaging stakeholders including clients, families, caregivers, service providers, city and state agencies, employers, and
 the public, with the intent to form the basis of how dedicated mill levy funding is programmed
 going forward.
- 3. Research possible governance models for determining/overseeing the disbursement of dedicated revenue, gathering stakeholder feedback on the governance models, and evaluating pros and cons of preferred models to form the basis of the process through which dedicated funding is allocated going forward.

This report summarizes the findings in the three areas identified above, including recommendations on the most pressing service gaps to address and features of the governance model.

Approach to the Health Needs Assessment

For this project, HMA consulted with both DHS staff and a project Steering Committee identified and selected by DHS in conjunction with the Mayor's Commission for People with Disabilities. The Steering Committee advised on the process of gathering community input to inform the needs assessment.

The assessment incorporated a multi-pronged approach to maximize the ways in which people could participate and information could be gathered. To begin, HMA conducted a document review of reports on the Denver mill levy, previous assessments, governance models and best practice concepts, followed by key informant interviews with community members and leaders regarding IDD services and supports. Participating interviewees were identified with the help of the project Steering Committee.

To be as representative of the demographics across Denver as possible, HMA implemented two supplemental approaches to collect community input - an anonymous survey and a series of focus groups with members of the Denver IDD community. Additionally, the selection of key informant interviewees, survey participants, public forum locations, and advertisement methods, intentionally sought to reflect Denver's population, including IDD type, age, gender, race, language, and income.

HMA provided multiple ways in which community members could engage, using approaches that met people where they were and supported various methods of communication, including in-person, telephone, and online opportunities as well as Spanish and American Sign Language (ASL) translation. For example, the key public meeting designed to gather broad public input was held in central Denver, on an RTD route, at an Americans with Disabilities Act (ADA) accessible facility familiar to many

members of the IDD community. All focus groups were conducted at locations where groups were already meeting or in central Denver in places easy to access (e.g., Denver Public Library).

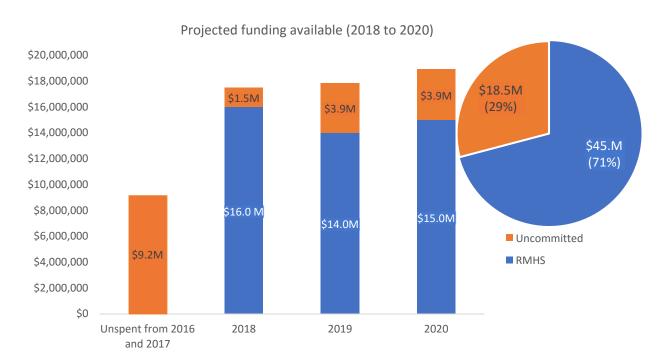
History of the Mill Levy

Since 2003, the City and County of Denver has imposed a mill levy dedicated to funding services for residents with IDD. In 2018, the levy is projected to generate approximately \$17.5 million.

Historically, revenue derived from this levy was allocated to fund services through Denver's Community Centered Board (CCB), Rocky Mountain Human Services (RMHS). In early 2017, Denver's City Council passed an ordinance to expand allowable uses of the mill levy to: 1) contract with providers outside of the CCB; 2) transfer funds to the Department of Health Care Policy and Financing (HCPF), Colorado's Medicaid agency, to reduce the Medicaid waiver waiting list for Denver residents; and 3) use 0.75% of the revenue to cover DHS' administrative costs.

As depicted in **Chart 1**, the remaining amount of unspent mill levy funds from 2016/2017 is \$9.2 million. The projected amount of funding for 2018 to 2020 reveals uncommitted funds of \$18.5 million (29%), with the remaining funds committed to RMHS. The needs assessment will help inform how the uncommitted funds are allocated.

Chart 1: Projected Mill Levy Funding Available from 2018 to 2020



Denver Residents with IDD Being Served through Metro-Area CCBs

In 2017, \$10.5 million of mill levy funds were spent on services for 4,584 unduplicated Denver residents with IDD.

Overall there are approximately 1,055 Denver residents with IDD on a Colorado Medicaid Home and Community Based Services (HCBS) waiver, including waivers for Developmental Disability (DD), Supported Living Services (SLS), and Children's Extensive Services (CES). It is important to note there are additional Denver residents who are served by other HCBS waivers. Some Denver residents are also served by various CCBs from the surrounding Denver-metro area, including, RMHS, Developmental Pathways, Developmental Disabilities Resource Center, North Metro Community Services, Imagine, and Foothills Gateway. **Table 1** displays the number of Denver residents with IDD on HCBS waivers, by waiver type. Although outside CCBs can be used for services, RMHS serves 82 percent of Denver residents enrolled in any of the three Colorado Medicaid HCBS waivers noted above.

Table 1: Service Coordination of Denver Residents on HCBS Waivers, as of February 2018

ССВ	Counties Served	DD Waiver	SLS Waiver	CES Waiver
Rocky Mountain Human Services	Denver	870 total on DD, SLS, and CES		
Developmental Pathways	Arapahoe, Douglas	62	23	11
Developmental Disabilities Resource Center	Jefferson and 3 others	51	14	1
North Metro Community Services	Adams	13	3	3
Imagine!	Boulder, Broomfield	4	0	0
Foothills Gateway	Larimer	0	0	0
	All		1,055	

Prevalence of Individuals with IDD in Denver

It is difficult to accurately determine the prevalence of IDD, as the definition of IDD varies across the United States and Colorado, ultimately limiting the ability to accurately count persons with IDD. There are many indicators for estimating the population of persons with IDD and metrics vary depending on age and defined cognitive ability. To best inform this report, HMA referenced one of the most credible and widely used sources for overall prevalence of persons with IDD in the U.S., the Residential Information Systems Project (RISP), a longitudinal study of long-term supports and services (LTSS) that people with IDD receive. The survey comes from state IDD agencies that gather a multitude of information. The most recent data is from 2016 and reports the following —

¹ Data in the table was provided by DHS. The information is as of mid-February 2018. DHS only reached out to the metro Denver area CCBs identified above. It is possible CCBs in other counties also serve Denver residents but likely not in great volume.

"Applying the prevalence rate of 69.9 per 1,000 for children from the 2016 NHIS (Zablotsky, et. al., 2017) and 7.9 per 1,000 for adults from the 1994/1995 NHIS-D (Larson, et al., 2001) we estimate there were 5,147,596 children, and 1,970,933 adults with IDD in the 2016 U.S. civilian noninstitutionalized population. An additional 255,873 people with IDD of all ages lived in congregate settings of four or more people, nursing homes, or psychiatric facilities on June 30, 2016. In total, we estimate that there were 7,374,402 people with IDD in the U.S. in 2016 (22.8 per 1,000)."²

In 2016, the population of Denver County was approximately 682,545 people. Applying the rate of 22.8 per 1000 population, HMA estimates there are approximately 15,562 persons with IDD. Using a simple percentage to determine the population of persons with IDD in Denver is flawed. Colorado has a more restrictive IDD definition than other states, which means this approximation may be high. This methodology did not look at specific state definitions of IDD, but did look at LTSS services across the board in each state for persons with IDD.

In 2017, RMHS reported serving 3,414 children and 1,170 adults, potentially indicating that there are a number of Denver residents with IDD who are not connected to RMHS. Denver residents with IDD may seek services at a CCB or provider other than RMHS, and there are individuals with IDD who are not connected to services at all, on waitlists, or do not meet eligibility requirements for HCBS waivers. The current waitlist for the HCBS-DD waiver as of June 2018 is 2,887 individuals statewide. There are currently 317 persons waiting for HCBS-DD enrollment that report a Denver zip code. Many of these residents waiting for HCBS-DD waiver enrollment are enrolled on another HCBS waiver and not completely without services.

What is the future population for individuals with IDD in Denver?

Predicting the future population of persons with IDD in Denver is as complicated as trying to understand the current prevalence. There are many influences on the growth of IDD population, including the overall population growth of the city, as well as the increasing capacity for identification and diagnosis of IDD. By 2025, the population of Denver County is expected to increase by 12.9 percent, from 682,545 in 2016 to approximately 770,900 in 2025. If the current estimated rate of IDD remains the same (22.8 per 1000 population) the estimated number of Denver residents with IDD is expected to be approximately 17,577 people in 2025.

The overall enrollment for Colorado Medicaid HCBS waivers has increased over time.³ Since 1985, the number of HCBS participants increased 16 times, from 600 in 1985 to 10,538 in 2015, at an average rate of 8.3 percent. While not all HCBS waivers are relevant to the IDD population, this average rate of growth presents a starting point for consideration. Specifically, for the HCBS-DD waiver, there has also been growth in enrollment. In FY2007/08 there were approximately 4,000 individuals enrolled in the DD waiver, which increased 24 percent to 5,000 by FY2016/17. Enrollment is projected to grow to somewhere between 6,500 and 7,000 by FY2019/20.⁴

Health Management Associates

² Larson, S.A. et al. (2018). In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2016. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

³ Braddock et al. (2017). Coleman Institute and Department of Psychiatry, University of Colorado.

⁴ CO HCPF HCBS-DD Waiver Waiting List Enrollments, May 2018.

Methodology for the Needs Assessment

Document Review

The background research for this assessment was conducted by collecting and reviewing relevant data sources identified by HMA, DHS, and other stakeholders. The background materials reviewed included:

- Relevant laws and rules;
- CCB contracts;
- CCB reports on use of mill levy funds;
- Feedback on use of mill levy funds;
- Historical financial information on mill levy revenues, expenditures, and balances;
- Projected mill levy revenue;
- Estimated number of persons with IDD living in the City and County of Denver, and demographics of such individuals;
- Number of persons with IDD accessing services in Denver, including types of services utilized;
- Number of Denver residents with IDD accessing IDD services in surrounding Metro counties, including types of services utilized; and
- > Eligibility categories of clients served by the CCB.

Key Informant Interviews

Personal interviews were conducted with eight community stakeholders to develop a deeper understanding of the health issues and needs facing people with IDD across Denver. These individuals were identified by the project Steering Committee and included professionals and advocates with indepth knowledge of the challenges and needs facing people with intellectual and developmental disabilities living in Denver. All interviews were conducted by HMA between April and June 2018. HMA developed a semi-structured interview guide which included a set of key questions and allowed for enough flexibility for interviewers to probe further into issues, while maintaining consistency in data collection across interviews (See **Appendix A** for HMA Interview Guide).

Interviewees included executives and staff of Denver-based IDD nonprofits, leadership from Denver's CCB, early childhood and IDD experts, and a caregiver advocate. Interviews were conducted in-person or over the telephone, based on the preference of the interviewee, and were audio-recorded with prior consent. All interviews were between 30-45 minutes in length and were transcribed by the HMA team.

Survey of Needs of People with IDD in Denver

With guidance from both DHS and the Steering Committee, HMA developed a web-based survey comprised of 37 questions, titled *Denver Human Services Needs Assessment Survey for Individuals with Intellectual or Developmental Disabilities*. The purpose of the survey was to better understand the unique needs of the Denver IDD community by seeking input beyond traditional health surveys. Data collection occurred between April 30 and July 1, 2018; of copy of the questionnaire is included in **Appendix B** of this report.

Survey questions are summarized below:

- > Demographics, including age, race, ethnicity, gender, and type of respondent within the IDD community (i.e. self, advocate, parent, etc.);
- > To rate understanding of the voter-approved dedicated mill levy that is set aside for children and adults with IDD in the City and County of Denver;
- > To rate understanding of the services the mill levy is currently funding.
- To rate level of support for the services the mill levy is currently funding (e.g., Individualized Client Assistance, Individualized Annual Plans, Enhanced Services from the Denver CCB, Community Agency Programs);
- > To rate experience with applying for mill levy funding;
- To rate experience with 32 services and supports identified in the survey that are available in Denver for individuals with IDD;
- > To rate how big a problem each of 21 issues identified in the survey are for people with IDD in Denver; and
- > To rate experience with case management services.

Respondents were provided the opportunity to comment on and address additional issues not directly addressed in the survey.

It was decided in collaboration with the Steering Committee, HMA, and DHS, that survey dissemination and participant recruitment would be done through a "snowball" sampling method. This approach used respondents to identify additional respondents and is especially valuable in populations that are difficult to reach and may generally be excluded from traditional survey methods. This allowed for increased participation from individuals with IDD, parents/guardians, and professionals involved with the IDD community. Survey participation was voluntary. The survey was intended for residents of Denver, who:

- Identify as having an IDD;
- > Provide care or guardianship of adults or children with IDD;
- > Represent and advocate for the IDD population (i.e. community-based organizations, state/local government offices);
- ➤ Are academic researchers, physicians, public health professionals, health and wellness promotion specialists, health administrators and health policy experts; and
- ➤ Have interest in the health and well-being of those with IDD.

Initial dissemination of the survey occurred on April 30, 2018, to members of the project Steering Committee. Members were then asked to forward the survey to their respective IDD networks (Appendix C). Several partner organizations circulated the survey to their contacts and broadcasted information regarding the survey though social networks (i.e., Facebook, Twitter, agency websites). Flyers produced by DHS also accompanied any outreach (Appendix D), as well as suggested language for emails (Appendix E). Additionally, respondents could participate via telephone by calling a designated number to connect with an HMA surveyor. Frequent reminders and invitations were distributed by the Steering Committee to respective networks, with requests to both complete and forward the survey.

The survey closed on July 1, 2018, with a total of 417 respondents, 315 of which fully completed the survey (76%). Most of the respondents were female (81%), between the ages of 35-44 (27%), White (78%), did not identify as Spanish/Hispanic/Latino (81%), and spoke English at home (97%). Details on demographics are available in **Appendix F**. Additionally, the survey captured the city or town of residence, shown as a map in **Figure 1**. As the map reveals, not all respondents were Denver residents. However, these individuals responded to the survey because they may work in Denver or provide/receive IDD services in Denver.

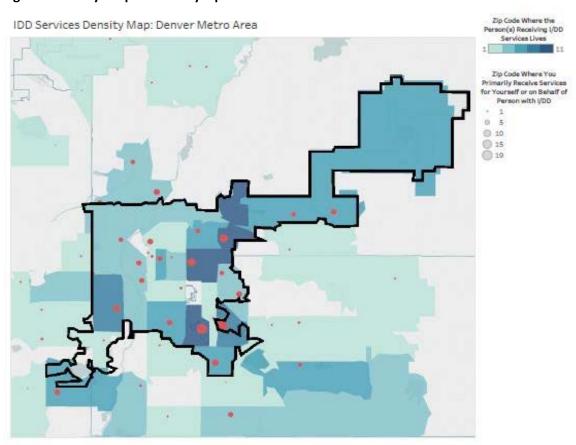


Figure 1: Survey Respondents by Zip Code

Approximately one third of the respondents identified as a family member, guardian, or caregiver to an adult or child with I/DD. Another third identified as an IDD service provider or case manager, while the remainder identified as an individual with IDD, community leaders or concerned citizens. A detailed description of respondent representation within the IDD community is provided in **Appendix F**.

Survey analyses were conducted based on three population sub-group, defined in **Table 2**, including: 1) Recipient of IDD Services; 2) Provider of IDD Services; and 3) Other.

Table 2: Respondent Sub-Groups

Type of Respondent	Population Sub-Group
Self-Advocate (person with IDD)	1) Recipient of IDD Services
Guardian of a person with IDD	(n=164, 44%)
Family member of a person with IDD	
Host home family	
Health Care Provider	
Service provider for people with IDD	2) Provider of IDD Services
School personnel	(n=147, 37%)
Case Manager for persons with IDD	
Advocate/Legal Aid	
Behavioral Health Care Provider	
Legislator or legislative staff	
Taxpayer/Citizen/Other Interested Party	3) Other (n=59, 19%)
State or local agency	
Other, please describe.	

Focus Groups

Based on the findings from key informant interviews and surveys, along with input from DHS and the project Steering Committee, HMA identified target populations and developed a *Focus Group Interview Guide* (included in **Appendix G**). These focus groups were structured to gather information from Denver residents with IDD about their experiences with services and recommendations regarding mill levy funds. An open-ended interview process was applied, where question wording and sequencing were flexible and driven by participants.

A total of three focus groups were conducted with participants from the Laradon Officer's Club, the Colorado Fund for People with Disabilities Mission Support, and early childhood leadership from Denver Public Schools. Since these perspectives were underrepresented in the survey, these three groups were selected because they offered the opportunity to speak with Denver residents with IDD, residents with IDD experiencing homelessness, and capture the experiences and opinions of parents of young children with IDD. Participation in focus groups is shown in **Table 3**.

Table 3: Focus Group Participation

Focus Group	# of Participants
Laradon Officer's Club	15 individuals with IDD
Colorado Fund for People with	4 CFPD Staff and 6 individuals with IDD
Disabilities Mission Support	experiencing homelessness in Denver
Early Childhood Providers	14 early childhood providers/leaders

Public Meeting

A public meeting was held in Denver at the Laradon Community Room on June 11, 2018. Two opportunities were provided for community members to attend, including one at 4:00pm and one at 5:30pm. The same agenda was used for both meetings. Outreach promoting the meetings occurred via similar networks as the survey dissemination (see above). Fliers were developed and disseminated in both English and Spanish, as well as posted to the DHS website. See **Appendix H** for the public meeting flyer. Spanish and ASL interpreters were available during both meetings. Several methods for participants to engage were provided, including in-person, telephone, WebEx (online conferencing), and Facebook Live. The number of participants by method of participation is shown in **Table 4**.

Table 4: Number of Participants at Public Meeting

Type of Participation	Approximate Number of Community Members		
In-person	27		
Webex / Phone	28		
Facebook Live	8		

During the public meeting, HMA discussed the needs assessment and presented preliminary survey findings. In addition, small, facilitated, group discussions occurred to allow community members to share opinions and perspectives regarding:

- 1. What is working regarding access to services for individuals with IDD living in Denver;
- 2. The barriers to accessing services; and
- 3. What is working and not working regarding accessing/using mill levy funds.

The public meeting agenda can be found in **Appendix I**.

Findings from the needs assessment are presented below and organized as follows:

- 1. Services Inventory;
- 2. Service Delivery Challenges;
- 3. Needs of Denver's IDD Community; and
- 4. Recommendations.

Services Inventory

Those with IDD who reside in the City and County of Denver access services through a variety of entry points and service-funding platforms. Services, entry points, payors, and eligibility can be complicated to understand as evidenced by the following overview.

IDD Definition

Colorado defines Developmental Disability as a disability that: (10CCR 2505-10 8.600)⁵:

- A. Is manifested before the person reaches twenty-two (22) years of age;
- B. Constitutes a substantial disability to the affected individual, as demonstrated by the criteria below at **C.1** and/or **C.2**; and
- C. Is attributable to intellectual or developmental disability or related conditions which include cerebral palsy, epilepsy, autism or other neurological conditions, when such conditions result in either impairment of general intellectual functioning or adaptive behavior similar to that of a person with intellectual or developmental disability.
 - 1. Impairment of "general intellectual functioning" means that the person has been determined to have a full scale intellectual quotient equivalent which is two or more standard deviations below the mean (70 or less assuming a scale with a mean of 100 and a standard deviation of 15).
 - a. A secondary score comparable to the General Abilities Index for a Wechsler Intelligence Scale that is two or more standard deviations below the mean may be used only if a full scale score cannot be appropriately derived.
 - b. Score shall be determined using a norm-referenced standardized test of intellectual functioning comparable to a comprehensively administered Wechsler Intelligence Scale or Stanford-Binet Intelligence Scales, as revised or current to the date of administration. The test shall be administered by a licensed psychologist or a school psychologist.
 - c. When determining the intellectual quotient equivalent score, a maximum confidence level of ninety percent (90%) shall be applied to the full scale score to determine if the interval includes a score of 70 or less, and shall be interpreted to the benefit of the applicant being determined to have a Developmental Disability.
 - 2. "Adaptive behavior similar to that of a person with intellectual or developmental disability " means that the person has an overall adaptive behavior composite or equivalent score that is two or more standard deviations below the mean.
 - a. Measurements shall be determined using a norm-referenced, standardized assessment of adaptive behaviors that is appropriate to the person's living environment and comparable to a comprehensively administered Vineland Scale of Adaptive Behavior, as revised or current to the date of administration. The assessment shall be administered and determined by a professional qualified to administer the assessment used.
 - b. When determining the overall adaptive behavior score, a maximum confidence level of 90 percent shall be applied to the overall adaptive behavior score to determine if the interval range includes a score of 70 or less and shall be interpreted to the benefit of the applicant being determined to have a developmental disability.
- D. A person shall not be determined to have a Developmental Disability if it can be demonstrated such conditions are attributable to only a physical or sensory impairment or a mental illness.

⁵ Services for Individuals with Intellectual and Developmental Disabilities. 10 CCR 2505-10 8.600.

Entry Point

Colorado maintains a complex system of case management and complicated entry into the systems that serve persons with IDD. Primarily, persons with IDD access Medicaid services through a designated CCB. For Denver, the assigned CCB is RMHS. As required by federal rules, Colorado is in transition toward conflict-free case management, designed to ensure that constituents have the right to access case management from a variety of providers and are not limited geographically.

Case Managers conduct assessments to determine eligibility for Medicaid waiver services based on a "Level of Care" determination and assist in finding additional community resources for clients. Furthermore, Colorado has a separate process to apply for state Medicaid benefits (branded as "Health First Colorado"), which is accessed online or through a County Application Site. For children birth to three years of age, families, doctors, child care workers, and others, may make referrals to CCBs for Early Intervention Services. Child Find, affiliated with Denver Public Schools, is part of a system to identify children suspected having developmental delay, and an adaptive assessment process exists for school-age children, where the child is put on an Individualized Education Program.

What services are currently available for Denver's IDD population?

The assessment reviewed services offered by HCBS waivers for individuals with IDD via Colorado Medicaid. The following waivers were included in the assessment.

Developmental Disabilities Waiver

The Developmental Disabilities (DD) waiver provides access to 24-hour services for adults who require extensive supports to live safely in the community and who do not have other sources for meeting those needs. Services include: Behavioral Services, Day Habilitation (Specialized Habilitation, Supported Community Connections), Dental Services, Prevocational Services, Residential Habilitation Services (24-hour individual or group), Specialized Medical Equipment & Supplies, and Vision Services.

Supported Living Services Waiver

Supported Living Services (SLS) provide aid to adults who can live independently with limited help and adults who are principally supported from other sources, such as family. SLS are not intended to provide 24-hour care. Services include: Assistive Technology, Behavioral Services, Day Habilitation, Services (Specialized Habilitation, Supported Community, Connections), Dental Services, Home Modifications, Homemaker Services, Mentorship, Personal Care, Personalized Emergency Response System (PERS), Prevocational Services, Professional Services (Includes Hippotherapy, Massage & Movement Therapy), Respite Services, Specialized Medical, Equipment & Supplies, Supported Employment, Transportation, Vehicle Modifications, and Vision Services.

Children's Extensive Support Waiver

Children's Extensive Support (CES) serves children from birth through age 17 who have significant medical and/or behavioral needs. These children are at high risk of out-of-home placement and require near constant supervision. Services include: Adapted Therapeutic Recreation and Fees, Assistive Technology, Community Connector, Home Accessibility Adaptations, Homemaker, Parent Education, Professional Services (includes Hippotherapy, Massage & Movement Therapy), Respite, Specialized Medical Equipment and Supplies, and Vehicle Adaptations.

Children's Habilitation Residential Program Waiver (CHRP)

The Children's Habilitation Residential Program Waiver (CHRP) serves children from birth to age 20, who have a developmental disability (developmental delay ages 0-4), and who are in the custody of the County Department of Human/Social Services, residing in an out-of-home CHRP-approved placement. Services under this waiver include: Community Connection Services, Habilitation Services, Cognitive Services, Communication Services, Emergency Assistance Training, Independent Living Training, Personal Care Services, Self-Advocacy Training, Supervision Services, Travel Services, Respite Services, Professional Services (Hippotherapy, Massage and Movement Therapy). In 2018, the Colorado approved shifting CHRP waiver administration from counties to CCBs and no longer requiring an out-of-home placement, but these modifications do not take effect immediately.

Elderly Blind Disabled Waiver (EBD)

The Elderly Blind Disabled Waiver (EBD) serves elderly persons with a functional impairment (aged 65+) or blind or physically disabled persons (aged 18-64). Services include: Adult Day Services, Alternative Care Facilities, Community Transition Services, Consumer Directed Attendant Support Services (CDASS), Home Modifications, Homemaker Services, In-Home Support Services (IHSS), Non-Medical Transportation, Medication Reminder, Personal Care, Personal Emergency Response System (PERS), and Respite Care. The EBD waiver is not specifically for persons with IDD and has slightly different Level of Care (LOC) eligibility requirements. The EBD waiver has traditionally been accessed through case managers at the Single Entry Point (SEP) system instead of the CCBs. Persons with IDD may choose EBD over traditional DD waivers because of the Consumer Direction option.

Non-Waiver Services

Beyond the Medicaid HCBS waiver services, there are those offered via the CCB and funded through various other sources including Medicaid State Plan (often referred to as "traditional Medicaid"), Education, various grants, donations, and other revenue. Services are limited and may have lengthy waiting lists. These are broken down into services for children and adolescents, and those for adults.

Services for Children and Adolescents

- Children's Clinical Services Comprehensive assessment, consultation and intervention services for children from birth to age 18, including case management. Many of these services are associated with Early Intervention.
- ➤ Early Intervention Services funded through the Individuals with Disabilities Education Act (IDEA), including case management, for infants and toddlers with delays or disabilities with a focus on the basic and new skills that babies learn during the first three years of life.
- Family Support State-funded individualized support and services to families who are caring for a child or adolescent with developmental disabilities.
- > Transition Services Services for children and adolescents to support the transition from a mental health institution or hospital to a community setting.

Services for Adults

> State Funded Supportive Living Services - Personal care, employment services, transportation, assistive technology, home modification, and professional therapies. The state funded SLS

⁶ CO HCPF Informational Memo (HCPF IM 18-013). 2018 Children's Habilitation Residential Program (CHRP) Waiver Expansion.

- program provides similar supports as the HCBS-SLS waiver, but is funded by Colorado General Fund. The state SLS program does not have the same Medicaid waiver regulations.
- ➤ Behavioral Health Specialized therapeutic interventions using evidence-based approaches for people with cognitive challenges, including case management funded by Medicare and Medicaid State Plan.
- > Transition Services Services for adults with a dual diagnosis of an IDD and a mental health issue to support the transition from an institution or hospital to a community setting, including case management funded by the Colorado Department of Human Services Office of Behavioral Health.

In addition to state and Medicaid services for persons with IDD, Denver adds mill levy funds to fill in where there are gaps in services or to enhance existing services. Historically, Denver's mill levy funds have been distributed only to RMHS as the CCB to enhance its services and, more recently, for RMHS to distribute funding to community partners and individuals with IDD requesting assistance.

In 2017, the total mill levy contract value to RMHS was approximately \$14.5 million, which accounted for about 31 percent of the total costs of all services and supports provided by RMHS. More than 73 percent (\$10.6M) was spent on services to the IDD community. Of this \$10.6M, 37 percent (\$5.4M) funded services delivered through RMHS and 36 percent (\$5.2M) went through RMHS to community agencies, providers, and family members for the benefit of individuals. The remaining mill levy funds (\$3.9M) were unspent and are available for use by DHS for services and supports for Denver residents with IDD. Service enhancements funded by the mill levy dollars are delivered in one of four ways by RMHS⁷:

- 1. <u>Individualized Annual Plan</u>: Building additional programs and resources above Medicaid caps into annual service plans, such as more respite care or a fifth day of adult day programming. RMHS has established contracts with 63 community agencies to increase capacity and access to services for Denver residents with IDD.
- 2. <u>Individualized Requests</u>: Funding personal requests for individuals with IDD. In 2017, RMHS received 2,985 individual requests for mill levy funding from 1,149 individuals. Approved requests totaled more than \$1.8 million.
- 3. <u>Community Agency Programs</u>: Support of innovative programs through other community agencies, including educational and supportive services for school-age children with autism, tailored financial health classes, and more than 20 others. Approximately 36 percent of Denver mill levy 2017 funds supported community agencies in developing, implementing and managing new projects and services. In 2017, RMHS received 30 proposals for mill levy funds, 26 of which were approved for a total of more than \$2.8 million in support.
- 4. <u>Enhanced Services from RMHS</u>: Provides additional funding for services when there are no funds from the state, Medicaid or other sources; includes services such as additional case management, first aid training to family members providing care, and therapies for infants and toddlers. In 2017, approximately \$5.4 million was spent on these types of enhanced services.

Table 5 below provides the breakdown, by service. Approximately 46 percent of services were to children and 54 percent were to adults.

-

⁷ 2017 RMHS Annual Mill Levy Report.

Table 5: Rocky Mountain Human Services Spending on Enhanced Services in 2017

Service	\$	%	# of Denver Individuals	
Early Intervention	\$762,427	14%	2,266	Services to
Family Services and Supports	\$687,907	13%	1,289	Children
Assessment and Consultation Team (Children's Clinical Services)	\$1,030,781	19%	805	\$2,481,115 46%
Life Essentials Provider Network	\$566,924	11%	232	Services to
Service Coordination	\$1,407,085	26%	1,020	(primarily) adults
Comprehensive Residential Services ⁸	\$238,558	4%	20	\$2,885,692
Behavioral Health	\$572,555	11%	115	54%
Community Outreach/ Communications	\$100,570	2%	n/a	
Total	\$5,366,807	100%		

The largest allocation of funds (37%) to community agencies, providers, and family members was for "client education/increasing independence" priority area, which is intended for the benefit of individuals with IDD primarily to support opportunities for individuals to "learn, grow, and increase self-determination over their lives." This was followed by an allocation of mill levy (27%) towards addressing system gaps within the IDD systems and across other systems⁹, social and recreational activities, and meeting basic needs such as housing and transportation. ¹⁰ Specifically, **Table 6** below provides the percent allocation of these funds for 2017.

Table 6: Mill Levy Distribution of Funds to Community by Priority Area in 2017

Priority Area	\$	%
Client Education/Increasing Independence	\$1,917,619	37%
System Gaps	\$1,399,343	27%
Social/Recreational	\$932,895	18%
Basic Needs/ Environmental Enrichment	\$570,103	11%
Behavioral/Mental Health	\$259,137	5%
Medical/ Dental	\$51,827	1%
Training and Support	\$51,827	1%
Total	\$5,182,755	100%

Review of how funds are distributed provides a snapshot of the services Denver residents are receiving as a result of the mill levy. In 2017, of the enhanced internal services provided by RMHS, early intervention, children's clinical assessment and consultation, and service coordination are the services

⁸ As of January 2018, mill levy funding no longer funds residential services.

⁹ In 2017 RMHS Annual Mill Levy Report, RMHS defines the "system gaps" priority areas as "addressing areas such as the transition out of foster care, provision of music therapy, testing for I/DD eligibility, and services beyond those covered by Medicaid or other funders". A primary service in this priority area is respite care.

¹⁰ 2017 RMHS Annual Mill Levy Report

being funded in the highest amount. Behavioral health services account for 11 percent of the allocation for enhanced services, yet are serving fewer Denver residents than these other services.

Distribution of funds from RMHS to community-based providers and individuals reveals similar spending as it pertains to percent allocation to physical health services and mental health services. Five percent of mill levy funds go to mental health services, with even smaller distributions (1% each) to medical/dental services and education/training. The largest percentages of these funds are distributed to community providers and individuals to support client education with a focus on increasing independence (37%), and addressing system gaps and program service limitations of other funding sources, such as Medicaid and state-funded services (27%).

Service Delivery Challenges

While the inventory indicates services are available and delivered to Denver residents with IDD, these services are often insufficient to meet the full extent of needs. Therefore, the one of the goals of the needs assessment was to explore what barriers the IDD community experiences when accessing services.

One of the purposes for mill levy funds has been to overcome gaps and serve individuals who have no access or inadequate access to Medicaid HCBS waivers and services funded by other sources. Reasons for lack of access may include eligibility, long waitlists, service caps, or other barriers. How well people understand the mill levy, its intent, who it is meant to serve, and what services it funds can be a barrier to effective delivery of services. The needs assessment asked stakeholders in Denver to describe their understanding of the mill levy and their experience with services that are funded by it.

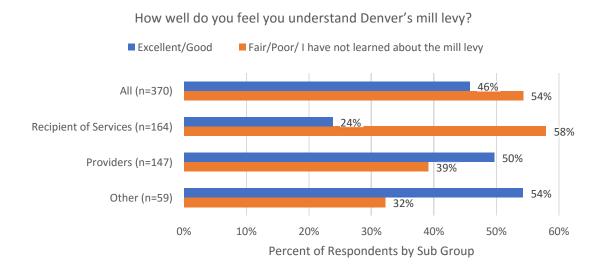
Key Findings: Mill Levy Understanding and Experience

- 1. Overall, there is low level of understanding about the mill levy. The vast majority of those with low level of understanding are the recipients of services.
- Community Agency Programs and Enhanced Services from the Denver CCB (RMHS) are least understood relative to Individualized Client Assistance and Individualized Annual Plans.
- 3. There is a high level of support for the services that the mill levy is currently funding, with slightly higher support for Individualized Client Assistance, and the Individualized Annual Plans. The variation in support may be in part be due to the lower level of understanding about Community Agency Programs and Enhanced Services from the Denver CCB.
- 4. Applying for mill levy funds is generally a positive experience. The vast majority of those who applied felt that the process and funds met their expectations; nearly half of those reported that it exceeded their expectations.

Overall Understanding of the Mill Levy

A fundamental challenge of service delivery via the mill levy is the overall limited understanding of the mill levy itself. Across all respondents, as shown in **Chart 2**, more than half (54%) report a poor to fair understanding of the mill levy. Chart 2 also breaks this down by sub-group including recipients of services, providers and other. Findings reveal that more than half (58%) of recipients have little understanding of Denver's mill levy, with just about one third of providers (39%) or other types of respondents (32%) reporting poor to fair understanding.

Chart 2: Understanding of the Mill Levy, by Sub Group



When asked to "describe what you need to learn more about" in regard to the mill levy, 44 individuals added open-ended responses. The most common response was for more information regarding what the mill levy supports and what resources are available. Nearly a quarter of these respondents are

interested in learning about how eligibility to receive mill levy funds is determined, how to access funding and who it is that benefits from mill levy funds. One in 10 respondents asked what the mill levy is.

Transitioning from child to adult funding/services, CCB guidelines, and implications of proposed changes to the mill levy were also described. Additionally there was interest in learning more about how to best serve people experiencing homelessness with mill levy funds.

"Learning about the mill levy services is essentially 'ask if something is covered and we will see if we can get funding for it,' so we ask and then learn".

- Guardian of a person with IDD

Chart 3 provides an assessment of the overall understanding of the specific services currently being funded by the mill levy, including Individualized Client Assistance, Individualized Annual Plans, Enhanced Services from RMHS, and Community Agency Programs. Providers and other stakeholders were more likely to have excellent or a good understanding of the funded services than recipients of services. Nineteen percent of recipients of services reported an excellent/good understanding of the services, compared to 45 to 46 percent of providers and other stakeholders.

Chart 3: Understanding of the Services Funded by the Mill Levy, by Sub-Group

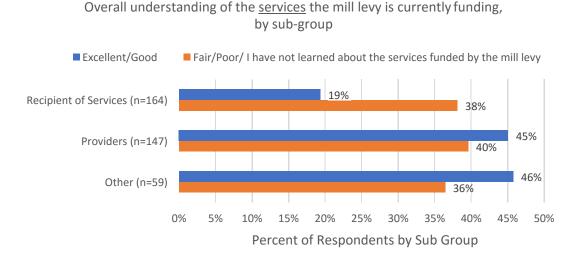
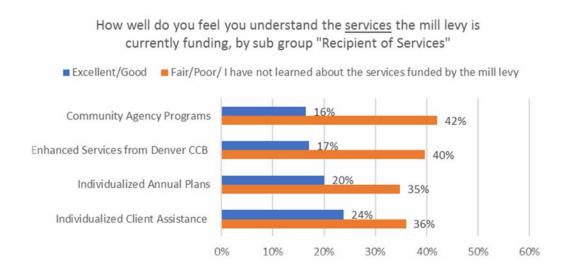
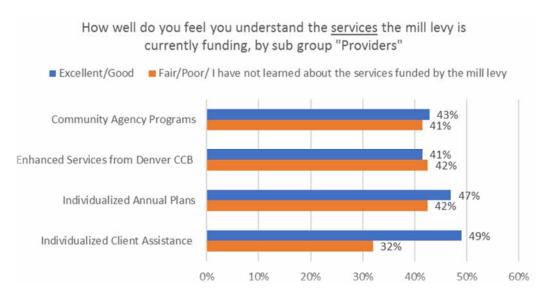


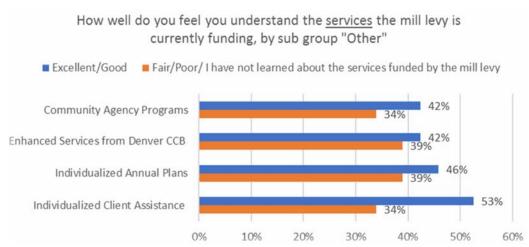
Chart 4 assesses each of the four services funded by the mill levy and the level of understanding by subgroup. This analysis reveals that overall, Community Agency Programs and Enhanced Services from RMHS are least understood relative to Individualized Client Assistance and Individualized Annual Plans. Overall, respondents had questions about how to access these services and potential coverage of these services through the mill levy. Many individuals have questions regarding limitations, parameters, and caps on these services. Many respondents had questions about individual services including respite care, transition services, and transportation, as well as services for specific populations, such as the elderly, part-C Medicare population, individuals experiencing homelessness, and people waitlisted for Medicaid HCBS services and other services.

Beyond the four service areas, respondents indicated a need to understand better to what extent mill levy funds are used for staffing and administrative overhead, accessing mill levy funds for people enrolled in Medicaid, funding for support groups, and Medicaid HCBS waiver eligibility assessments. A better understanding of the long wait times for approval of eligibility determination, including an estimation of that wait time, was also mentioned by respondents.

Chart 4: Services Funded by the Mill Levy and the Level of Understanding, by Sub-Group

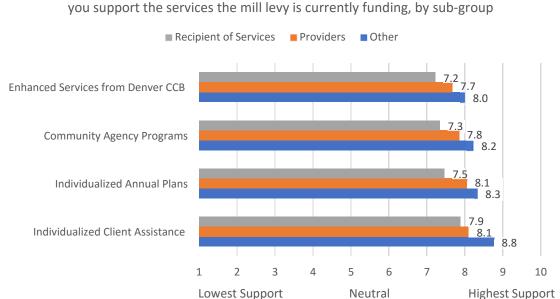






Overall, there is a high level of support for current mill levy services. As shown in **Chart 5**, the highest level of support across all respondents is the Individualized Client Assistance, and the Individualized Annual Plans. The Community Agency Programs and Enhanced Services from the Denver CCB have slightly less support relative to the other two services. This may in part be due to the lower level of understanding for these programs, as identified and discussed above.

Chart 5: Support for Mill Levy Services, by Sub-Group



On a scale of 1-10 where 10 is the highest level of support, how much do

Experience Applying for Milly Levy Funding

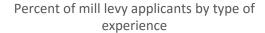
Approximately one third of respondents (n=81) reported having experience applying for mill levy funds. Of these respondents, 81 percent reported they do so on the behalf of a person with IDD and 6 percent responded doing so on the behalf of themselves. Another 16 percent reported they applied on the behalf of a community partner. ¹¹ By subgroup, of those who applied for mill levy funds, 53 percent were recipients of services and 42 percent of providers. ¹²

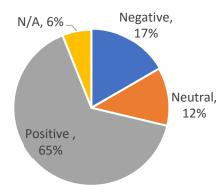
Overall, the experience of applying for mill levy funds is positive. Respondents were asked to rate their experience on a scale of 1 to 10, with 1 being "extremely negative" to 10 being "extremely positive." Generally, respondents' experience was positive, with an average score of 7.3 out of 10. Specifically, as shown in **Chart 6**, 65 percent of respondents who have applied for mill levy funds found the experience positive. However, 17 percent of applicants did report that they had a negative experience, while 12 percent said they were neutral about their experience.

 $^{^{11}}$ Percentages do not add up to 100% because some respondents indicated submitting applications on the behalf of both a person with I/DD and community partner.

¹² Five percent of applicants identified as "other". Specifically, three identified as "state or local agency" and one identified as "legislator or legislative staff".

Chart 6: Overall Experience with Applying for Mill Levy Dollars





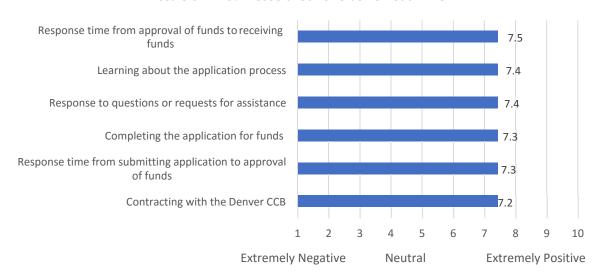
There were six aspects of the application process that respondents were asked to assess, including:

- 1. Contracting with RMHS;
- 2. Response time from when an application was submitted to when funds were approved;
- 3. Completing the application for funds;
- 4. Response to questions or requests for assistance;
- 5. Learning about the application process; and
- 6. Response time from approval of funds to receiving funds.

Overall, again, the experience was positive, with an average score of 7.2 to 7.5 for each aspect of the application process, as shown in **Chart 7**.

Chart 7: Milly Levy Application Experience

If you have ever applied for mill levy funds, how was your experience, on a scale of 1-10? Please check one box on each line.

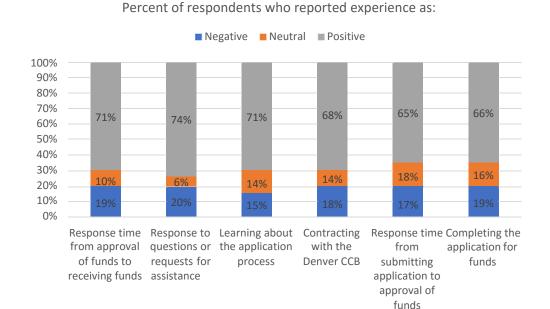


Specifically, approximately 70 percent of applicants who took the survey had a positive experience with the response time from approval to receipt of funds, learning about the application process, and response to their questions or requests for assistance. This is shown in **Chart 8**. Completing the application, the response time from submitting application to approval of funds, and contracting with the Denver CCB received the least positive ratings. This is due to more respondents being neutral about their experience. Overall, the survey shows that a small subset of respondents who applied for funding (approximately 18%) had a negative experience across all aspects of the application process.

"Time between approval and funding of Family Support Service requests is a challenge. I can't apply for respite or diapers until money is exhausted from previous request. Say I'm out of funds at the end of April, I have to wait until May to reapply. If approved, will be sent funds at the end of May or possibly beginning of June. So, I'm out funding for that month."

- Parent of a Person with IDD

Chart 8: Assessment of Application Process Experience



For those who applied for mill levy funds, on average, the funding met the need or filled a gap experienced by the applicants. The average score, on a scale of 1 to 10, with 1 being "It did not meet my needs" to 10 "It exceeded my expectations," was 8.3. Specifically, 82 percent of applicants responded that it met their expectations (of which 43% reported that it exceeded their expectations). Eight percent of applicants felt it did not meet their expectations, while 6 percent felt neutral about their experience. The negative responses again suggest that a subset of respondents who had bad experiences, had them consistently throughout the application process, including the outcome of that application process.

Assessment of Individual Service Delivery and Challenges

In addition to the mill levy specific service delivery challenges, the needs assessment also reviewed overall challenges with a set of 23 services that are available for people with IDD.

For each of the 23 services, respondents were asked to select whether the service "works well." If they did not feel the service worked well, they were then asked to select one of the below reasons for why it did not work well for them:

Available but not enough;

- Needs to be developed;
- Do not have access to the service;
- Don't know about the service; and
- Don't use the service.

A summary is provided below of the results, revealing the top five and bottom five service ratings within each of these categories. **Appendix J** provides the ratings for all 23 services.

As shown in **Chart 9,** the top 5 services that "worked well" were:

- 1. Vision services
- 2. Medical services
- 3. Early intervention (services for children 0-3 vears)
- 4. Durable medical equipment
- 5. In-home respite

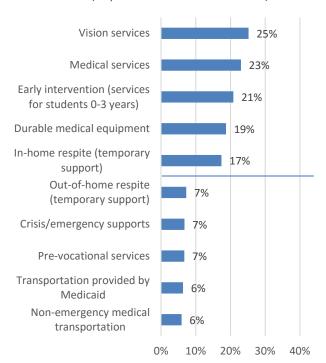
It is important to note that while these services were the most frequently reported to be working well, it still reflects only the experience of approximately one in five respondents.

The five services that the least respondents said "worked well" were:

- 1. Non-emergency medical transportation
- 2. Transportation provided by Medicaid
- 3. Pre-vocational services
- 4. Crisis/emergency supports
- 5. Out-of-home respite (temporary support)

Approximately 95 percent of respondents felt that something was not working well with these services.

Chart 9: Percent of respondents who report that the service "works well" (Top 5 and Bottom 5 Services)



As shown on **Chart 10**, the top 5 services that were found to be "available but not enough," were:

- 1. Home and community-based supports
- 2. Clinical services (OT, PT, SLP)
- 3. Recreational activities
- 4. Transportation provided by Medicaid
- 5. Mental health services

Approximately one third of respondents had this experience of insufficient service for these five services.

The bottom five services that were found to be "available but not enough," were:

- 1. Vision services
- 2. Durable medical equipment
- 3. Home modifications
- 4. Infant services
- Out-of-home respite (temporary support)

As shown in **Chart 11,** the top 5 services identified as "needs to be developed," were:

- 1. Educational services
- 2. Pre-vocational services
- 3. Mental health Services
- 4. Crisis/emergency supports
- 5. Home and community-based supports

The services that respondents least felt "needed to be developed," are:

- 1. Infant services
- Early intervention (services for children 0-3 years)
- Pre-school special education (services for students 3-5 years)
- 4. Dental services
- 5. Durable medical equipment

Chart 10: Percent of respondents who report that the service "available but not enough"

(Top 5 and Bottom 5 Services)

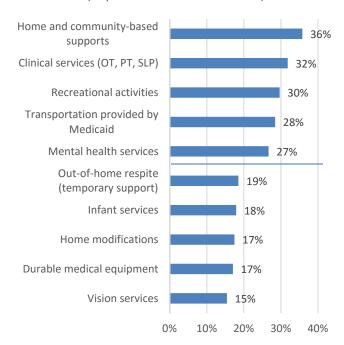
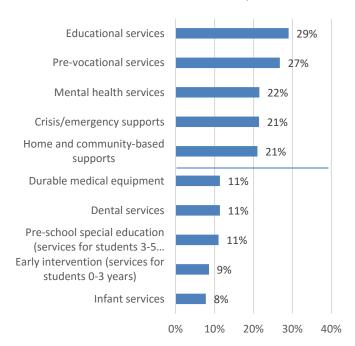


Chart 11: Percent of respondents who report the service "needs to be developed" (Top 5 and Bottom 5 Services)



As shown in **Chart 12**, the top 5 services where respondents reported "I do not have access," were:

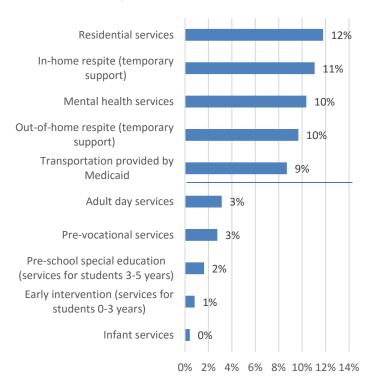
- 1. Residential services
- In-home respite (temporary support)
- 3. Mental health services
- 4. Out-of-home respite (temporary support)
- Transportation provided by Medicaid

Approximately 1 in 10 respondents reported not having access to these services.

The services where access is not an issue include:

- 1. Infant services
- Early intervention (services for children 0-3 years)
- Pre-school special education (services for students 3-5 years)
- 4. Pre-vocational services
- 5. Adult day services

Chart 12: Percent of respondents who report the service "I do not have access" (Top 5 and Bottom 5 Services)



It is important to note that while access might not be a problem for respondents regarding these services, they may find that there is not enough of those services (e.g., adult day services) or that it is not a problem because they do not use the services (e.g., infant services).

As shown in **Chart 13**, the least common services used by respondents, were:

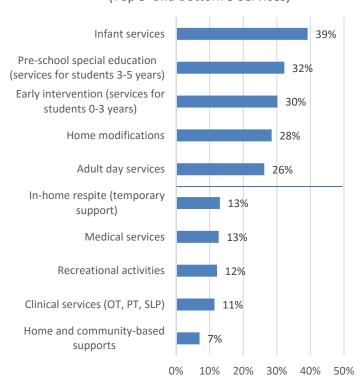
- 1. Infant services
- 2. Pre-special education
- 3. Early intervention
- 4. Home modifications
- 5. Adult day services

For these services, 26 percent to 39 percent of respondents indicated they did not use them.

The most common service used (or fewest respondents indicated they "don't use these services"), were:

- 1. Home and community-based supports
- 2. Clinical services
- 3. Recreational activities
- 4. Medical services
- 5. In-home respite

Chart 13: Percent of respondents who report the service "I don't use these services" (Top 5 and Bottom 5 Services)



Gaps in Service: Top 10 "Big Problems"

Each respondent answered a series of questions aimed at assessing the level of need for a specific health indicator. The questions began, "In your opinion, are the following things problems for people with IDD living in Denver?" Categories included items such as health insurance, transportation, housing, preventive care, and healthy foods, among others.

Chart 14 shows the percent of respondents who reported that the issue was a "big problem" for people with IDD in Denver. Affordable housing was indicated as a big problem by 87 percent of respondents, followed by waiting lists for services and supports (70%), adequate mental health services (65%), obtaining employment (63%), and transition to adulthood, including both transition planning (54%) and continuing education (50%).

Chart 14: Percent of Respondents Identified Issues as "Big Problems"

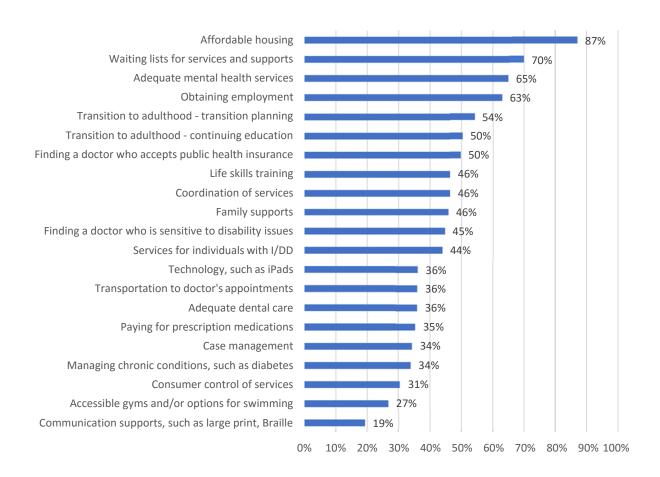


Table 7 presents the assessment of the extent to which an issue was noted as a problem for people with IDD living in Denver, by sub-group. There was a difference in the perception of what the big problems are for people with IDD living in Denver between providers and recipients of services. Recipients of services in aggregate identified just two issues that were big problems - affordable housing and obtaining employment. Meanwhile, providers in aggregate rated five things as big problems, including those listed above (affordable housing, waiting lists, obtaining employment, adequate mental health service, and transition to adulthood). This suggests that the priority problems common across both populations – affordable housing and obtaining employment – are two that deserve the most consideration for use of mill levy funds. A second tier of key issues would be waiting lists, adequate mental health services, and transition to adulthood.

Table 7: Assessment of Extent of the Problem, by Issue Area and by Sub Group

	Overall	Provider	Recipient of Services	Other	Prioritization
1. Affordable housing	Dia	Dia		Dia	Tier One
1. Altordable nousing	Big Problem	Big Problem	Big Problem	Big Problem	Her One
2. Obtaining employment	Big	Big	Big	Big	Tier One
2. Obtaining employment	Problem	Problem	Problem	Problem	riei Olie
3. Waiting lists for services and	Big	Big	Small	Big	Tier One
supports	Problem	Problem	Problem	Problem	Tier one
4. Transition to adulthood -	Big	Big	Small	Big	Tier One
transition planning	Problem	Problem	Problem	Problem	
5. Adequate mental health services	Big	Big	Small	Big	Tier One
	Problem	Problem	Problem	Problem	
6. Finding a doctor who accepts	Small	Big	Small	Big	Tier Two
public health insurance	Problem	Problem	Problem	Problem	
7. Transition to adulthood -	Small	Small	Small	Big	Tier Two
continuing education	Problem	Problem	Problem	Problem	
8. Family supports	Small	Small	Small	Big	Tier Two
	Problem	Problem	Problem	Problem	
9. Finding a doctor who is sensitive	Small	Small	Small	Big	Tier Two
to disability issues	Problem	Problem	Problem	Problem	
10. Transportation to doctor's	Small	Small	Small	Small	Tier Two
appointments	Problem	Problem	Problem	Problem	
11. Communication supports, such	Small	Small	Small	Small	Tier Two
as large print, Braille, CART	Problem	Problem	Problem	Problem	
readers, etc.					
12. Managing chronic conditions,	Small	Small	Small	Small	Tier Two
such as diabetes	Problem	Problem	Problem	Problem	
13. Paying for prescription	Small	Small	Small	Small	Tier Two
medications	Problem	Problem	Problem	Problem	
14. Accessible gyms and/or options	Small	Small	Small	Small	Tier Two
for swimming	Problem	Problem	Problem	Problem	
15. Life skills training	Small	Small	Small	Small	Tier Two
16 Consideration of complete	Problem	Problem Small	Problem	Problem	Tion Time
16. Coordination of services	Small Problem	Problem	Small Problem	Small Problem	Tier Two
17. Technology, such as iPads	Small	Small	Small	Small	Tier Two
17. Technology, such as iPaus	Problem	Problem	Problem	Problem	Her Two
18. Case management	Small	Small	Small	Small	Tier Two
10. Case management	Problem	Problem	Problem	Problem	TIEL TWO
19. Consumer control of services	Small	Small	Small	Small	Tier Two
25. Consumer Control of Sci vices	Problem	Problem	Problem	Problem	TICL TWO
20. Services for individuals with IDD	Small	Small	Small	Small	Tier Two
	Problem	Problem	Problem	Problem	
21. Adequate dental care	Small	Small	Small	Small	Tier Two
	Problem	Problem	Problem	Problem	

Respondents were provided an opportunity to comment on or describe their experience with each of these issue areas via the survey, focus groups, public meeting, and/or interviews. Themes for each of five high priority areas are provided below. Findings and recommendations begin to uncover what missing services are necessary/desired based on Denver's IDD population's needs.

Independent and Affordable Housing

For many, affordable housing is difficult to access, insufficiently available, or has long wait lists. In a focus group with individuals with IDD, none of the participants lived independently. However, when asked who desired to live on their own, each person raised their hand. There were six barriers identified to independent and affordable housing. The biggest concerns around housing were first the lack of affordable housing, with safety as the next priority. The issues that ranked less significant to obtaining housing are isolation, life skills for independent living, accessibility, and resources and supports.

Lack of Affordable Housing

Affordability is one of the biggest barriers for individuals with IDD. One reason stated that is unique to individuals with IDD are the income or wages they are likely to earn. While housing vouchers are used to support individuals with IDD in affording housing, there are an insufficient number of vouchers available to those with IDD and, many times, vouchers do not cover the high and rising rent costs in Denver.

Safety

Affordable may not mean safe. In addition to affordability, the access and availability of safe housing should be considered. Individuals with IDD are at greater vulnerability to violence and other forms of victimization. Therefore, protection and safety should be prioritized when serving this community. In addition to safe neighborhoods and limited access for outside threats, other things that make people feel safe include: a welcoming environment, and the companionship of friends, pets, and family.

Isolation

Loneliness is a frequent experience for individuals with IDD. Some individuals with IDD who responded to the survey mentioned that they have a difficult time making friends. Many reported this as the reason they prefer host homes and/or return to host homes following an experience with independent living. In addition to safety, the availability of companionship also protects against isolation.

Life Skills

A large piece of independent living is having the skills, training, knowledge, and resources to navigate life's demands. Math, cooking and paying bills are just some examples of the responsibilities of living independently. Increased access to resources such as technology, life skills classes, and other support services are needed to help the IDD community achieve the independence they desire. It should be recognized that not all individuals with IDD are able to fully live autonomously. Therefore, services should be available to allow individuals with IDD to live as independently as they want and are able to.

Americans with Disabilities Act (ADA) Standards for Accessibility

Housing often does not accommodate individuals requiring additional space and supports. Some participants reported ADA accessibility as a barrier when seeking affordable housing. Denver needs more opportunities for living and communal spaces that are accessible to all, regardless of physical ability, including canes, wheelchairs, motorized scooters, and walkers.

Resources and Supports

Resources and supports are needed for this population to find and apply for affordable housing, move into the housing, sustain rent payments, and live independently. When moving, it can be difficult to relearn local resources and resume daily activities. Transitional supports to help individuals with IDD become familiar with their community are needed. Resources and programs are needed to support

"Pathways to affordable housing are inaccessible for people who are unable to navigate paperwork."

Self Advocate

independent living, like food security programs. A gap in service exists with the SLS waiver, which does not support housing placement. Mill levy funds could be used to help fill that gap.

Community recommendations for mill levy funds:

- 1. Purchase houses and apartments located across Denver.
- 2. Support moving expenses, deposits and application fees.
- 3. Incentivize landlords to accept housing vouchers. 13
- 4. Support not only rent, but the transition process into housing and independent living.
- 5. Develop communal areas and activities to allow time and space for socializing. If these environments are not available within housing, then regular transportation to pro-social activity should be available.
- 6. Support independent living skills development, including skills like financial planning, cooking, cleaning, etc.
- 7. Facilitate groups that allow individuals with IDD to interact with their non-disabled peers in order to build social skills, or for groups that allow entire families (including those for whom they are providing care) to come together and build relationships.
- 8. Develop an online resource or calendar of Denver special needs-focused events (such as art or music)

Obtaining Employment

Respondents indicated two barriers to obtaining employment that may be supported or reduced by mill levy dollars. These barriers are limited employment opportunities, and lack of employment support.

Employment Opportunities

Overall, needs assessment participants reported few opportunities for meaningful or competitive integrated employment for individuals with IDD, as well as challenges finding correct job fit and appropriate compensation. Additional barriers to employment opportunities include businesses and employers themselves. Due to stigma and discrimination, some participants indicated they had been judged negatively or not taken seriously by employers due to their IDD. During the public forum, community members reported businesses and employers have concerns regarding liability and fears of employing someone with IDD.

¹³ The City and County of Denver recently approved an ordinance that will prohibit landlords from discriminating on the basis of income source (i.e., vouchers).

Employment Support

Customized support is needed for individuals with IDD to find and sustain employment, as well as additional training for employers to utilize evidence-based practices. This requires supported employment of individual employees and disorder specific needs to ultimately increase employment opportunities for persons with IDD. Applying for employment is daunting. It requires completing applications (e.g., assistance with reading, writing, and remembering details), interviewing, and getting to and from an interview. Once a job is obtained, ongoing support is needed to sustain employee placement. Experiences with job coaches and these types of services are varied in Denver. There is a unique skill set required to serve individuals with IDD and more training opportunities need to be available to increase the number qualified and effective job coaches. Lastly, there is a fear among individuals with IDD and their families that existing benefits will be lost because of changes in employment status. It is important for individuals with IDD to receive coaching and education, before and during employment, on potential benefit shifts.

Community recommendations for mill levy funds:

- 1. Soft skills training to those with IDD, including ongoing support with necessary education and skill building to keep jobs following placement.
- 2. Benefits counseling and education after employment on available benefits.
- 3. Employer education or awareness-building regarding individuals with IDD to reduce stigma and fear of liability.
- 4. Build awareness among employers on the benefits of hiring individuals with IDD.
- 5. Create incentives for employers to hire individuals with IDD and offer competitive wages for individuals with IDD.
- 6. Educate families on the employment opportunities available for loved ones with IDD.
- 7. Review current Workforce Innovation and Opportunity Act (WIOA) funding utilization to ensure maximum employment opportunities.

Case Management and Waitlist Coordination

Communication, Empowerment, and Support

Waiting for important services can feel like limbo. Waitlists for Medicaid HCBS Waivers can be very difficult to manage, especially when people may be experiencing homelessness and poverty. For individuals with IDD, it is important to regularly communicate regarding the process in a way that

"People languish on waitlists with little hope of accessing services when they need it." — Advocate/Legal Aid

can be understood. Furthermore, persons with IDD should be educated and empowered while they wait, including education on rights, protections, and what to expect when they begin services.

Case Management and Coordination of Services

Many parents/caregivers of persons with IDD do not know or understand waivers, so potential opportunities go unaccessed. As waivers change, it can be difficult for caregivers to plan for a person with IDD. While some participants reported that they are happy with their case management,

"Finding and checking out services is a full-time job for me."

- Parent of a Person with IDD

others indicated that coordinating agencies could work together better, such as greater communication and teamwork. Participants indicated issues with case workers/managers including high turnover, lack of agency/case worker accountability and transparency, inconsistency in skills of case workers, and large caseloads/case workers being overworked. As a result, this coordination and management of services often falls to the family or caregiver. Educating families about the process, resources, and funding available is key to using and benefiting from services.

Community recommendations for mill levy funds:

- 1. Waitlist resources should be equipped to handle emergencies or crises between services.
- 2. Additional funds should be made available to support those who are not at the top of the waitlists.
- 3. Increase the capacity of the services available to cut down on the waitlist times.
- 4. Create a clear process for communicating waitlist information from HCPF (State Medicaid Agency) to Case Managers and to clients.
- 5. Increase the number of Case Managers serving clients with complex cases and high needs and ensure a lower caseload for these staff.

Mental Health Services

Inadequate Provider Capacity

Overall, there is a sense among the community that there are not enough mental health care workers who are able to provide quality care to the IDD population. Many providers are not sufficiently trained to serve persons with IDD. Evidence-based practices and treatments should be supported, and providers should have opportunities and incentives to participate in continuing education to improve quality of care for IDD clients, especially those with mental health needs.

"There is not enough knowledge around dual diagnosis and how to distinguish between mental health symptoms [and] symptoms of disability."

- Case Manager for Persons with IDD

In addition to the overall lack of understanding of IDD, participants reported a total lack of services to adequately treat those with dual-diagnoses. Currently, there are not enough resources or professionals within Denver to treat IDD patients with a co-occurring mental or behavioral health diagnosis and therefore a need to increase the capacity to address these complex issues.

In many cases, wrap-around services and integrated services as referenced by a stakeholder, can help to improve the quality of treatment along the continuum of care. Participants indicated that increased wrap-around services and integrated services that further support inclusivity and understanding of the IDD community, could improve care throughout Denver.

As mentioned in above themes, care coordination and transitional support between services is needed to help ensure the continuity of care for this population. Additionally, participants cited provider turnover as impeding the quality of care for persons with IDD in Denver because it disrupts treatment.

In addition to a lack of understanding, there is a lack of clear responsibility for who treats persons with IDD and behavioral health diagnosis. Colorado's structure for the previous Regional Care Collaborative Organizations (RCCOs) and Behavioral Health Organizations (BHO), which now have been combined into new Regional Accountable Entities (RAEs), is difficult for families and other stakeholders to understand. Persons with IDD often are told they should be getting services from "the other system."

Community recommendations for mill levy funds:

- 1. Increase the availability of support groups.
- 2. Work with the RAE in Denver to create specialized support for patients with dual mental health and IDD diagnoses.
- 3. Build IDD workforce capacity by incentivizing education and specialization.
- 4. Create opportunities for continuing education for health care professionals.

Transition to Adulthood

Information, Awareness, and Navigation

The community indicated a need for greater awareness and understanding of services available in Denver for transitions to adulthood. When services drop-off after high school, individuals lose the routine or structure, as well as the resources, that were provided within the school system. For some, this feels like a "cliff." In part, this is due to limited knowledge among families about programs and resources available at this stage of an

"There is a cliff for individuals with IDD leaving educational settings."

- Advocate/Legal Aid

Transition from school is like getting "kicked off a cliff for family."

- Family member of a person with IDD

individual's life. This includes information on eligibility for services, as well as the role of the guardian or power of attorney, specific state IDD services, and Social Security Disability Insurance (SSDI). When information is available, community members indicated that it can be "indigestible" and overwhelming. Community members recommended classes or guidance for parents who would like to help facilitate their child's transition to adult services.

There is a sense that public school staff are and should be a resource for families about to or currently experiencing a transition. As a result, there needs to be more education and information for public school staff related to referrals for transitioning students and families to community supports such as the CCBs. This also includes educating families on options related to CCBs.

Lack of Services

Transitioning from the daily structure of school into the unknowns of adult life can be very difficult for persons with IDD. They leave school programing between the ages of 18 and 21, are limited in their opportunities to seek higher education and have limited opportunities for employment. Needs assessment participants reported a current lack of services for adults over the age of 18, and more specifically a lack of day programs for individuals with IDD that are integrated within the community across Denver.

Systems Coordination

Coordination between the two systems – child and adult IDD services – is reported be limited, including both collaboration and communications. Systems should be coordinated so that records and information can be passed on from provider to provider without barriers that interfere with quality care. One potential reason expressed for this is that case managers do not always have the capacity to attend client transition meetings.

Continued Education

There are few opportunities for persons with IDD to pursue lifelong learning including higher education. There are higher education programs that make integrated and successful efforts to support persons with IDD as they pursue education, but they are limited. Successful programs dedicate staff to support persons with IDD in finding the correct living arrangement and peer network, locating classes and meeting educators, working to ensure additional time for tests and school work, and offering ongoing support for issues that come up.

Transitional Support

Support is needed for those experiencing a transition from child IDD services to adult services, as well as their families. It is felt that too often transitional support starts too late in a child's life. Some respondents felt that the education and awareness building for this phase of life should start as early as the age of five. Some supports identified by the community include: financial education, independent living skills including strategies for community integration and engagement, and training and education towards meaningful employment. Other supports include day-to-day supports such as reliable and safe non-medical transportation. Transportation to community events and for activities of daily living was often cited as lacking. Caregivers of people with IDD indicated a need for opportunities to connect with other families preparing for or experiencing a transition.

Community Recommendations for mill levy funds:

- 1. Develop and maintain a resource list for families that is digestible, comprehensive, and current.
- 2. Support collaboration and communication between child and adult IDD services.
- 3. Provide additional opportunities for peer support groups.

Underlying Reasons for Service Delivery Challenges

Stigma

Through this assessment, stigma was revealed be one of the underlying challenges and barriers for persons with IDD across employment, housing, and mental health services.

An overall lack of community acceptance for individuals with IDD was described, with some participants reporting societal pushback when trying to participate within the larger Denver community. Increased community education and awareness about persons with IDD could to help reduce this stigma and create safer, more welcoming environments. A strength of host homes to some community members is that they offer a culturally sensitive environment for individuals with IDD compared to other housing options, such as apartment buildings.

For employers, stigma can perpetuate the belief that those with IDD are unemployable or a liability to employ. Some participants reported societal pushback and/or workplace discrimination. Educating businesses on the benefits of employing those with IDD and teaching employers how to best work with this population, could help to eliminate stigma and increase acceptance.

Additionally, landlords might be reluctant to accept vouchers because of their lack of acceptance for and understanding about persons with IDD. In a rising and competitive rental market, there are no incentives for landlords or rental companies to accept housing vouchers. Mill levy funds could potentially support incentives for landlords to accept vouchers and work to integrate those with IDD with other community members. Integrating services and supports into the community could help to increase inclusivity and acceptance of this population.

Regarding mental health services, stigma creates barriers to an adequate provider workforce of those with compassion and training to treat those with IDD. This could potentially be addressed by developing and including special education on IDD needs within curriculum for those working to become mental health providers.

Rights and Advocacy

Family members and caregivers reported often feeling their voices were marginalized or ignored, and some reported a lack of knowledge on individual rights for those waiting for or enrolled in IDD services. For example, some may be unaware of policies in place to inform waitlist placements, or qualifications to receive mental health and other service benefits. Increased outreach to families and persons with IDD to educate and train them in self-advocacy could help to empower families and individuals throughout Denver. Empowering families and individuals could improve outcomes for those with IDD by ensuring they are able to advocate for quality care, in turn creating effective workforces, fostering integration into the community, and helping to ensure those with IDD, starting from birth, have the services they need to transition into adulthood and thrive.

Training and Education of the Public

A general lack of understanding by the public was reported as an underlying challenge across all top five themes. Participants indicated very little community awareness and support for persons with IDD and recommended funds be made available to educate community members on interacting with and supporting those with IDD. In addition, participants suggested that city workers, inclusive of police and public-school staff, receive additional training on the unique needs of persons with IDD to better serve the population. Further law enforcement training could help to deescalate and improve outcomes in certain situations. Special training for public-school staff could help to identify children who may need services and better equip educators to work with students with IDD and maintain classroom integration.

IDD Provider Capacity

Participants reported limited IDD provider capacity throughout Denver, in part due to lack of training and knowledge on the needs of their patients with IDD, as well as number of providers offering IDD services. This issue constrains access to appropriate and timely services. For example, some community members find that with existing provider capacity, bi-monthly services are delivered when the need is in fact for more frequent care. Increasing the qualified workforce to adequately meet the demand and lower caseloads could improve overall care for clients.

Participants indicated that this problem is particularly significant among children with IDD, reporting a lack of

"There is mental health coverage under Medicaid, and mill levy dollars could certainly be used to fill in gaps but if there are not adequate providers, then money isn't the issue. Finding folks who are capable of understanding the unique challenges of someone with IDD and a mental health diagnosis has been difficult."

Public Meeting Participant

specialized early childhood support for these children and their families. Systems should support and implement evidence-based early childhood intervention models. Birth to age five is a crucial time for brain development and appropriate services implemented during these ages can set children up for later success. It takes specially trained providers to treat babies, and due to lack of funding, participants reported underqualified professionals delivering support during such a critical stage. Participants also expressed concerns regarding the ratio of care coordinators to early childhood professionals, recommending that additional funds be used to support the early childhood workforce. Additionally, concerns were raised regarding inequities between early childhood services for families of varying socioeconomic status. According to a stakeholder, providing oversight and regulation of these services, particularly early on, could avoid increasing disparities throughout the lifespan.

System Coordination

Increased system coordination could improve the overall quality and continuity of care across the continuum for persons with IDD. Needs assessment participants recommended that agencies across Denver better coordinate services to allow for improved support entering and transitioning through the system of care. For example, improved coordination between school-systems funded through Department of Education and community IDD resources such as Medicaid and the mill levy could help individuals transitioning into adulthood and community-based resources. Better coordinated services might more comprehensively meet a person's needs, and limit duplication of services. Better coordination of services also could potentially increase the availability of services and providers by generating efficiencies that could increase capacity.

Recommendations for these overarching service challenges identified through the needs assessment are provided below on how best to use and govern mill levy funds.

Governance Models

Across the U.S., there are primarily three models for how local tax revenues fund services for persons with IDD. The major governance models are conceptually generalized below:

- Model #1: Local tax revenues are directly granted to the local IDD network entity. Local IDD
 network entities are similar to the Colorado CCB system, but have different names in different
 areas. Many counties distribute all of the funding, while others take an administrative cut prior to
 distributing the funds.
- Model #2: Local tax revenues are given in some part to the local IDD network entity and in some
 part distributed directly in the community. The community funding is granted based on
 applications, RFPs, legacy partnerships, or emergency needs requests. Most of these hybrid
 funding models rely on a board or committee that determines the awards and grantees. The
 boards and committees are in some cases chosen based on application, chosen by appointment,
 or are structured based on statute.
- Model #3: Local tax revenues are put toward the state's Federal Medical Assistance Percentages (FMAP) to increase the amount of federal matching funds for that state's Medicaid expenditures. Every state has a federally predetermined FMAP rate that establishes the cost-sharing percentage between the state and federal governments for the Medicaid program. This model may limit the flexibility for the local community to spend dollars in ways that best meet local needs/desires. To address this limitation, some counties only put a portion of their local tax revenue toward the state's FMAP.

Across these main governance model structures, there is not a single best practice or recommendation that stands out above the other. Counties may elect to use a hybrid approach to meet different needs. Each model that HMA reviewed has quirks and limitations based its context or environment, including state and local governance, the demographics of the population, the delivery of Medicaid services, and the advocacy networks. **Table 8** describes locations by model type.

Table 8: Governance Models by Type of Model

Type of Model	Location
Model #1	Denver County, CO
Model #2	Douglas County, CO
	Broomfield County, CO
	Franklin County, OH
Model #3	Franklin County, OH
	Dane County, WI

Until 2017, Denver had operated using the Model 1 structure, where mill levy funds were going to the CCB. Denver now has the option to use governance Model #2 or #3, based on the 2017 change to City Code to expand the allowable uses of revenue to include contracting with other providers and transferring funds to HCPF to reduce the Medicaid waiver waiting list for Denver residents in addition to contracting with the CCB.

Douglas County, Colorado

Douglas County, Colorado, is part of the southern suburbs of the Denver Metro area. Douglas County is home to the seventh-highest median household incomes in the U.S. and is served by the largest CCB in Colorado - Developmental Pathways (DP). Like Denver, Douglas County struggles with barriers to affordable and accessible housing and transportation, the need for additional respite care options, and adequate behavioral health supports.

In 2016, Douglas County served 1,584 people with IDD. ¹⁴ Of DP's \$12,861,032 in mill levy revenue, \$4,786,472 was revenue from Douglas County; and of the DP mill levy revenue, 86 percent went to DP programs and services and 14 percent was set aside for board-designated funding. The DP funds are used for case management, community outreach, direct services, and administrative depreciation for program transportation. The board-designated funding is prioritized based on extensive community outreach assessments for the following targeted initiatives: Respite, Transportation, Capacity Building, Total Wellness Care, and the 3+ Program.

In addition to the funding to DP, Douglas County retains five percent of the mill levy funds for its Douglas County Developmental Disabilities Grants to community programs. ¹⁵ Grants range from \$1,000 to \$25,000 and reward collaboration and innovation. ¹⁶ Community organizations apply for funding and an advisory council makes the recommendations which are made final by the Board of County Commissioners. The advisory council uses public evaluation criteria to make their funding decisions for services and transportation. ¹⁷ There is a standard application process for the advisory council members, and members are selected to fill diverse positions with varying roles on the council. The five percent amount for the grant program is determined by the commissioners. ¹⁸

Broomfield County, Colorado

Broomfield County, Colorado, is a northern suburb that sits between Denver and Boulder. Broomfield's mill levy is different from Douglas County or Denver County because the funding supports a variety of community programs and supports, and is not exclusively to fund services for persons with IDD. Broomfield County distributes its mill levy funding to three distinct categories of services. The funds are provided first to Imagine! (the organization which serves as the CCB for Broomfield and Boulder Counties), and Mental Health Partners. The remining funds are distributed through Community Grants. A strength of the model is the clear distribution of funds and emphasis on mental and behavioral health.

Imagine! serves approximately 185 unduplicated residents and requested \$455,112 of mill levy funds for 2018. Services provided include educational and therapeutic services, job training and placement, recreational activities, opportunities for community living, behavioral health, technology solutions and family support. Imagine! has increased funding for Out & About and the Santa Fe Group Home, which

¹⁴ Developmental Pathways. (2016). 2016 Douglas County Mill Levy Report. Retrieved from https://www.douglas.co.us/documents/2016-mill-levy-report.pdf

¹⁵ Douglas County. (2017). 2017 DD Mill Levy Grant Awards. Retrieved from https://www.douglas.co.us/documents/developmental-disability-mill-levy-grant-awards.pdf

¹⁶ Douglas County. "Developmental Disabilities". Retrieved from https://www.douglas.co.us/community/partners-and-providers/developmental-disabilities/

¹⁷ Douglas County. (2017). 2017 DD Mill Levy Evaluation Criteria. Retrieved from https://www.douglas.co.us/community/partners-and-providers/developmental-disabilities/

¹⁸ Staff at Douglas County was unsure how the 5 percent allocation was determined by the commission.

provides housing for six adults in Broomfield with IDD. Mental Health Partners will receive \$405,560 to serve 395 individuals that represent the non-Medicaid clients in Broomfield who need services. Unlike in Denver where mill levy-funded services must go to residents with IDD, there is no requirement that these individuals have an IDD to receive services from Mental Health Partners.

The Community Grants policy states that agencies that wish to receive grant funding for public purposes of supporting the health, welfare and human service needs of Broomfield residents must apply through the Department of Health and Human services (HHS). ¹⁹ There is no requirement that grants fund services for people with IDD. A grant review committee considers the applications from a variety of agencies and makes recommendations. The funding for community grants in 2018 is \$365,072. The committee is made up of two HHS Advisory Committee representatives, two representatives from HHS, and two representatives from other departments within the City and County of Broomfield.

Franklin County, Ohio

Franklin County, Ohio, is home to Columbus and the surrounding area, which is the state capitol and the most populous city in Ohio, making it similar to Denver. The county has maintained voter-approved levy funding since 1992. It has a reputation for a transparent program that utilizes levy funding to supplement basic services for persons with IDD across the lifespan. Residents can access information about the process and understand where the allocations are being distributed. The state of Ohio Department of Disabilities is responsible for monitoring and oversight of the County Boards of Developmental Disabilities. Local county boards and their individual staff undergo an accreditation process and an employee certification. In 2016, Franklin County Board of Developmental Disabilities (FCBDD) received a 3-year accreditation with a 5-star rating.

The FCBDD is similar in nature to a Colorado CCB. The FCBDD conducts an operational and programmatic assessment, reviews the availability of services, and estimates future demand (Franklin County's enrollment for persons with IDD has increased regularly between 3.0%-5.0%) to determine the request for mill levy funding. The Franklin County Commissioners review the request and set a budget for the mill property tax. Levy funds are provided to the FCBDD and the funding is governed by a board of seven people. The FCBDD Board is comprised of statutorily determined members in which five are appointed by County Commissioners and two are appointed by the Probate Court Judge, and at least three must be parents or family members of individuals receiving or eligible to receive services provided by the board. Mill property tax levies represented 76.8 percent of the agency's revenue in 2016. 20

The FCBDD is a direct service provider and offers services through partnerships with community organizations and a board-driven Request For Proposal (RFP) process. The allocation of funding is decided between three categories of service that include: services for children, services for adults, and specialized services.

In addition to the RFP process for community organizations, and the flexibility to offer direct service when it is in the best interest of the consumer, FCBDD also uses tax revenue to provide state matching funds to Medicaid for consumers to be eligible for Medicaid waivers. In Ohio, the FMAP rate is 63.09

¹⁹ Broomfield City Council. (2018). City Council Meeting March 20, 2018.

²⁰ Franklin County Board of Developmental Disabilities.(2017). Human Services Levy Review Committee Report.

percent, which means for every person receiving Medicaid services in Ohio, federal funding supports 63.09 percent of the cost and the state must match 36.91 percent; that match may come from a variety of sources. For Franklin County, in their high cost client cases, it makes more sense to pay the Medicaid agency the 36.91 percent state match to receive federal matching funds and services through the waiver than for the county to pay 100 percent of service costs for any one individual not on a Medicaid waiver.

Dane County, Wisconsin

Dane County, Wisconsin, is a leader in providing consumer choice and family preference. The state of Wisconsin as a whole has established a strong network of long term supports and services that is often referenced by experts when modeling good systems. Denver cannot replicate the Dane County model because Colorado does not offer Medicaid managed care, or a system in which patients agree to utilize only certain providers and the cost of treatment is closely monitored, and would need to work with the state to be able to provide funding for Medicaid to match; however, the consumer focus is worth highlighting. Dane County has created an atmosphere where people with IDD have a strong voice in advocacy and the voting public see the issue of recognizing rights and supporting people as a civic issue. County case managers hold responsibility for identifying the needs of a person and the capacity of the system to meet those needs. Wisconsin moved to a managed care model of service in January of 2018. For persons with IDD who access Medicaid, the county pays a percentage of the FMAP funding directly to the state. In 2015, the county local match amount was \$11,116,261. The pooled funding model increases the total available services and Medicaid waiver programming for persons with IDD. Persons with IDD on a Medicaid waiver can choose to go with the Family Care Plan (which is a traditional managed care structure), or may choose the IRIS (Include Respect I Self-Direct). IRIS is the Wisconsin system for consumer directed long term supports and services, which is like Colorado's Consumer Directed Attendant Support Services (CDASS).

Dane County has 1,405 adults with IDD and 1,353 (96%) self-direct their supports though the Wisconsin Medicaid program. This population is supported by 92 support brokers and six county case managers. The IRIS self-directed model allows persons with IDD to organize their assistance and employ their own providers. Consumers are assigned a support broker who assists with the plan and coordinate care and services. Dane County established an array of generally available supports to help people establish a plan. The funding for Wisconsin waiver participants is blended from county, state, and in some cases, managed care plans.

Dane County has a strong philosophy for the residents with IDD to live and work in the community. ²³ Persons with IDD in Dane County live outside their family home at a rate of 66 percent compared to the average of 44 percent. An astounding 806 people with IDD in Dane County use self-directed supports to purchase assistance to live in their own place, alone or with housemates. This concept is aided by a high employment rate for persons with IDD - 70 percent receive supported employment services and 60 percent are in paid employment, compared to a national rate at 19 percent. Dane County has created a network of 890 business relationships to support these high employment rates. Dane County has partnered with Movin' Out, a non-profit housing organization with a mission to help people with

²¹ Wisconsin Department of Health Services Division of Medicaid Services (2017). 2015 Annual Long-Term Care in Motion Report.

²² The Dane County Department of Human Services and Support Broker Coalition. (2006). Quality Standards for Support Brokers.

²³ John O. Brien. (2015). Social Innovation: The Dane County Difference. The Centre for Welfare Reform.

disabilities experience stability, autonomy and connection in the community. Movin' Out has developed and purchased affordable and inclusive rental housing across Wisconsin with six units in Dane County. Owners and tenants are households of one to three adults with, as well as family households that include children with disabilities. Dane County Human Services endorsed the program and helped develop the housing counseling capacity.

Dane County is governed by a Long-Term Support Committee that is established by city ordinance 15.15(6). The committee make-up is highlighted in the Governance Model Recommendations section below and has multiple functions. The members advise the Health and Human Needs Committee of the County Board, the Human Services Board on long-term support, Badger Prairie Health Care Center and other program areas pertaining to the operation of the Adult Community Services Division of the Dane County Human Services Department in policy planning and budgetary matters.

Recommendations

Based on reviewed models for local funding, reoccurring themes from the key informant interviews, focus groups, stakeholder meeting, and the survey, HMA recommends the following steps when considering how to govern the mill levy funding and allocate funds for services.

Recommendations for Governance Models

Recommendation 1

DHS should establish a formal structure to disperse mill levy funding. Historically, DHS has given all the mill levy funds to RMHS; but in light of the unspent mill levy funds and the December 2015 RMHS audit findings, DHS has chosen to distribute funds to RMHS plus to additional community services.

A model where county tax revenues would be directly applied to the statewide FMAP (currently 50 percent for Colorado) could limit services for persons with IDD living in Denver to only those provided in Colorado Medicaid waivers, and remove the current flexibility that mill levy funding provides. In addition to the fact that once funding is given to HCPF for match, it would be subject to the rules and services of HCPF and Medicaid. Colorado operates waivers on a statewide basis. This means, HCPF could not target matching funds specifically to the

"RMHS should be applying for mill levy funds for their administrative overhead like everyone else, and not just taking the funds if they need them. People with IDD are at the mercy of case management and executive management at all the CCBs. They have too much power over the funds they receive."

 Parent and Advocate for Person with IDD

residents of Denver. The model where funds are applied for Medicaid match works well in a community where there are abundant providers, robust service packages, and county-run waiver systems. Therefore, HMA does not recommend this approach for DHS. Rather, DHS should consider a hybrid option to both continue to directly fund RMHS programs, and also distribute funds directly from DHS to community partners or services that support persons with IDD.

A common methodology for disbursing local tax revenues involves review and decision-making from a governing body. For example, a mill levy advisory board that consists of members who represent key stakeholders identified via an application process or an official appointment. There are many board structures DHS could consider, including:

- 1. State Councils on Developmental Disabilities are federally-mandated developmental disability decision making entities that exist in the same form in every state. These councils make policy recommendations for persons with IDD on a statewide basis. Members are appointed by the Governor and must consist of more than 60 percent individuals with IDD or their family members, advocates and agency representatives.²⁴
- HCPF uses a board model to approve Medical Services (Medicaid) Rules. The Medical Services Board
 consists of 11 members that represent each congressional district and no more than six members
 can be of the same political party. The Medical Services Board uses a standard Colorado Boards and
 Committees application process. The model is structured so the committee politically represents the
 state.
- 3. The Dane County committee consists of nine members. Five members must be consumers receiving long-term community support services or a relative or guardian of such a consumer, each of whom represents one of the following groups: (a) frail elderly persons, (b) physically disabled persons, (c) developmentally disabled persons, (d) chronically mentally ill persons, and
- 4. (e) chemically dependent persons. At least one member must be a member of the County Board. One member must be a member of the Human Services Board and one member must be a member of the Commission on Aging. Members must be chosen on the basis of interest in providing long-term support services for the frail, elderly and disabled persons. The long-term support committee must review and approve the county's community options plan and meet the requirements for a long-term support committee specified in s. 46.27(4), Stats.

DHS could consider a board which uses several different aspects of the above-referenced models. For example, a board consisting of geographic representation of the city, 60 percent or more persons with IDD or family members, and appropriate DHS policy staff and RMHS (and future CMAs) executive staff positions. A model that uses geographic representation, persons with a stake in IDD services, and policy making staff to guide implementation ensures key stakeholders and clients are fairly represented, and policies are effectively implemented.

The process to form the advisory board should include staff positions from DHS and RMHS appointed by City leadership and an application process for community members. The majority of boards reviewed in this research had positions ultimately selected by county leadership (commissioners, superintendents, etc.). Franklin County attributed the success of its FCBDD in part to the idea that members received no compensation and were not selected based on political appointment. Denver should consider replicating a board free of members looking to personally benefit from the committee including: reimbursement for committee activity, political advancement, or preference in professional contracts.

Recommendation 2

DHS should create a funding formula that provides transparency priority areas to the residents of Denver. As described above, the highlighted governance models have dedicated priority areas for mill levy funds. By creating a similar structure, DHS could ensure Denver residents are able to see the spending priorities and how community partners fit into the strategy. This would minimize the potential for DHS to be influenced by specific providers or groups, and would help to ensure the formula does not guarantee contracts with specific providers. Stakeholders would be informed of the

²⁴ Administration for Community Living. (2018). "State Councils on Developmental Disabilities". Retrieved from https://www.acl.gov/programs/aging-and-disability-networks/state-councils-developmental-disabilities

priority categories and could see how contracts align within those categories. Such a prescribed distribution model would increase accountability, transparency, and visibility in the community. The model should be organized and flow from DHS directly to RMHS and other community partners in a way that addresses the key initiatives outlined in this needs assessment and other needs that arise. The allocation percentages should be informed by the advisory board. Ranges could be used to allow for greater flexibility within defined parameters. For example, a hypothetical funding formula might look like this, with additional details that could be added under specific focus areas:

Focus Areas	Mill Levy Funding Allocation
RMHS	70 to 75%
Housing	10 to 15%
Mental Health Services	5 to 7%
Employment Support	3 to 5%
Transitions	2 to 4%
Consumer Directed Supports	2 to 4%

Recommendation 3

DHS should include reporting requirements for future contractors who are recipients of mill levy funds. DHS has a strong reporting requirement for the RMHS contract that include an annual report and monthly metrics. This accountability in reporting should be replicated across contracts with providers who receive any mill levy funds. A robust reporting structure ensures services are being delivered as expected and could be used by DHS and/or the advisory board to inform future contracting decisions.

Recommendations for Mill Levy Spending

The needs assessment found that there are many key areas where mill levy funds could make a significant difference for the people; however, the funding is not enough to make significant changes in all the areas of need. Therefore, the needs assessment offers a starting point for the City and County of Denver to prioritize what focus areas should be considered, including any new services or administration of the mill levy funds. Recommended areas of need are included below and have been prioritized as first tier, and second tier. Importantly, this does not mean that for some members of the IDD community, priorities in the second tier are not as significant. The needs assessment simply presents opportunities where DHS could implement ways to better serve and meet the needs of the most people based on feedback gathered from stakeholders. These include opportunities to improve the delivery of specific services, to meet basic needs of daily living, and to address overarching systemic barriers to members of the IDD community feeling heard and respected.

First Tier

First tier areas of need for consideration include housing, obtaining employment, services for persons on waitlists, adequate behavioral health services, and life skills training for transitions.

Affordable Housing

The needs assessment found the top issue for persons with IDD in Denver is the lack of affordable, accessible, and safe housing within Denver.

Recommendation 1: DHS could use mill levy funds to purchase housing for Denver residents with IDD. There are many different models to consider. For example, those like the Santa Fe Group Home in Broomfield County, Colorado, that offers dedicated supportive housing for people with IDD and works within the structure of Colorado Medicaid waivers. Denver could increase capacity by purchasing space and operating a group home within the regulations that already exist.

There are other models such as the Movin' Out Program in Dane County, Wisconsin, and the Creative Housing model in Franklin County, Ohio, where the county entity partners with a housing-specific organization to purchase, renovate, and maintain private space. In these models, the housing organization is responsible for the real estate, general contracting and maintenance staff and the county has case managers to assist persons with IDD to pay rent, find roommates, and establish providers to do in home services.

DHS would have to establish the criteria for housing, waitlists, and staff oversight. There are non-profit housing organizations in and around Denver that assist people to access safe and affordable housing through various channels that include, rental assistance, supportive services, counseling, and education. DHS could partner with one of these organizations for the operational side of housing assistance and create a targeted program for persons with IDD or expand the capacity of an existing program.

Recommendation 2: In a rising and competitive rental market, there are no incentives for landlords or rental companies to accept housing vouchers. Mill levy funds could potentially support incentives for landlords to accept vouchers and take part in implementing strategies to integrate those with IDD with other community members in their housing units. There are already initiatives in Denver to eliminate discrimination from landlords against people using housing vouchers, including a current effort by City Council to approve an ordinance that will prohibit landlords from discriminating on the basis of income source.

Obtaining Employment

Recommendation 3: Although the community provided many suggestions for addressing employment, it is recommended that mill levy first be used to address the lack of meaningful employment opportunities available to persons with IDD. Lack of opportunities has the largest effect on obtaining employment. The Dane County model highlighted in this report stresses the importance of business and community relationships. Mill levy funds could be used to incentivize businesses and to provide employment opportunities to individuals with IDD, and training to employers on interacting and managing persons with IDD.

Waiting Lists for Services and Supports

Recommendation 4: The needs assessment revealed that certain persons with IDD experienced frustration with the current HCBS-DD waitlist process. This is especially true for persons with IDD experiencing homelessness who were disconnected from services. In focus group conversations, these individuals relayed that they felt like they were not receiving the communication they needed to understand when services would be available to them. Mill levy can be used to ensure case managers are proactively reaching out to their clients during the enrollment process and on an ongoing basis. Outreach should include: relaying waitlist information, waitlist movement or changes, critical policy updates, and opportunities for Denver residents to participate in informing policy.

Recommendation 5: While Denver has no control over the wait list, it can use mill levy to improve the quality of life of those on it. Many individuals waiting for comprehensive services (including residential) are already enrolled in another HCBS waiver that does not fully meet their needs. Mill levy can be used to fill some of the unmet needs while an individual is waiting. This, in many cases, may be affordable housing, an earlier recommendation in this report.

Transition to Adulthood - Transition Planning and Services

Recommendation 6: Respondents to the needs assessment indicated that transition planning and services are insufficient or untimely. For example, public meeting attendees shared that transition planning is happening too late, and that earlier foresight in planning would better serve young adults with IDD. Some parents believe there is a lack of resources and lack of knowledge or awareness of those resources. Mill levy should support further evaluation and study of transition services in Denver to identify specific areas in which to enhance transition services, including an assessment of best practices in self-directed planning and family involvement. The needs assessment identified an opportunity for mill levy funding to enhance transition services through the development of resources for families, case managers, providers, and school personnel. Resources may include a database of available adult services, trainings or information sessions for parents and case managers, and materials on best practices that incorporate self-directed planning and family involvement.

Adequate Mental Health Services

Recommendation 7: DHS could contract with mental health provider(s) trained to serve IDD populations. Like in Broomfield County, additional mental health provider(s) would be available to partner with community IDD service providers to enhance or supplement their services with additional mental health services. DHS could put out an RFP and award grants to providers to serve persons with IDD in Denver under a specific payment structure; or it could create an application process where providers apply and those who meet the qualifications become preferred providers and accept cultural competency requirements and a predetermined reimbursement rate. The dedication of mental health provider(s) to the IDD community would increase capacity to competently serve individuals with IDD. Funding enhanced mental health services using the mill levy might begin to close the gap between the cost of providing these services to people with IDD and the current reimbursement rates for those services through other sources.

Second Tier

Second tier areas of need for consideration include increasing provider capacity for IDD services, case management, and consumer-directed support.

Increase Provider Capacity for IDD Services

The need for both primary care and other services was a common theme identified as a challenge with the delivery of services in Denver. For example, finding a doctor who accepts public health insurance and finding a doctor who is sensitive to disability issues, was identified as small or not a problem by 51 percent of respondents (relative to other issues where more than half of respondents found them each to be a "big problem"). The availability of providers stems from many issues, including how providers are paid, the extent they can afford to live and/or work in Denver, and overall awareness, comfort, and/or sensitivity to serving persons with IDD.

Recommendation 8: Based on a stakeholder recommendation, DHS should explore the option to offer discounted housing for IDD providers to incentivize them to live and work in Denver. According to Indeed.com (an employment website), the average salary for all positions in Denver that reference developmental disabilities is \$35,038 (for all levels of expertise). Further research must be done to consider any evidence-based workforce support models and the plausibility of implementing them in Denver under the current City Code, which states mill levy funds must be used for the purpose of purchasing services and supports for persons with IDD. Parameters could be established to ensure that dollars are used to benefit Denver residents with IDD. For example, the incentive dollars could be based on a minimum threshold of Denver residents with IDD served and/or include a requirement that providers who receive funds must serve Denver residents with IDD for a minimum time frame. This has the potential to not only increase capacity and access in Denver, but also to create more continuity of services over time.

Recommendation 9: The assessment revealed an overall lack of providers to serve the number of Denver residents with IDD. Based on this, there is a recommendation to create a campaign to inform new and potential providers about persons with IDD in Denver, as well as all of the services currently offered for them and what is lacking. There are many potential partners DHS could work with; however, JFK Partners is federally designated as Colorado's University Center of Excellence in Developmental Disabilities (UCEDD).

The UCEDD network is nationally authorized under public law under the Developmental Disabilities Assistance and Bill of Rights Act of 2000 or "the DD Act" and their funding is administered by the Administration on Intellectual and Developmental Disabilities (AIDD). The UCEDDs have played key roles in every major disability initiative over the past four decades. Issues such as early intervention, health care, community-based services, inclusive and meaningful education, transition from school to work, employment, housing, assistive technology, and transportation have been directly benefited by the services, research, and training provided by UCEDDs.²⁵

²⁵ Association of University Centers on Disabilities. "About UCEDD". Retrieved from https://www.aucd.org/template/page.cfm?id=667

As the UCEDD, the purpose of JFK Partners is to provide interdisciplinary pre-service training, continuing education, clinical services, community collaboration, research and information dissemination. ²⁶ Denver could collaborate with JFK Partners to offer information and incentives to providers to work specifically in Denver with residents with IDD.

Case Management

Overall, case management was found to be a "small problem" across all respondent sub-groups. Generally, experiences were positive among those who received case management services. However, in talking with community members and reviewing those survey responses that indicated a negative experience, it is clear that there are problems with case management for a subset of needs assessment respondents. Cultural competency, respect and knowledge of case managers were reported to be some of the key issues Additionally, staff turnover was a challenge and inconsistent communications were the source of many of the negative experiences.

Recommendation 10: Evaluate the need for additional case managers to serve persons with IDD in Denver, the training needs for case managers, retention strategies, and the ability to use evidence-based practices to evaluate service outcomes. Based on the determined need, mill levy funding could be used to support the appropriate number of case managers for persons with IDD in Denver, and specifically consider the right case load ratio of case managers for persons with extremely complex cases. For those case managers with the training and capacity to take on complex clients, it is important to reduce their case load so they can be more responsive. This may also help to sustain the case manager workforce if case managers begin to feel that their case load is manageable and that they are having a positive impact for their clients. This may be a challenge to implement while the shift to conflict-free case management is in process and final details are unknown.

Create Additional Infrastructure for Consumer Directed Supports

One of the themes heard from stakeholders is the desire to have self-directed funding options for persons with IDD. Person-centered choice for needs like transportation, housing, equipment, and technology were all reoccurring discussions. The state of Colorado offers Consumer Directed Attendant Support Services (CDASS) for four Medicaid HCBS waivers that address physical disabilities, but is only now beginning to expand this option to one of the waivers that serve persons with IDD administered by CCBs.²⁷ The survey respondents were mostly satisfied with the individual process for accessing mill levy funds through RMHS, but a subset of people were consistently unhappy with the process to access individual funds. DHS should consider creating an infrastructure to offer consumer-directed funds for people who are currently unserved or underserved by existing programs. This system should be easy to use, easy to track, and have controls in place to limit the opportunity for fraud and abuse.

Recommendation 11: Implement a voucher or flexible spending account (FSA) program supported by mill levy dollars to supplement existing housing, transportation, technology, or other targeted needs for

 ²⁶ CU School of Medicine. "Welcome to JFK Partners". Retrieved from
 http://www.ucdenver.edu/academics/colleges/medicalschool/programs/JFKPartners/Pages/JFK%20Partners.aspx
 ²⁷ CO HCPF Policy Memo (HCPF PM 18-002). Consumer Directed Attendant Support Services (CDASS) Implementation in Supported Living Services (SLS) Waiver.

persons with IDD. Vouchers or an FSA program offer opportunities for persons with IDD to increase their autonomy over when and how they want to use the funds; however, still within the confines of their intent or defined need. A voucher system is tailored to a specific category or need and an FSA -type system permits a consumer to spend funds across a variety of different needs with one single card. To implement programs such as this, careful consideration must be given to oversight enforcement, eligibility determination, and equitable distribution of funding. DHS could engage external stakeholders or an advisory committee to work through these difficult questions.

Address Overarching Themes Around Stigma and Service

Understanding of the Mill Levy

The needs assessment found that the community's understanding of the mill levy was limited. For some, the assessment was an educational experience, with respondents indicating that they learned about a service or set of services for the first time by taking the survey.

Recommendation 12: DHS should reconsider how it currently brands the mill levy and services provided through it, including whether or not to call it the "mill levy." Communication materials are needed that clearly articulate the services provided by the mill levy, who is eligible for them, and the ways in which those eligible can access services.

Recommendation 13: Mill levy funds spent on communications and outreach are approximately 2 percent of the total mill levy contract with RMHS. In Douglas County, communications is one of four priority areas identified via regular community outreach and assessments. The lack of understanding among the IDD community in Denver regarding the mill levy suggests that more needs to be done to support communications about it. This recommendation to design and implement a multi-pronged communications plan builds on the prior recommendation of developing better branding and communication materials.

Recommendation 14: Develop policies and procedures for case managers to follow regarding explaining the mill levy funds and how they may be used to meet unmet needs of clients. The needs assessment found that there is an even split between those who receive case management services and reported that their case manager discussed with them availability of mill levy funds for unmet needs and those whose case manager did not make them aware of the mill levy funds and services. This interaction between case managers and members of the IDD community is essential to ensuring persons with IDD know about all the services available to them, as the case managers are often the gateway to these services.

Cultural Competence and Sensitivity

The needs assessment found that persons with IDD desire to be valued community members of the City and County of Denver but often did not feel as such.

Recommendation 15: Mill levy funds should be used to offer public information and awareness to Denver residents to reduce stigma and increase inclusivity within the community. Specifically,

suggestions from needs assessment participants included workshops with Denver first responders to better understand IDD and how to help persons with IDD who are experiencing a crisis or educational materials for transportation professionals to understand the unique needs of persons with IDD. Participants added that it is important to include those with IDD in the development and design of materials, as well as the delivery of trainings, to improve overall effectiveness.

Conclusion

The needs assessment was designed to inform decisions regarding the governance and distribution of mill levy funds dedicated to services for Denver residents with IDD. The findings begin to uncover important complexities. Each individual with IDD has a unique set of needs and circumstances that inform the resources available to him or her to meet those needs – including awareness of services, capacity to utilize services, and access to those services. There are also significant barriers that underlie service access and delivery that call for increased awareness and competency for providers and the public to better serve, understand, and respect those individuals with IDD. These are not simple barriers to overcome with easy solutions, as they often involve multiple systems of care. However, the information gleaned from this needs assessment begins to inform how DHS should approach its prioritization and decision-making to support and enhance services funded by the mill levy funds for people in Denver with IDD.

Appendix A: Key Informant Interview Guide

Introduction:

(Read to each key informant)

We have been selected to conduct a third-party assessment of services for Denver County residents with Intellectual and Developmental Disabilities (I/DD). The assessment seeks to:

- 1. Identify and engage relevant stakeholders
- 2. Identify the service gaps and potential ways to address these gaps
- 3. Research possible governance models for determining/overseeing the disbursement of dedicated revenue, gathering feedback, and presenting pros and cons of each model
- 4. Develop a written report summarizing findings from the inventory, gap analysis, and governance model options, including recommendations for how dedicated levy funding might be programmed going forward to address the most pressing gaps

As one component of engagement, we are conducting key informant interviews with individuals identified by the needs assessment steering committee. We are talking with Denver-based services providers, advocates, and self-advocates. The purpose of this interviews is to:

- 1. To collect input regarding the current and desired state of service delivery as well as the governance model for mill levy funding dollars.
- 2. To collect ideas for stakeholder engagement strategies, including:
 - o dissemination strategies for the city-wide survey
 - o ideas for public meeting time and locations
 - o ideas for focus group locations and demographics

Anything you say will not be attributed to you. High level themes from the interviews will be included in our final written report to Denver Human Services.

Questionnaire

Advocates / Self Advocates Questions

- 1. Can you describe the process that an individual with IDD goes through when attempting to access services in the City and County of Denver? We know this is a big questions, so please describe at a high level.
 - a. For this process, what do you think is important for DHS to know?
 - b. What barriers come up?
 - i. Are there any differences to the individual for accessing mill levy versus other services?
 - c. What gaps exist in the current system of care?
 - d. What successes do you see with the current system of care? What would you not want changed?

- 2. What do you most frequently hear from parents/individuals/advocates about what needs go unmet?
- 3. Are there any research, studies, assessments etc... that you recommend we consider for the needs assessment?

Service Providers Questions

- 4. Can you describe the process that an individual with IDD goes through when attempting to access services in the City and County of Denver? We know this is a big questions, so please describe at a high level.
 - a. For this process, what do you think is important for DHS to know?
 - b. What barriers come up?
 - i. Are there any differences to the individual for accessing mill levy versus other services?
 - c. What gaps exist in the current system of care?
 - d. What successes do you see with the current system of care? What would you not want changed?
- 5. What do you most frequently hear from Denver parents/individuals/advocates about what needs go unmet?
- 6. What do you most frequently hear from other types of service providers as barriers to service delivery?
 - a. Service coordination between and among providers?
 - b. Eligibility for services?
 - c. Staffing?
 - d. Other Resources?
- 7. If an individual with I/DD presents at your service location, do you feel confident meeting their needs?
 - e. Why or why not?
 - f. If no what type of support do you need to be able to provide services to this population?
 - g. If no who could potentially provide those missing services?
- 8. Are there barriers to becoming a service provider or receiving reimbursement for your services?
 - h. Do you serve persons with IDD in other counties?
 - i. Are there provisions that make it more or less difficult to be a provider in other locations?
- 9. Are there any helpful research, studies, assessments etc... that you recommend we consider for the needs assessment?

Shared Questions

An important aspect of the needs assessment is stakeholder engagement and "listening". In addition to talking with you, we will be conducting a survey, several focus groups, and a public meeting.

Survey: The goal of the survey is to ensure it represents a cross-section of the community – including providers, families, and individuals with I/DD and diverse in spectrum of diagnosis, age, need, and eligibility. We intend to disseminate the survey April 23rd.

- 10. Do you have any strategies for us to consider and deploy to ensure broad representation?
 - a. Providers, support groups, and other networks that may be willing to disseminate the survey and who primarily serve Denver residents?

Public Meeting & Focus Groups: We will conduct one public meeting in late May and a few focus groups to provide an opportunity to share preliminary findings of the needs assessment and collect additional input.

- 11. Do you know of a location that you feel has worked well for gatherings in Denver? Where should we go to meet people where they are at?
 - b. Do you know of any groups or meetings that currently take place that may be willing to include the needs assessment or have the needs assessment as their agenda item?
- 12. Do you feel there is a general preference for timing of the meeting (e.g. during the day, evenings, or weekend)?
- 13. Are there any other considerations we should keep in mind for the publicmeeting?

Appendix B: Survey Instrument

Denver Human Services Needs Assessment Survey for Individuals with Intellectual or Developmental Disabilities

This survey is intended to learn about your experience with services in the City and County of Denver for people with intellectual or developmental disabilities (I/DD). We wish to know about what services are available and if these services work for you and/or the person(s) you support.

Findings from the survey will be used to better understand opinions and perspectives from the community about:

- What is working regarding access to services for individuals with I/DD living in Denver
- The barriers to accessing services
- What is working and not working regarding accessing mill levy dollars

If you are assisting someone to complete the survey, please do your best to capture the perspective of the person you are assisting. Please contact Jaime Gilliland at jgilliland@healthmanagement.com if:

- You need assistance understanding or explaining specific questions or answer options
- You need assistance accessing this survey
- You would like to complete this survey by telephone

Participation in the survey is voluntary. All responses are completely anonymous. Individual responses will not be released and we will not able to identify the names of individual respondents. There are no right or wrong answers; it's your opinion that matters! **Completing this survey will not affect your ability to receive services in any city or county, or at any organization.**

Questions

1. Please select <u>one</u> category that you feel best describes you. You will have an opportunity to								
select others that you may iden	tify with in the next question. (Select only one)							
☐Self-Advocate (person with I/DD)	☐Family member of a person with I/DD							
☐Guardian of a person with I/DD	☐Case Manager for persons with I/DD							
☐Host home family	□Advocate / Legal Aid							
☐Health Care Provider	☐Behavioral Health Care Provider							
\square Service provider for people with I/DD	☐Legislator or legislative staff							
□School personnel	□Child welfare							
☐State or local agency	□Taxpayer / Citizen / Other Interested Party							
□Other, please describe								

2. Please se	elect any other categor	y that you feel describes you. Please select that all that apply.
□Self-Advocate	(person with I/DD)	☐Family member of a person with I/DD
\square Guardian of a	person with I/DD	☐Case Manager for persons with I/DD
☐Host home far	nily	□Advocate / Legal Aid
☐Health Care Pr	ovider	☐Behavioral Health Care Provider
☐Service provid	er for people with I/DD	□ □ Legislator or legislative staff
□School person	nel	☐Child welfare
□State or local a	- ,	☐ Taxpayer / Citizen / Other Interested Party
□Other, please	describe	
3. Please d	escribe your current re	sidency status or living arrangements.
\square I am a person	with I/DD living in a ho	st home
□I am providing	a host home	
\square I am a person	with I/DD living with m	y caregiver (family or friend)
□I am living wit	n my care recipient wh	o is a person with I/DD
\square I am a person	with I/DD who is curre	ntly incarcerated or recently incarcerated
□I am a person	with I/DD experiencing	homelessness or recently experienced homelessness
□I am a residen	t of Denver.	
□Other, please	describe.	
4 Jam resi	oonding to the survey o	on hehalf of
4. Tallifes	Johanng to the salvey t	on behall of.
□Myself		
•	with I/DD I serve	
□An organizatio	n that serves individua	ls with I/DD
5. What is	your gender?	
<i>□</i> Male	□Female	
□Transgender n	nale 🗆 Transgender	female
□Another gende	er (please self-identify)	
□Prefer not to r	espond	
6. What is	your age?	
□Under 18	□18-24	
	□35-44	
□45-54	□55-64	

□65-74	1 □75-84								
□85 or	older								
7.	Select the category that hest de	scribes th	ne population you represent (Select all that apply).						
, .	□People with physical disabiliti		re population you represent (select an inatapply).						
	□People with intellectual or de		ntal disabilities						
	□People with mental illness								
	□Older adults with disabilities								
	☐People who are Deaf or Hard	of Hearin	g						
	☐People who are blind								
	☐Children and Youth with disabilities								
	☐People with multiple disabilities								
	☐People with Autism								
	Other, please describe.								
8.	If applicable, what is the zip coo	de where v	you primarily receive services for yourself or on the						
	behalf of a person with I/DD? _								
9.	If applicable, what is the zip coo	de where t	the person receiving I/DD services lives?						
			, , , , , , , , , , , , , , , , , , ,						
10.	What is your race? (Select all th	at apply.)							
	•	ас арріу.,							
□Ame	rican Indian or Alaska Native	□Asian							
□Black	or African American		fic Islander						
□Whit			□Another race not listed						
□Don'	t know	□Prefer	fer not to answer						
11	Is your othnicity Spanish / Hispan	sic/Latino	2						
11.	Is your ethnicity Spanish/Hispar	IIC/ Latillo	•						
□No, n	ot Spanish/Hispanic Latino	[□Yes, Puerto Rican						
□Yes, I	Mexican, Mexican American, Chi	cano/a [□Yes, Cuban						
□Yes, o	other Spanish/Hispanic/Latino		☐Prefer not to answer						
12.	What language do you mainly s	peak at ho	ome?						
□Engli	sh □Spanish	[□Chinese						
□Russi	·	_	□Vietnamese						
□Polisl	-		□Prefer not to answer						

□Another language (ple	ase specify)
13. If you are a recip □Medicaid □Medicare □Tricare	ient of services, what is your insurance? (Select all that apply). □Private insurance □No insurance □Not applicable
Other (please specify)	
ntellectual and develop and families with I/DD w for individuals or organia appropriated to the Den Human Services (RMHS) county of Denver. In 201	pproved dedicated mill levy to be set aside for children and adults with mental disabilities. The funding is intended to provide assistance for individuals hen other resources are unavailable or inadequate. Funds may also be used to ations to expand or create new programs. The funding was originally wer Department of Human Services through a contract with Rocky Mountain RMHS is the designated community centered board (CCB) for the city and 7, the city council approved an ordinance expanding the allowable uses of acting with other providers for services for residents with intellectual and es.
□ Excellent. I ha □ Good. I have a additional educa □ Fair. I have a f (for example, un □ Poor. I lack the □ I have not lear	feel you understand Denver's mill levy? Ye a high level of current knowledge regarding the mill levy. In appropriate level of knowledge regarding the mill levy, but could benefit from tion. Bir level of knowledge regarding the mill levy, but need to update my knowledge sure of current changes). It level of knowledge needed to effectively discuss the mill levy. The level of knowledge needed to effectively discuss the mill levy. The level of knowledge needed to effectively discuss the mill levy. The level of knowledge needed to effectively discuss the mill levy. The level of knowledge needed to effectively discuss the mill levy. The level of knowledge needed to effectively discuss the mill levy.

How well do you feel you understand the <u>services</u> the mill levy is currently funding? Please check one box for each service.

	Excellent	Good	Fair	Poor	I have
	I have a high level of current knowledge regarding this service funded by the mill levy.	I have an appropriate level of knowledge regarding this service funded by the mill levy, but could benefit from additional education.	I have a fair level of knowledge regarding this service funded by the mill levy, but need to update my knowledge.	I do not have the level of knowledge needed to effectively discuss this service funded by the mill levy.	not learned about this service funded by the mill levy.
Individualized Client Assistance (using mill levy to fund specific requests for individuals—for example, therapies not covered by other sources, transportation, mattresses, clothing, adaptive technology, one-time rental assistance, etc.)					
Individualized Annual Plans (using mill levy funding to provide services above Medicaid service caps—for example, a fifth day of dayhab or behavioral health services beyond the limit)					
Enhanced Services from Denver CCB (using mill levy to fund enhancements to State and Federal programs administered by the CCB—for example, greater staffing to provide better customer service and reduced wait times for Early Intervention, Family Support, and Service Coordination)					
Community Agency Programs (using mill levy to fund various services through third party providers—for example, education, training, employment services, behavioral health services, support groups, travel, etc.)					

	Excellent	Good	Fair	Poor	I have
	I have a high level of current knowledge regarding this service funded by the mill levy.	I have an appropriate level of knowledge regarding this service funded by the mill levy, but could benefit from additional education.	I have a fair level of knowledge regarding this service funded by the mill levy, but need to update my knowledge.	I do not have the level of knowledge needed to effectively discuss this service funded by the mill levy.	not learned about this service funded by the mill levy.
Discontinuity to the transport of the tr					
Please describe what you need to learn more abo	HIT				

•	

15. On a scale of 1-10 where 10 is the highest level of support, how much do you support the services the mill levy is currently funding? Please check one box for each service.

	1 Lowest support	2	3	4	5 Neutral	6	7	8	9	10 Highest support
Individualized Client Assistance (using mill levy to fund specific requests for individuals—for example, therapies not covered by other sources, transportation, mattresses, clothing, adaptive technology, one-time rental assistance, etc.)										
Individualized Annual Plans (using mill levy funding to provide services above Medicaid service caps—for example, a fifth day of day-hab or behavioral health services beyond the limit)										
Enhanced Services from Denver CCB (using mill levy to fund enhancements to										

State and Federal programs administered by the CCB—for e greater staffing to provide bett customer service and reduced times for Early Intervention, Fa Support, and Service Coordinate	er wait mily												
Community Agency Programs mill levy to fund various service through third party providers— example, education, training, employment services, behavior services, support groups, trave	es -for ral health]	-									<u> </u>
16. Have you ever applied fo □Yes □No	or mill levy fu	unds?											
 17. Who did you apply for m ☐Individual ☐Person(s) with I/DD ☐Community Partner 18. If you have ever applied check one box on each lied 	for mill levy			' was '	your	experi	ence,	on a	scale	of 1-1	LO? Ple	ease	
	1 Extremely negative	2	3	4	5 Ne	eutral	6	7	8	9) xtremely ositive	n/a
Learning about the application process													
Completing the application for funds													
Contracting with the Denver CCB													
Response time from submitting application to													

Response time approval of fundameters receiving funds	ds to														
Response to questions or requests for assistance															
19. If you have scale of 1				•	funds	s, how	v did th	ne fundi	ng mee	a need	l or fil	l a gap	o, on a		
It did not meet my needs.	2	3	4	5 Neu	utral		6	7	8	9		xceed ectati	ed my ions.		n/a
						ı									
20. In this serindividua about ear	ls with ch serv	IDD and ice listed	d their fa	Availa but n	able,	Ne de tra ed kn	heck tl	be ed (e.g. n, ge of	Do r acce prov curr can		e no not ligible	Do kn	•	or on beha anyo	ces nyself If of
individua	ls with ch serv	IDD and ice listed well	d their fa	Availabut neenou	able, ot gh	Ne de tra ed kn co	eeds to velope nining, ucatio owled mmun	be ed (e.g. n, ge of ity)	Do r acce prov curr can	est desc not hav ss (e.g. riders, i ently el not affo	e no not ligible	Do kn	on't ow	these service for more on beha anyo	e ces nyself l lf of ne

	Works	Available,	Needs to be	Do not have	Don't	Don't use			
	well	but not	developed (e.g.	access (e.g. no	know	these			
		enough	training,	providers, not		services			
			education,	currently eligible,		for myself			
			knowledge of	cannot afford)		or on			
			community)			behalf of			
						anyone			
Home and community-									
based supports									
If you selected "do not ha	ive access",	please select	all that apply from t	he following options	to help us	understand			
what is impacting your ab	ility to acce	ss these servi	ces:						
☐Lack of trained provide	rs in my area	a 🗆	Affordability/financi	al limitations					
☐Program/financial assis	tance qualif	ications \square	Lack transportation	to service locations					
☐Scheduling challenges			Waitlists						
☐Providers are not sensit		•	·	oviders					
☐Other, please specify									
Adult day services									
Addit day services									
If you selected "do not ha		•		he following options	to help us	understand			
what is impacting your ab	ility to acce	ss these servi	ces:						
☐Lack of trained provide	rs in my area	a 🗆	Affordability/financi	al limitations					
☐Program/financial assis	tance qualif	ications \square	Lack transportation	to service locations					
☐Scheduling challenges			Waitlists						
□Providers are not sensitive to disability issues □Lack of Medicaid providers									
☐Other, please specify					<u></u>				
	Γ	Г	Τ	Γ	Γ	Г <u></u>			
Pre-vocational services									
If you selected "do not ha		•	• • •	he following options	to help us	understand			
what is impacting your ab	ility to acce	ss these servi	ces:						
☐Lack of trained provide	rs in my area	a 🗆	Affordability/financi	al limitations					
☐Program/financial assis	tance qualif	ications \square	Lack transportation	to service locations					
☐Scheduling challenges	-		□Waitlists						

	Works well	Available, but not enough	Needs to be developed (e.g. training, education,	Do not have access (e.g. no providers, not currently eligible,	Don't know	Don't use these services for myself			
			knowledge of community)	cannot afford)		or on behalf of anyone			
□ Providers are not sensitive to disability issues □ Lack of Medicaid providers □ Other, please specify									
Transportation provided by Medicaid									
If you selected "do not ha what is impacting your ab		•		he following options	to help us	understand			
□Lack of trained providers in my area □Affordability/financial limitations □Program/financial assistance qualifications □Lack transportation to service locations □Scheduling challenges □Waitlists □Providers are not sensitive to disability issues □Lack of Medicaid providers □Other, please specify. □									
RTD transportation, including Access-a-Ride									
If you selected "do not have access", please select all that apply from the following options to help us understand what is impacting your ability to access these services:									
□ Lack of trained provider □ Program/financial assist □ Scheduling challenges □ Providers are not sensit □ Other, please specify	tance qualif	ications □ □ ility issues □	•	to service locations					

	Works well	Available, but not enough	Needs to be developed (e.g. training, education, knowledge of community)	Do not have access (e.g. no providers, not currently eligible, cannot afford)	Don't know	Don't use these services for myself or on behalf of anyone		
Non-emergency medical transportation								
If you selected "do not have access", please select all that apply from the following options to help us understand what is impacting your ability to access these services:								
□ Lack of trained providers in my area □ Affordability/financial limitations □ Lack transportation to service locations □ Scheduling challenges □ Waitlists □ Providers are not sensitive to disability issues □ Lack of Medicaid providers □ Other, please specify. □ Other, please specify. □ Affordability/financial limitations □ Lack transportation to service locations □ Waitlists □ Waitlists □ Lack of Medicaid providers □ Cother, please specify. □ Other, please specify.								
Dental services								
If you selected "do not haw what is impacting your about the control of the cont	rs in my are tance qualif	a	ices: Affordability/financ Lack transportation Waitlists Lack of Medicaid pro	ial limitations to service locations oviders				
Medical services								
If you selected "do not haw what is impacting your about the selected of trained provide ☐ Program/financial assis ☐ Scheduling challenges ☐ Providers are not sensit ☐ Other, please specify	oility to acce rs in my are tance qualif tive to disab	a	ices: Affordability/financ Lack transportation Waitlists Lack of Medicaid pro	ial limitations to service locations oviders	to help us	understand		

	Works well	Available, but not enough	Needs to be developed (e.g. training, education, knowledge of community)	Do not have access (e.g. no providers, not currently eligible, cannot afford)	Don't know	Don't use these services for myself or on behalf of anyone	
Mental health services							
If you selected "do not ha what is impacting your ab		•		he following options	to help us	understand	
□Lack of trained provided □Program/financial assist □Scheduling challenges □Providers are not sensit □Other, please specify	tance qualif	ications 🗆	Affordability/financi Lack transportation Waitlists Lack of Medicaid pro	to service locations			
Crisis/emergency supports							
If you selected "do not haw what is impacting your ab		•		he following options	to help us	understand	
what is impacting your ability to access these services: □Lack of trained providers in my area □Program/financial assistance qualifications □Lack transportation to service locations □Scheduling challenges □Providers are not sensitive to disability issues □Lack of Medicaid providers □Other, please specify.							

	Works well	Available, but not enough	Needs to be developed (e.g. training, education, knowledge of community)	Do not have access (e.g. no providers, not currently eligible, cannot afford)	Don't know	Don't use these services for myself or on behalf of anyone
In-home respite	<u> </u>	T			1	
(temporary support)						
If you selected "do not haw what is impacting your also what is impacting provide program/financial assis Scheduling challenges Providers are not sensition of the young the young what is impacting your also what is impacting y	oility to acce rs in my are tance qualit tive to disak	a Efications	ices: Affordability/financ Lack transportation Waitlists	ial limitations to service locations	to help us	understand
Out-of-home respite (temporary support)						
If you selected "do not haw what is impacting your about the lack of trained provide ☐ Program/financial assis ☐ Scheduling challenges ☐ Providers are not sensit ☐ Other, please specify	oility to acce rs in my are tance qualit tive to disak	ess these serving a	ices: Affordability/financ Lack transportation Waitlists	ial limitations to service locations	to help us	understand

	Works well	Available, but not enough	Needs to be developed (e.g. training, education, knowledge of community)	Do not have access (e.g. no providers, not currently eligible, cannot afford)	Don't know	Don't use these services for myself or on behalf of anyone			
Educational services									
If you selected "do not have access", please select all that apply from the following options to help us understand what is impacting your ability to access these services: Lack of trained providers in my area									
Clinical services (occupational therapy, physical therapy, speech/language therapy)									
•		•		he following options	to help us	understand			
If you selected "do not have access", please select all that apply from the following options to help us understand what is impacting your ability to access these services: Lack of trained providers in my area									
Vision services									

	Works well	Available, but not enough	Needs to be developed (e.g. training, education, knowledge of community)	Do not have access (e.g. no providers, not currently eligible, cannot afford)	Don't know	these services for myself or on behalf of anyone			
If you selected "do not have access", please select all that apply from the following options to help us understand what is impacting your ability to access these services:									
□Lack of trained provide □Program/financial assis □Scheduling challenges □Providers are not sensit □Other, please specify	tance qualif	ications ility issues		to service locations oviders					
		T	T		T	Г			
Durable medical equipment									
what is impacting your about the control of the co	If you selected "do not have access", please select all that apply from the following options to help us understand what is impacting your ability to access these services: □Lack of trained providers in my area □Affordability/financial limitations □Program/financial assistance qualifications □Lack transportation to service locations								
If you selected "do not haw what is impacting your about the control of the cont	oility to acce rs in my are tance qualif tive to disab	a	ices: Affordability/financi Lack transportation Waitlists Lack of Medicaid pro	ial limitations to service locations oviders	to help us	understand			

	Works well	Available, but not enough	Needs to be developed (e.g. training, education, knowledge of community)	Do not have access (e.g. no providers, not currently eligible, cannot afford)	Don't know	Don't use these services for myself or on behalf of anyone	
Early intervention (services for students 0-3 years)							
If you selected "do not ha what is impacting your ab		•		he following options	to help us	understand	
□Lack of trained provided □Program/financial assist □Scheduling challenges □Providers are not sensit □Other, please specify	tance qualif	ications \square	Affordability/financi Lack transportation Waitlists Lack of Medicaid pro	to service locations			
Due cab a la marial					I		
Pre-school special education (services for students 3-5 years)							
If you selected "do not haw what is impacting your ab	-	•	• • •	he following options	to help us	understand	
what is impacting your ability to access these services: \[\textsquare{\textsquare} \textsquar							

	Works well	Available, but not enough	Needs to be developed (e.g. training, education, knowledge of community)	Do not have access (e.g. no providers, not currently eligible, cannot afford)	Don't know	Don't use these services for myself or on behalf of anyone		
					<u> </u>			
Infant services								
If you selected "do not haw what is impacting your about the control of the contr	oility to acce rs in my area tance qualif tive to disab	ss these servi	ces: Affordability/financi Lack transportation Waitlists	al limitations to service locations	to help us	understand		
Recreational activities								
If you selected "do not ha								
•		•		The following options	to help us	anacistana		
what is impacting your ability to access these services: □Lack of trained providers in my area □Affordability/financial limitations □Program/financial assistance qualifications □Lack transportation to service locations □Scheduling challenges □Waitlists □Providers are not sensitive to disability issues □Lack of Medicaid providers □Other, please specify. □								
Other therapies (music, recreation)								
If you selected "do not haw what is impacting your about the selected to be a selected to b		•		he following options	to help us	understand		

	Works well	Available, but not enough	Needs to be developed (e.g. training, education, knowledge of community)	Do not have access (e.g. no providers, not currently eligible, cannot afford)	Don't know	Don't use these services for myself or on behalf of anyone
□Lack of trained providers	in my are	a □/	Affordability/financ	ial limitations	.I	<u>.I</u>
□Program/financial assista	nce qualif		•	to service locations		
☐Scheduling challenges	ıa ta disah		Waitlists	ovidore		
□ Providers are not sensitive □ Other, please specify		-				
21. In your opinion, are	the follow	ing things pro	blems for people w	ith I/DD living in Denv	/er?	
	Big	problem	Small problem	Not a problem	Othe	er
Affordable housing						
Please describe.						
Adequate dental care						
Please describe.						
Adequate mental health services						
Please describe.						
Finding a doctor who is sensitive to disability issue	es 🗆					
Transportation to doctor's appointments						
Please describe.						

	Big problem	Small problem	Not a problem	Other
Communication supports, such as large print, Braille, CART readers, etc.				
Please describe.				
Managing chronic conditions, such as diabetes				
Please describe.				
Paying for prescription medications				
Please describe.				
Finding a doctor who accepts public health insurance				
Please describe.				
Accessible gyms and/or options for swimming				
Please describe.				
Transition to adulthood – continuing education				
Please describe.				
Transition to adulthood – transition planning				
Please describe.				
Life skills training				

	Big problem	Small problem	Not a problem	Other
Please describe.				
Family supports				
Please describe.				
Technology such as iPads				
Please describe.				
Waiting lists for services and supports				
Please describe.				
		ı	ı	T
Coordination of services				
Please describe.				
	T	ı	ı	T
Case management				
Please describe.				
	T	Γ	Γ	T
Consumer control of services				
Please describe.				
Comitace for pains in dividuals	T			
Services for aging individuals with I/DD				
Please describe.				
Obtaining employment				
Please describe.	_			_
i lease describe.				

	1	Big problem	Small problem	lem Not a problem		Other			
				•					
22. To what o		ers treat you, and t	he individual you	provi	de care to,	with respo	ect and		
Not at all		Somewhat		Very	much	I don't k	now.		
23. Do you feel like you receive services with cultural competence and in a language that ensures you or your care recipient's comprehension? Not at all Somewhat Very much I don't know.									
					- Inden				
<u> </u>	Ш		Ц			Ш			
		or how to improve							
□Yes □	o do you receive	case management							
□Develo	pmental Disabiliti	Services □De es Resource Cente	r (DDRC)	·			_		

28. On a scale from 1 to 10, how satisfied are you with the case management services you receive?

Health Management Associates

1	2	3	4	5	6	7	8	9	10	
Least satisfied				Neutral					Extren	nely satisfied
29. On a scale from 1 to 10, does the case management have a sufficient level of knowledge and expertise to appropriately manage your case or the case of your care recipient?										
1	2	3	4	5	6	7	8	9	10	
Least sufficient				Neutral					Extre suffic	•
30. On a scale services y	ou are			4 5		ve regard	ding the	case ma	nageme	10
					eutral					
	ust									Very trusted
	case m ∃No eel your	anager o	discussed	d Mill Levy fu	unding fo	or unmet	needs?			Very trusted □
□ 31. Has your □Yes □	case m ∃No eel your	anager o	discussed	d Mill Levy fu	unding fo	or unmet	needs?			Very trusted □
31. Has your Yes 32. Do you fe services?	case m]No eel your	anager o	discussed heard w	d Mill Levy fu	unding fo	or unmet your opi	needs? nions, co	oncerns,	or need	Very trusted □

33	Have you ever received negative feedback or felt retaliation after voicing your opinions, concerns, need for services? □Yes □No	
If so, w	hat happened?	ny other services in Denver that you would like us to know about.
34	Please describe any other services in Denver that you would like us to know about.	
		_
35	Please tell us about any additional services, including family-focused services, that Denver needs.	
	<u> </u>	
36	Additional Comments:	

Thank you!

Thank you for completing the survey. Your input is important to us. The data collected will be aggregated and along with other data collected, used by Health Management Associates to conduct a third-party assessment of services for Denver County residents with Intellectual and Developmental Disabilities.

Please stay tuned for information on an upcoming public meeting to discuss survey results and for opportunities to participate in a focus groups.

Any questions, please contact: Jaime Gilliland, jgilliland@healthmanagement.com

Appendix C: Survey Dissemination Partners

Colorado Developmental Disabilities Council	Rocky Mountain Human Services	Atlantis Community, Inc.	JFK Partners
Denver Regional Council on Governments	Denver Health	Easterseals Colorado	Advocacy Denver
The Arc of Colorado	Alliance Colorado	Parent to Parent	Family Voices
Colorado Cross Disability Coalition	CDHS Office of Early Childhood	Colorado Department of Education, Office of Special Education	CO Fund for People with Disabilities
Denver Public Schools	Samaritan House	Mission Supports	Mental Health Center of Denver
CDPHE Maternal Health	Rocky Mountain Down Syndrome Association	Denver Parks and Recreation	Ad Comma
Mayor's Commission	Lutheran Family Services	PAD-CO	Jewish Community Center
Catholic Charities	Denver Health and Hospitals	Autism Society	Sewall Child Development Center
	Anchor Center	Laradon	





Please take our survey about services for people living in Denver with intellectual or developmental disabilities

- Are you the caregiver of a person with intellectual or developmental disabilities (I/DD) living in Denver?
- Are you a person with I/DD receiving services in Denver?
- Are you a provider of services for persons with I/DD?
- Are you an advocate for persons with I/DD?
- Do you live and/or provide or receive services in Denver?

If you identify with any of these roles, you are invited to participate in the City and County of Denver's Assessment of Services for Denver residents with I/DD.

The goal of the survey is to understand the experience of delivering and/or receiving services for Denver residents with I/DD.

Findings from the survey will be used to better understand opinions and perspectives from the community about:

- What is working regarding access to services for individuals with I/DD living in Denver
- · The barriers to accessing services
- · What is working and not working regarding accessing mill levy dollars

To access the survey, visit: www.surveymonkey.com/r/DenverIDDSurvey

Survey will be open through May 14, 2018.

To learn more, visit http://bit.ly/IDDmilllevy.

Questions? Contact Jaime Gilliland, Health Management Associates, jgilliand@healthmanagement.com.

Appendix E: Survey Outreach Email

Subject: We Need Your Voice! Take our survey about services for people living in Denver with intellectual or developmental disabilities.

Dear residents and partners,

The voice of our community is critical in shaping our future work for people living and working in Denver with intellectual or developmental disabilities (I/DD). We are pleased to share a new survey that seeks to help understand the experience of those living and working in Denver with accessing services for persons with intellectual or developmental disabilities (I/DD).

Intended survey participants are:

- Individuals with I/DD;
- Caregivers or guardians of adults or children with I/DD;
- Disability advocates;
- Staff at community-based organizations or state and local government offices that serve people with I/DD;
- Academic researchers, physicians, public health professionals, health and wellness promotion specialists, health administrators and health policy experts; and
- Denver residents with an interest in the health of people with I/DD in Denver

Findings from the survey will be used to better understand:

- What is working regarding access to services for individuals with I/DD living in Denver
- The barriers to accessing services
- What is working and not working regarding accessing mill levy dollars

The goal of the survey is to gather data that reflects the diversity of those with an invested interest in ensuring that Denver residents with I/DD can access the services they require when they require them. [Feel free to add a sentence about why the participation of your specific constituency is important, e.g., representation of participation of minority and special interest groups in data collection efforts, etc.]

To take the survey, visit https://www.surveymonkey.com/r/DenverIDDSurvey

The survey will take about 10 to 15 minutes to complete.

Please be sure to take the survey before it closes on May 14, 2018

Thank you,

<<NAME>>

Appendix F: Survey Respondent Demographics

Table 1: Demographics Al	I Respondents.	N=315
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Gender			
Male	15.05%		
Female	81.05%		
Other	3.45%		
Age			
Under 18	1.89%		
18-24	3.15%		
25-34	17.35%		
35-44	27.44%		
45-54	20.50%		
55-64	22.71%		
65+	6.94%		
Race			
American Indian or Alaska Native	2.22%		
Black or African American	8.25%		
White	78.41%		
Asian	1.59%		
Pacific Islander	0.95%		
Another race not listed	5.08%		
Prefer not to answer	6.67%		
Don't know	0.63%		
Ethnicity			
Not Spanish/Hispanic Latino	81.17%		
Mexican, Mexican American,	5.84%		
Chicano/a			
Other Spanish/Hispanic/Latino	5.19%		
Prefer not to answer	7.79%		
Language			
English	94.15%		
Spanish	0.63		
Other	0.32		
Prefer not to answer	1.90%		

Respondents were asked to select one category that best describes who it is they represent. Among the 370 respondents who answered, 5 percent reported they themselves as having an I/DD, 39 percent reported being a family member/guardian/caregiver to an adult or child with I/DD, and 32 percent reported being a I/DD service provider or case manager. About 13 percent of respondents identified as a community leader or concerned citizen, while 5 percent of respondents identified as health or behavioral health care provider. When given the opportunity, many respondents identified as being in more than one category. Respondent types are shown in **Table 2.**

Table 2: Respondents by Category

	Pick One Category that Best Describes You		Select All Categories that Apply	
Respondent Type	%	#	%	#
Person with I/DD	5.4%	20	8.1%	25
Family/Caregiver of an adult or child with I/DD	38.9%	144	56.0%	173
I/DD Service Provider	32.2%	119	35.9%	111
Other Health Care Provider	4.9%	18	11.7%	36
Community Leader or Concerned Citizen	13.2%	49	48.2%	149
Other	5.4%	20	7.8%	24
Total	100.0%	370		

Respondents were asked to describe their residency status and/or living arrangements, as shown in **Table 3**. Nearly half (40%) responded that they were a resident of Denver.²⁹ Approximately 6 percent of respondents were in a host home situation, while privately 22 percent were living with their caregiver or care recipient who is a person with I/DD. Five respondents (1.6%) responded that they were a person with I/DD experience homelessness or recently experiences homelessness.

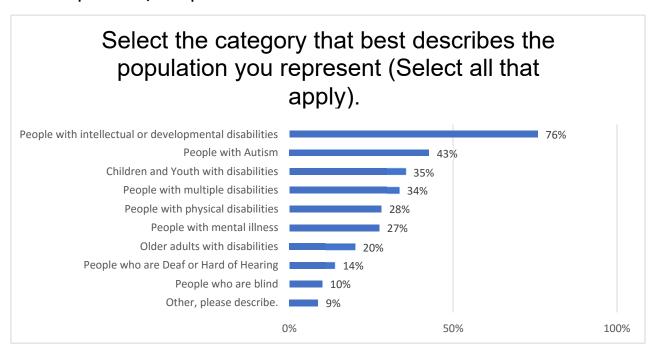
Table 3: Residency Status or Living Arrangements by Respondent

Answer Choices	%	#
I am a person with I/DD living in a host home	0.96%	3
I am providing a host home	5.13%	16
I am a person with I/DD living with my caregiver (family or friend)	2.88%	9
I am living with my care recipient who is a person with I/DD	19.23%	60
I am a person with I/DD who is currently incarcerated or recently incarcerated	0.32%	1
I am a person with I/DD experiencing homelessness or recently experienced homelessness	1.60%	5
I am a resident of Denver	40.38%	126
If none of the above, please describe "other".	29.49%	92

²⁹ Respondents were not able to "select all that apply". Therefore, this estimates likely underrepresents respondents who were also residents of Denver who identified with one of the other answer choices. This same logic may apply to the other answer choices as well.

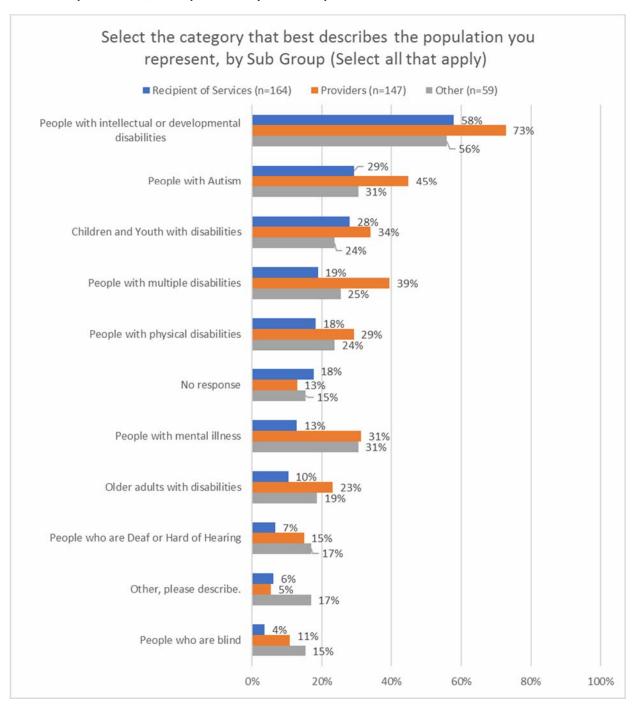
Respondents were asked to describe their affiliation with the I/DD community and who it is they represent (e.g. they consider themselves as part of this particular group or work with people of that group), as shown in **Chart 1**. More than three quarters of respondents (76%) selected that they represent people with I/DD. Forty-three percent of respondents represent people with autism, following by children and youth with disabilities (35%), people with multiple disabilities (34%), and people with physical disabilities (28%) and mental illness (27%). Older adults with disabilities were represented by 20 percent of respondents. The least common voice was among those representing people who are deaf or hard of hearing (14%) and people who are blind (10%).

Chart 1: Represented I/DD Population



An analysis of the reported affiliation with the I/DD community and who it is they represent was also conducted by sub-group, as shown in **Chart 2**

Chart 2: Represented I/DD Population, by Sub-Group







Open to the public, providers, people with intellectual or developmental disabilities (I/DD), and other stakeholders

Monday, June 11 4 - 7 p.m.

HOSTED AT:

Laradon 5100 Lincoln Street Denver, CO 80216

Survey results from the City and County of Denver's Assessment of Services for Denver residents with I/DD will be presented at 4 p.m. and 5:30 p.m.

Attendees will have the opportunity to react and provide additional feedback after each presentation.

Please join so Denver Human Services can better understand opinions and perspectives from the community about:

- What is working regarding access to services for individuals with I/DD living in Denver
- · The barriers to accessing services
- What is working and not working regarding accessing mill levy dollars

Can't attend in person?

Some other options for participation:

- Call in via phone: 1-877-668-4493 access code 732 060 503#
- Join online via Webex: http://bit.ly/2sB8lzx
- Join on Facebook Live: https://www.facebook.com/ DenverHumanServices/

A sign language interpreter or open captioning via CART provided upon request by contacting SignLanguageServices@denvergov.org.

Questions? Contact Robyn Odendahl, Health Management Associates, rodendahl@healthmanagement.com.





Abierto al público, proveedores, personas con discapacidades intelectuales o del desarrollo (I/DD) y otras partes interesadas

Lunes, 11 de junio 4 - 7 p.m.

LUGAR:

Laradon 5100 Lincoln Street Denver, CO 80216

Los resultados de la encuesta de la Ciudad y el Condado de Denver sobre los servicios para los residentes de Denver con I/DD se presentarán a las 4 p.m. y 5:30 p.m.

Los participantes tendrán la oportunidad de reaccionar y ofrecer opiniones adicionales después de cada presentación.

Por favor, únase a nosotros para que los Servicios Humanos de Denver puedan entender mejor las opiniones y perspectivas de la comunidad sobre:

- Qué está funcionando en cuanto al acceso a los servicios para individuos con I/DD que viven en Denver
- Las barreras para acceder a los servicios
- Lo que está funcionando y lo que no está funcionando sobre el acceso a los fondos de la recaudación impositiva

¿No puede asistir en persona?

Otras maneras de participar:

- Llamar por teléfono: 1-877-668-4493 Código de acceso 732 060 503#
- En línea por Webex: http://bit.ly/2sB8lzx
- Participar en Facebook Live: https://www.facebook.com/

 DenverHumanServices/

Si necesita un interprete de lengua de seña, contactar <u>SignLanguageServices@derwergov.org</u>.
¿Tiene preguntas? Comuníquese con Robyn Odendahl, Health Management Associates, <u>rodendahl@healthmanagement.com</u>.

Appendix I: Public Meeting Agenda



Public Meeting on Needs Assessment of Services for Residents with I/DD

June 11, 2018

First Session: 4:00 p.m. - 5:15 p.m.

Second Session: 5:30 p.m. - 6:45 p.m.

Agenda for first session is repeated in the second session.

10 minutes: Presentation by Health Management Associates

15 minutes: Individual idea-sharing on five issues facing individuals with intellectual and developmental disabilities living in Denver.

- 1) Affordable housing
- 2) Waiting lists for services and supports
- 3) Adequate mental health services
- 4) Obtaining Employment
- 5) Transition to adulthood planning, life skills and education

25 minutes: Small group discussion to identify specific solutions (funded by mill levy revenue) to barriers and challenges identified in previous session.

25 minutes: Sharing out key points from each small group discussion

Closing remarks

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Table Topic Discussion Guide for Facilitator

Instructions to Facilitator

- Remind participants that the discussion is an opportunity to discuss their perspectives and ideas to be included in the final assessment report to DHS.
- Discussion is intended to last 25 minutes. Use a phone or identify a person at the table who can provide a 5 minute warning before the time is over.
- Identify a person at your table who is willing to record the discussion. Ideally, the note taker
 would be using a laptop to record notes, if at all possible. HMA and DHS staff will have laptop's
 available.
- Identify a person at your table who is willing to report high level themes from the discussion to the larger group during the "report out".

Discussion Questions

1) What challenges were the most common? (approximately 10 minutes)

- a. Review together as a group the topic paper with participant sticky notes that describe challenges and issues with the topic at hand. This may be done either by reading the notes on the page, organizing the notes on the page by challenge (e.g. for affordable housing – organize all the notes together that suggest "funding or paying" as the challenge).
- b. Once the notes have been reviewed, organized and discussed ask the group to reflect on "what challenges are the most common"?
 - i. Follow up questions might be:
 - Is there anything surprising to you?
 - What challenges do you feel might be missing?

2) What recommendations do you have for Denver's Mayor regarding what to do with the \$9M of unspent tax dollars dedicated to I/DD Services? (approximately 10 minutes)

a. For each major challenge identified in the previous question, ask the group to brainstorm recommendations for the Mayor.

3) How should the dollars be governed? (5 minutes)

- a. First, ask this question generally to collect responses. If you need to prompt ideas, consider the following:
 - i. Prompt: Advisory Committee?
 - If yes, ask why? Who should be the committee? How should the public be included?
 - ii. Prompt: Public Hearing?
 - If yes, ask why? How frequently should there be a hearing? How should the hearing be structure?
 - iii. Prompt: Community Survey?
 - If yes, ask why? How frequently should the survey be? What should the survey ask about?

Appendix J: Ratings for 23 Services included in the assessment

