Boulder County Community Needs Assessment:

Systems, Services, and Supports for People with Intellectual and Developmental Disabilities

Submitted to Boulder County Department of Housing and Human Services
January, 2019

OMNI

KEYSTONE POLICY CENTER

BOULDER COUNTY HOUSING & HUMAN SERVICES

Boulder County Community Needs Assessment:

Systems, Services, and Supports for People with Intellectual and Developmental Disabilities

For more information or questions, please contact:

Emily Murillo, MSW
Senior Researcher/OMNI Institute
emurillo@omni.org
www.omni.org
p. 303.839.9422 Ext. 155

Lorez Meinhold
Senior Policy Director/Keystone Policy Center
lmeinhold@keystone.org
p. 970.512.5805

Contents

Acknowledgements 3

Project Background 4

Community Voices In Boulder County 8
- Information And Access To Services 8
  - Survey Findings 9
  - Related Themes In Stakeholder Dialogue 13
- Priority Needs Identified By Stakeholders 14
  - Survey Findings 15
  - Related Themes In Stakeholder Dialogue 18
- Priority Needs Identified By Stakeholders: Top Areas With Recommendations 20
  - Housing 20
  - Systems Navigation, Case Management And Advocacy 23
  - Mental Health 25
- Self-Advocacy, Community Engagement, And Social Connectedness 26
- Ongoing Monitoring And Evaluation 28

National Context: Service Delivery Approaches And Evaluation 31
- Movement Toward Community-Based, Person-Centered Services 31

Boulder County Service Delivery 35
- Eligibility And Service Determination 35
- Service Delivery Structures In Boulder County 37
- Medicaid Utilization Data 38

Medicaid Funding Trends And Potential Shifts 42
- Potential Medicaid Shifts And Recommendations 51

Prioritized Recommendations And Opportunities 59

Appendix A: Detailed Evaluation Methods 72

Appendix B: Community Survey And Data Tables 75

Appendix C: Participant Characteristics From Community Event Surveys 99

Acknowledgements

We express our sincere appreciation to all community members who provided critical input for this needs assessment. The time, willingness to participate, lived experience, and thoughtful insights of these individuals were a critical component of the assessment process.

25 Boulder County community members participated in individual or small group conversations and identified as one or more of the following:

- self-advocates
- citizen experts
- community members with IDD and/or autism spectrum disorders
- individuals receiving IDD services in Boulder County

51 Boulder County community members participated in individual or small group conversations or community forums, and identified as one or more of the following:

- family members of individuals with IDD
- systems professionals
- community members active in IDD-related issues and support systems

313 survey participants who identified as:

- Individuals with IDD
- Family members of individuals with IDD
- Service providers
- Concerned community members

We also thank the following organizations that provided expertise in the form of local, state or national context, stakeholder engagement, and/or innovative or best practices for services and supports in the IDD community. A total of 38 systems professionals participated in these conversations.

- The Arc Arapahoe & Douglas
- The Arc of New Jersey's Training and Consultation Services
- The Arc of Northeastern Chesapeake
- The Association for Community Living in Boulder and Broomfield Counties
- Association of People Supporting Employment First
- Boulder County Public Health GENESIS Program
- Boulder Parks and Recreation
- Boulder Valley School District Parent Liaison
- Center for People with Disabilities
- City and County of Denver
- Colorado Cross Disability Coalition
- Colorado Department of Health Care Policy and Financing (5 different people within agency)
- Colorado Developmental Disabilities Council
- Easter Seals Lakewood
- HOPE Foundation
- Imagine! Colorado
- InCommunity
- Life's WORC
- Mental Health Partners
- National Association of Medicaid Directors
- National Association of State Directors of Developmental Disabilities Services (NASDDDS)
- New England Business Associates
- Options in Community Living
- Play Foundation/EXPAND
- The Resource Exchange
- Rocky Mountain Human Services
- St. Vrain Valley School District

Project Background

Boulder County Department of Housing and Human Services (BCDHHS), with the support of the Boulder County Commissioners, hired OMNI Institute (OMNI) and Keystone Policy Center (Keystone) to conduct a county-wide assessment to explore the needs of individuals with intellectual and developmental disabilities (IDD). Boulder County voters approved the developmental disabilities property tax in 2002 to fund programs for individuals with developmental disabilities and their families. The funding from this Mill Levy tax "pays to help people of all ages with cognitive and developmental disabilities live fuller, more satisfying and independent lives" (BHHS, 2018), with funded services primarily provided through Imagine! Colorado. BCDHHS is committed to ensuring that county Mill Levy funds are utilized efficiently and effectively, with up-to-date information about the needs of the IDD community. The needs assessment sought a wide range of feedback from individuals with IDD, families, direct service providers, and community partners to understand the positive impacts of Mill Levy funds as well as gaps in the services continuum that could be addressed through future investments. For the purpose of this report, intellectual and developmental disabilities are defined as:

- A developmental disability that is manifested before the person reaches 22 years of age or brain injury acquired as an adult.
- A disability attributed to a diagnosed intellectual 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 a diagnosed intellectual disability.

From June-October of 2018, OMNI and Keystone employed a range of information gathering methods to fulfill the goals of the assessment. Key project components are outlined in Table 1 on the following page.

Table 1. Boulder County Needs Assessment Components

Stakeholder Engagement Efforts

- Community surveys for individuals with IDD, family members, providers and Boulder County community members
- Community forum discussions for individuals with IDD and their families
- Small group and individual interviews with individuals with IDD and their families
- Interviews with Boulder County service providers and state and national-level systems professionals

Review of Literature and other State and Federal Information

- Service delivery models and best practices
- Evaluation best practices and indicators to monitor quality of services
- General costs and benefits of targeted investments
- Medicaid utilization data for the IDD population in Boulder County
- Medicaid scenario funding trends and potential Medicaid shifts

Process and Systems Mapping

- Review and documentation of available information regarding services and systems in Boulder county including:
    - Eligibility and service determination processes: the process by which services are allocated to eligible clients as well as ineligible clients who may need services
    - Systems and service delivery structures including key providers and partners, recipients of mill levy funds, and organizations providing services to the IDD community

Methods and Participants

Table 2 below provides a snapshot of the primary needs assessment methods. Additional detail including outreach approaches and limitations of data can be found in Appendix A. See Appendices B and C for complete demographics and survey data.

Table 2. Summary/Snapshot of 2018 Needs Assessment Methods

Data Source	Description	Timing and Location(s)	Participants	Analysis
Online Community Survey	Survey were developed by OMNI in collaboration with BCDHHS and multiple community stakeholders to explore access to IDD information and services as well as top community needs and priorities for services and supports.	August-October	313 participants ▪ 19% respondents with IDD ▪ 41% family members ▪ 26% community members ▪ 26% providers	Descriptive statistics and frequency distributions by respondent group
Community Forums	OMNI offered 3 community forums for Boulder County community members with IDD and their families, including one in Spanish which was cancelled due to low participation.	July: East Boulder Recreation Center October: Longmont	61 participants	Qualitative thematic analysis
Focus groups and individual or small group interviews	OMNI conducted outreach through various individuals and community organizations for focus groups and interviews with people with IDD and their families as well as field professionals from community organizations, provider agencies, state and national level systems. Interviews were conducted largely by phone with several in person meetings as well.	July: Interviews with Arc of Louisville Employees at job location Oct: Focus group at Center for People with Disabilities Oct: Drop in interview day in Longmont July-Oct: Phone Interviews and in-person meetings	▪ 24 participants with IDD ▪ 5 family members ▪ 38 systems professionals	Qualitative thematic analysis

Table 2 Continued. Summary/Snapshot of 2018 Needs Assessment Methods

Data Source	Description	Timing and Location(s)	Participants	Analysis
Literature and publicly available service information from local, state and national sources	OMNI and Keystone reviewed literature and publicly available information related to best and emerging practices and trends, available program cost information, evaluation tools and relevant policy and rules.	July-Oct	n/a	Qualitative thematic analysis Synthesis of summary data
Medicaid Data Analysis	Keystone completed a formal data request to Department of Health Care Policy and Financing (HCPF) to explore Boulder County Medicaid data and trends in utilization.	Sept-Oct	Secondary data from HCPF	Frequency distributions

Community Voices in Boulder County

A critical component of the needs assessment process was to gather the perceptions and recommendations of community members from a range of perspectives, including those who receive services and their family members; service providers and other systems professionals who interface with the IDD community in their work; and additional community members who may have a general interest in understanding and weighing in on funding needs. This section of the report highlights key community survey findings as well as qualitative data gathered through community forums and stakeholder interviews. See 'Methods and Participants' and Appendix A for more information about stakeholder information gathering methods.

First, a few overarching themes related to stakeholder engagement are important to understanding the scope of the feedback provided:

- **Stakeholders expressed great enthusiasm and eagerness to provide input** and to have their voices heard.
- **The need for ongoing community input was expressed** across sources and stakeholder groups as a fundamental component that should drive decisions related to IDD funding and service provision.
- **Dialogue was highly focused on potential opportunities** that would have the greatest benefit for the IDD community. Although a few participants shared personal anecdotes or experiences to illustrate key points, most conversations revolved around ways to make systems-level change.
- **Having tangible programs and impacts was important to stakeholders**, as there was concern that funds often appear to be subsumed by existing systems. Complex systems and administrative processes can have the effect of appearing to "swallow up" funds, whereas targeted and explicit programs are more understood and visible to the community.

Additionally, stakeholders shared positive experiences and perceived strengths of the system, despite the focus of dialogue on community needs.

- **The power of positive support and engagement with peers** was strongly emphasized by stakeholders.
- **Community support, mentorship, information-sharing, and co-advocacy** experiences were highlighted by individuals with IDD and family members.
- **Self-advocacy trainings** have equipped many individuals with IDD to use their voices and protect themselves when safety concerns arise and have fostered greater independence and engagement in the community.
- **Positive experiences with service providers in Boulder County** were also emphasized. Many individuals with IDD and family members noted specific individuals working within organizations who had shown care, respect, investment and expertise. Some mentioned

experiences with advocacy organizations that were able to provide needed systems navigation support and resolve access issues. A few reported that they experienced the single-entry point process the way it was intended and that they were able to connect to needed services in an efficient manner.

INFORMATION AND ACCESS TO SERVICES

Issues related to the overall functioning of IDD service systems as well as how people with IDD access needed services were ongoing themes across the survey and stakeholder dialogues. Stakeholder dialogues emphasized that a lack of clear information about available services, along with arduous processes for determining eligibility for different services, often prevented timely access. Survey findings are outlined below, followed by relevant qualitative themes from stakeholder dialogues.

Survey Findings

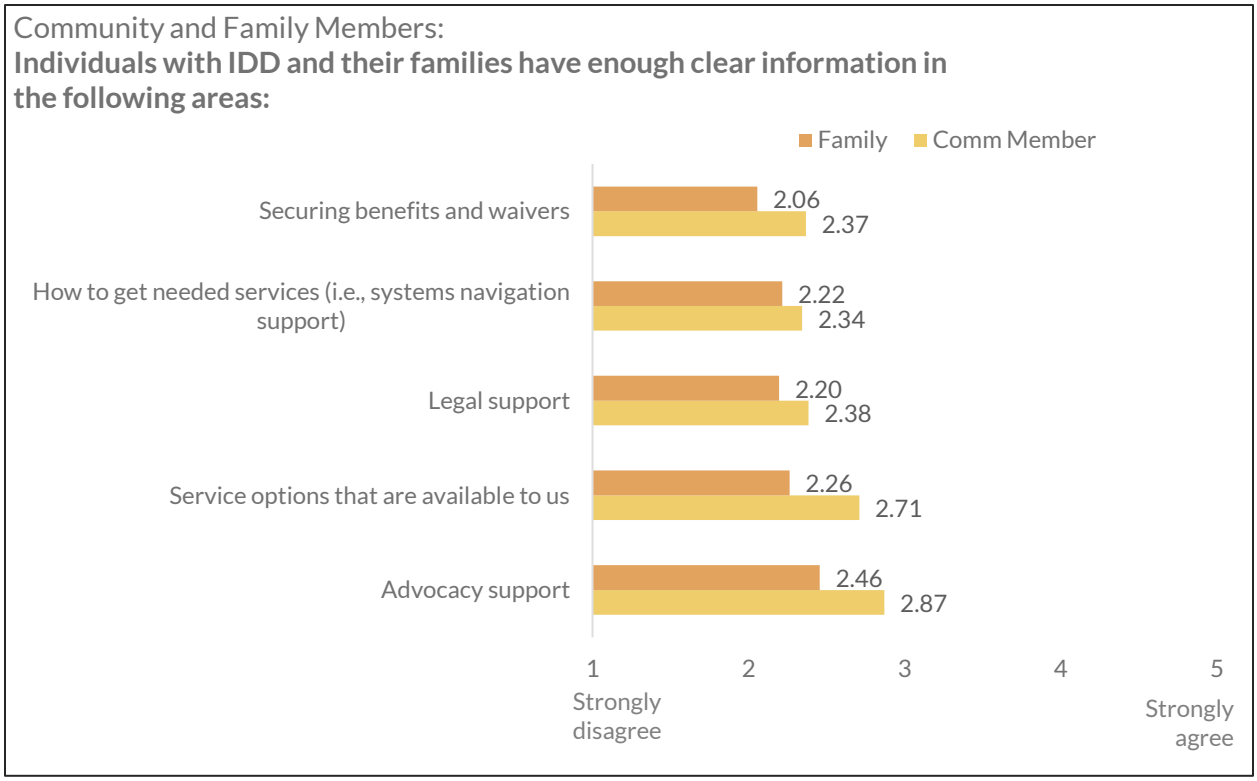
Surveys for all groups included several questions related to overall **availability of information about services and supports.**

- Over half of individuals with IDD reported that their service providers do not (32%) or only 'kind of' (35%) have the information they are seeking
- Additionally, 32% of family members strongly disagreed or disagreed that their providers had the information they need.

Family and community members were then asked to rate the availability and clarity of information for individuals with IDD and their families across a number of specific service areas. **Securing benefits and waivers, legal support,** and **how to get needed services/systems navigation support** received relatively lower ratings from both respondent groups, with all ratings falling below the midpoint of 3. Lack of information for these service areas can have a direct impact on an individual's ability to secure such services.

Figure 1 below displays the mean ratings of information availability for each of the service areas.

Figure 1. Ratings of Information Availability By Service Area



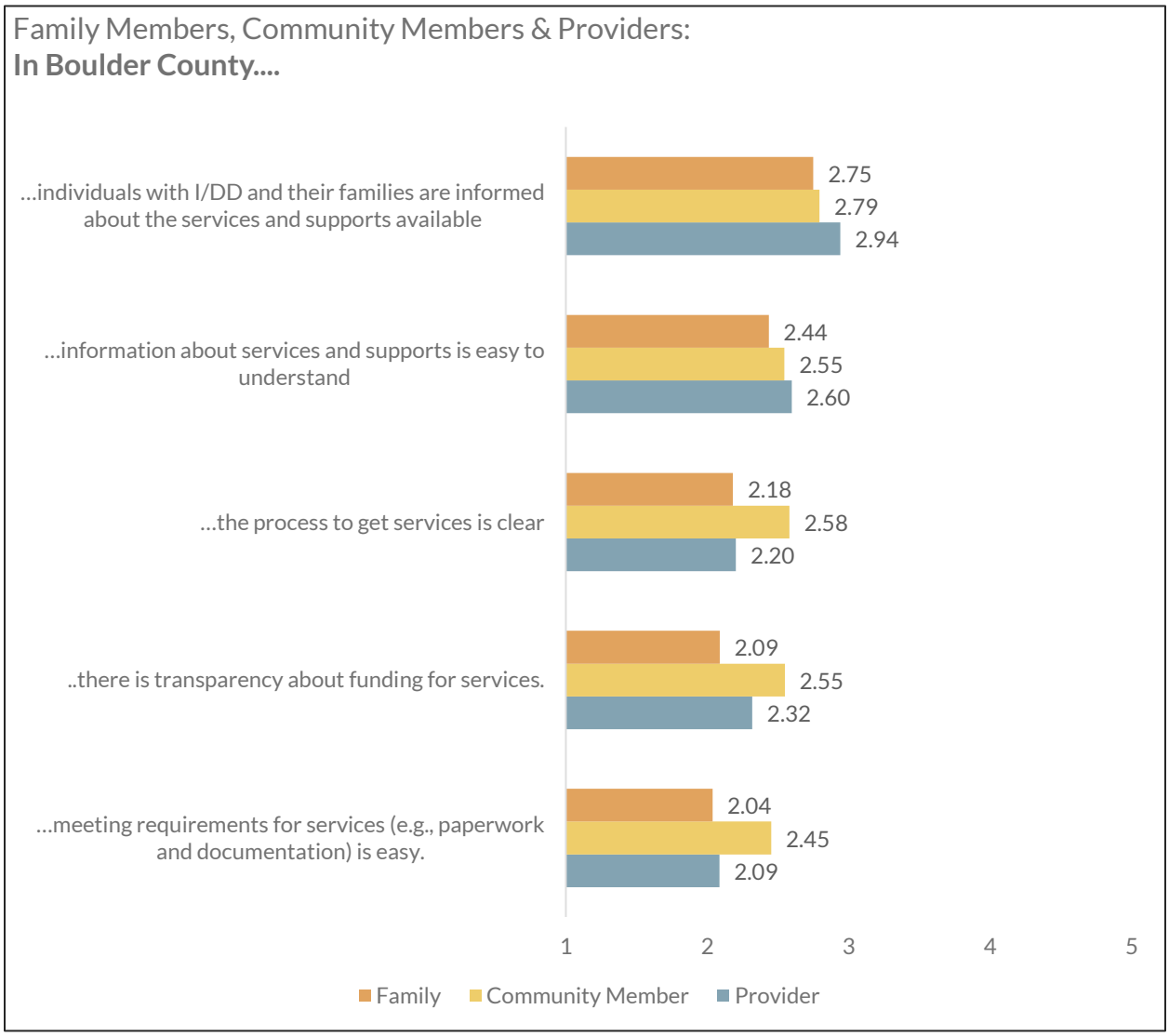
Overall Access to Services

A number of survey items assessed perceived accessibility of services including whether individuals with IDD generally have access to the range of services they need, ease of access, timeliness, and clarity of requirements and processes.

- 33% of individuals with IDD reported it was **not easy to get the services they need** and another 29% reported it was only "kind of" easy to get the services they need.
- **Meeting requirements for services (e.g., paperwork and documentation) was the lowest rated item** across family members, community members and providers.
- Survey respondents' ratings also indicated that **the process for getting needed services is unclear**.

Figure 2 below displays the mean ratings of accessibility for each of the service areas.

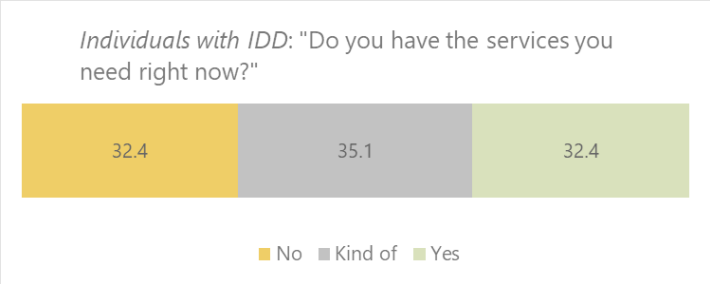
Figure 2. Ratings of Ease and Accessibility By Service Area

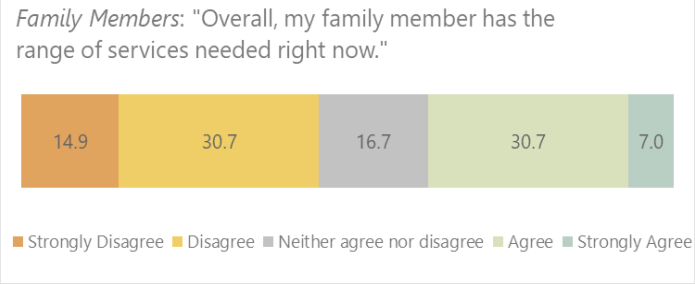


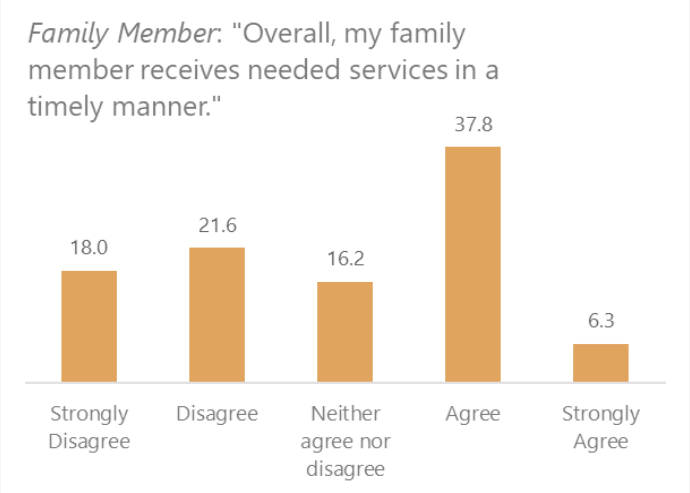
OMNI

All surveys also included questions about whether service needs overall and in key areas were being met. As shown in the figures below, sizable proportions of individuals with IDD and family members indicated they **do not have needed services**, with a range of family member perceptions regarding timeliness of services. Figures include percentages of participants for each response option.

Figures 3-5: Ratings of Service Access and Timeliness (%)







Related Themes in Stakeholder Dialogue

Themes about access to information and services were also highly present in all stakeholder dialogue and woven throughout conversations regarding nearly all service needs.

First, stakeholders expressed a **widespread gap in understanding of available options, from information about funding eligibility, to core services such as housing and transportation.** Many noted the need for more information about waiver options and included services, as well as more counseling about which waiver would best serve the individual. Discussion emphasized gaps in knowledge for families and individuals with IDD as well as for provider staff who may not have sufficient training. Many believed that improvements to the case management system and/or enhancements in systems navigation and advocacy services are critical to addressing this gap. Others suggested developing structured processes for streamlining and sharing information with the community such as websites that compile existing resources and update these as needed. See 'Systems Navigation, Case Management and Advocacy' for further detail on this need and corresponding recommendations.

> *"The systems are letting us get to crisis point until we get help."*
>
> -Community Member with IDD

> *"There is a lack of knowledge of the options. Then as part of strategies, getting the info out to the community about the resources and options. I think even before that, the providers, the professionals need to get the information also. I think there's a gap in knowledge there.*
>
> -Family Member

Stakeholders also frequently expressed confusion about the process for **accessing needed eligibility evaluations**. Some believed that case managers assist with this process and that the CCB can pay for evaluations if no other funding is available. Others were told that case managers are not able to provide assistance with the evaluation process and that there were no funds for evaluations. Stakeholders also shared varying experiences of being encouraged or discouraged from getting a functional evaluation in addition to an IQ test. Some noted that if families do not have evaluation funds, they often give up on the process and continue without needed services.

Several systems professionals and family members also mentioned **challenges with connecting individuals to the proper providers once eligibility has been determined.** Typically, case management staff will draft a Request for Proposals (RFPs) which includes essential information about the individual's specific case and service needs. Potential providers then respond with a proposal to provide the needed services and the individual decides among available options. Stakeholders noted that individuals often face issues with getting responses to the RFP and endure lengthy waiting periods. Many do not know that they can override this process and connect directly with potential service providers as well. Some stakeholders believe that case

management staff do not have the skills to write strengths-based RFPs that highlight individual needs and abilities and make providers want to serve them.

Many systems professionals as well as individuals with IDD noted **a need for more intentional outreach to locate and connect unidentified individuals with IDD to longer-term services**. Stakeholders in all groups noted that community members with IDD may not be accessing IDD-specific services at all, and instead end up rotating in and out of various crisis systems. Some of these individuals may have faced barriers to access and given up, while others simply aren't aware of services for which they may be eligible. One service provider reflected on an example of a community member who had a case worker within another system for many years before receiving an assessment and being diagnosed with an intellectual disability: *"We have to teach systems to stop asking 'what is wrong with this person or family' and instead ask what else might be going on and how we can connect them to the services they really need."* Many stakeholders reflected on this general knowledge gap in the community, noting that systems are not often trained to recognize and connect people with IDD to services they may need.

> *"An ounce of prevention is worth a pound of cure…if you get to an emergency situation, you get some help. But before that, you cannot get anything. You have selected for yourself to let the boulder fall down the hill and then move it back. Instead of stopping the boulder from falling in the first place"*
>
> -Community Member with IDD

PRIORITY NEEDS IDENTIFIED BY STAKEHOLDERS

The community survey allowed participants to rate service needs as well as to generate their own needs in open-ended survey responses. Community forums, individual and small group conversations also offered dialogue around core needs in various formats. Across the range of stakeholder engagement and information gathering efforts, clear overarching themes surfaced related to core needs and priorities. These themes largely aligned across methods and stakeholder groups, with a few distinctions/nuances for each group. Survey findings are outlined below, followed by relevant qualitative themes from stakeholder dialogue.

Survey Findings

All survey respondents were asked about core service needs in various formats. A combination of items related to specific key services and open-ended items provided several opportunities for respondents to share feedback about service needs.

First, family members, community members and providers were asked about needs in a broad range of service areas. Family respondents were asked to report if their family member currently receives the service, needs but is waiting for the service, wants the service but is unsure how to access it, or doesn't currently need the service. Community members and providers were asked to rate the extent to which they believe service needs in each area are being adequately met in Boulder County. This section of the survey contained 36 items organized into the following 6 service areas (see Appendix B for survey results in all areas):

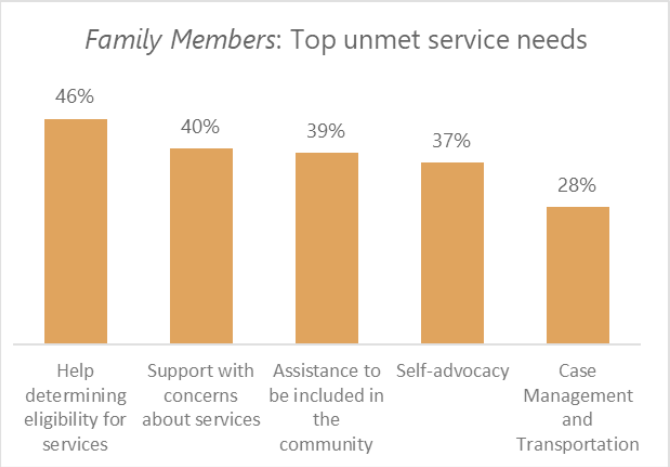
- **Core service areas** including mental health, housing, transportation, dental and medical care, employment and education (9 items)
- **Age-specific services** such as transition and aging services (4 items)
- **Systems navigation** services (5 items)
- **Advocacy** services (4 items)
- **Justice-legal system services** such as civil rights and legal services (4 items)
- **"Other" specialized services** such as respite care, home and vehicle modifications, therapies and recreation (10 items)

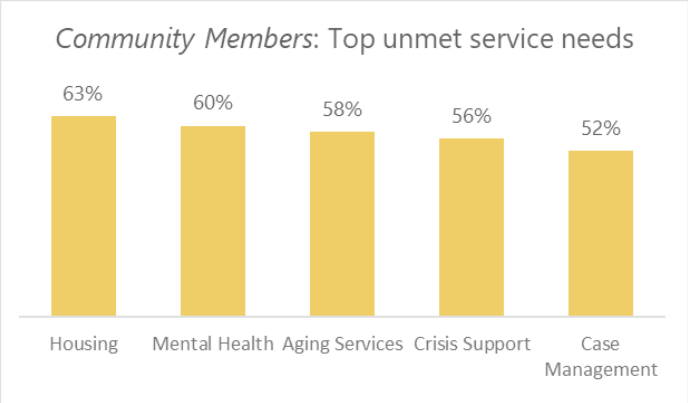
Although each respondent group was asked about the same 36 service areas, the top needs differed by group. It is important to note again that community members and providers were asked more broadly about service needs of Boulder County whereas family members were asked specifically about whether their family members' needs were currently being met in each area.

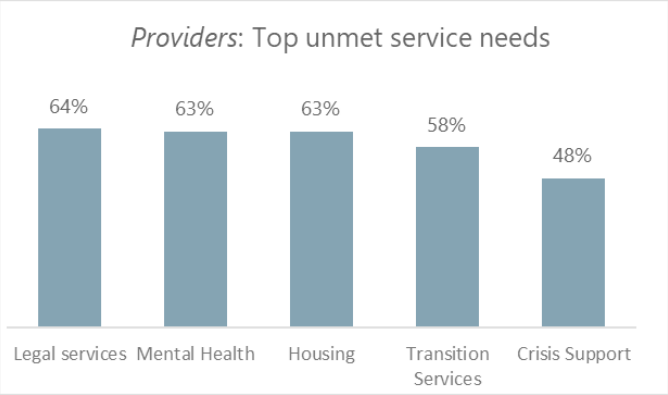
- There was overlap among community member and provider perceptions, with **mental health, housing,** and **crisis support** among the highest perceived areas of need.
- Family members, on the other hand, reported the highest needs in areas largely related to service access with **eligibility determination, support with concerns about services,** and **assistance to be included in the community** all among the highest perceived areas of need. Self-advocacy, case management, and transportation were also top reported needs.

These top areas of unmet need identified by each group are reflected in the figures below. These were defined for families as the percentage who were currently waiting for the service or needing it but unsure how to access it; and for community members and providers as the percentage who 'disagreed' or 'strongly disagreed' that the service need is currently being met.

Figures 6-8. Top Areas of Unmet Need by Group







All surveys also included open-ended items for respondents to share their views about top service priorities for Boulder County. Survey questions for respondents with IDD included:

- *If you do not have all the services you need, what do you need the most to live your life the way you want?*
- *How do you think money could be spent to best help people with IDD get the support they need? Think about what you would choose to do with the money that is available for all services.*
- *Is there anything else you want to share that we haven't asked you about?*

For family members, community members and providers, the following question was included:

- *In your opinion, what are the top 3 priority service areas for Boulder IDD community as this time? Think about the top 3 areas that would most benefit the Boulder IDD community if those areas received additional funding at this time. You may use areas from the list below (included for reference) or additional areas that are not on the list.*

Figure 9 below displays the top needs and priorities surfaced through open-ended survey questions for all participant groups.

Figure 9. Service Needs Identified Through Open-Ended Survey Questions

<table>
<tr><th colspan="3">TOP THEMES ACROSS ALL STAKEHOLDER GROUPS</th></tr>
<tr><td>HOUSING</td><td>MENTAL HEALTH</td><td>ACCESS
to information, systems navigation, case management, and advocacy services.</td></tr>
<tr><th colspan="3">ADDITIONAL TOP THEMES BY GROUP</th></tr>
<tr><td colspan="2">INDIVIDUALS WITH IDD
Self-advocacy, social connectedness and community engagement, including transportation as a key variable that interfaces with these issues
Community education and disability awareness</td><td>FAMILY MEMBERS
Planning for transitions and long-term services, including housing and respite care</td></tr>
<tr><td colspan="2">PROVIDERS
Systems change, navigation, and community engagement</td><td>COMMUNITY MEMBERS
Improvements to funding-related issues including transparency in funding, expenditures, and better monitoring of program outcomes</td></tr>
</table>

Related Themes in Stakeholder Dialogue

Qualitative findings validated survey data, with the themes that surfaced across stakeholder dialogue aligning with top needs reported by survey respondents. Top themes from stakeholder dialogue were identified through analysis of dialogue transcriptions, interview notes, and documentation of voting and prioritizing exercises completed at community forums.

- The top theme across all groups was **housing** as a basic need that supersedes all others
- **Systems navigation, case management needs and advocacy** services were also discussed across groups as related to ability to secure funding and access vital services.
- Individuals with IDD often spoke at length about **inclusion**, as well as needs for **community education.**
- Community members and organizations more commonly raised issues related to **funding and accountability**.
- Providers often focused on **systems issues** from problems with waiver administration to needs for **community education and involvement** to sustain services.

Additional themes also surfaced throughout information gathering efforts (see Table 3 below). Many stakeholders believed these needs to be of equal importance as those listed above. Still, these themes emerged with less regularity across sources and/or were less frequently mentioned as the most critical needs or areas in which mill levy funds could have the most impact at this time.

Table 3. Additional Themes in Stakeholder Dialogue

Supported employment for individuals with IDD	Stakeholders perceived that Colorado is moving backward in this area from 20 years ago when it was among the top states in the nation for employment for people with IDD. Stakeholders emphasized that people need to be integrated into a typical work setting with a support rather than working in isolation with a group or even 1:1 in a distinct space. People with IDD frequently commented that they need more opportunities (just like anyone else) to connect with community and to network. Some noted groups such as Sample Supports that are working toward this goal but lack sufficient funding. A few systems professionals commented on the urgency of this need, as funding from the state is insufficient to comply with federal legislation about supported, integrated employment for individuals with IDD.
Transportation issues	Barriers to transportation increase isolation and create a negative ripple effect on access to services and independence. Stakeholders noted that transportation options can be unreliable and underfunded. Many emphasized the need to build upon existing infrastructure. A few suggested exploring collaborations with Uber and Lyft to provide affordable accessible transportation as has been implemented in other cities.
Transition planning	Key transition points for people with IDD include the transition from youth to adult services and then to services for individuals over 60. Some stakeholders noted that transition periods increase vulnerability significantly and people often lose services, at least temporarily. Stakeholders raised possible strategies such as increased planning for transitions for caregivers, educating parents on elevating levels of independence and alternatives for guardianship.
Age-specific supports for seniors with IDD	The intersection of disability with age creates additional risks for seniors with IDD, such as misdiagnoses and abuse in care settings.
Access to technology	There is need to explore technologies that can be used to supplement care, and to ensure access to these. A few systems professionals commented that internet should be covered along with basic utilities such as gas or water. One suggested conducting pilot projects to assess the effectiveness of technology in service provision and using the findings to inform policy and funding decisions for basic technology access.

PRIORITY NEEDS IDENTIFIED BY STAKEHOLDERS: TOP AREAS DETAILED WITH RECOMMENDATIONS

To adequately address the key service needs identified by stakeholders, remaining assessment findings are organized into the themes seen in Figure 10 below. The report highlights survey, qualitative and literature-based findings related to each theme. Additional survey findings and information about qualitative efforts are included in Appendices A and B. Recommendations and potential opportunities are embedded within each section as well and are later compiled in the 'Recommendations' section of this report.

Figure 10. Priority Needs Identified by Stakeholders

Housing

As indicated previously, the need for safe, affordable and accessible housing was the top issue identified across all stakeholder groups and information gathering efforts. The specific housing market context in Boulder County increases the relevancy and urgency of this need. Current literature indicates that there may not be a universal model for housing for people with IDD but rather a recommendation to provide a range of options that allow for individualized, person-centered services and supports[1]. Some of the key variables requiring careful consideration include who individuals choose to live with, the type of housing they prefer, the level of support needed,

[1] Ray Graham Association, Clearbrook, and Aspire. (2013). Housing and Support Options for People with Individual and Development Disabilities. Retrieved from http://colemanfoundation.typepad.com/files/housing_support_options_people_w_idd_2013.pdf.

and how that support is funded. Increasing affordable housing options for people with IDD is costly and challenging but arguably the most vital need before other service needs can be addressed. Stakeholders emphasized the following key issues related to housing:

"A host home is a provider and caregiver who is also living alongside the person with IDD they are caring for. Families are hard. Dynamics are hard. We have to consider this idea of 'uncoupling' residents from their service providers in this way."

-Service Provider

Access to clear information regarding housing options and processes was raised consistently. Stakeholders surfaced housing as a core systems navigation need (discussed further in 'Systems Navigation, Case Management and Advocacy').

The need for options and choices rather than a universal housing model was emphasized by individuals with IDD as well as family members. Stakeholders stressed the importance of addressing individual preferences related to type of housing and who an individual wants to live with, as well as level of independence and corresponding supports needed. Many noted that investing in adequate support for people living independently would ensure more sustainable long-term housing and overall health, thereby reducing costs in the long run. Parents and caregivers, in particular, underscored the need for options and long-term planning for when they are no longer available to care for their family members with IDD. As one family member shared: *"The bottom line is that there just are not enough [housing] choices for our population and the existing model is basically host homes…these solutions are not enough…The choice of host homes is something that we don't view as a viable long-term solution...It does not give us comfort."* Some Boulder County families have reacted to a lack of housing options by trying to implement group home models while others view this as backtracking in gains related to community integration. A few stakeholders noted that families should be able to apply for funding to create their own individualized housing solutions.

"Why options? Because some people live independently, some people want to live in a host home and some people just want to live next to their best friend, right?"

-Family Member

Safety issues also surfaced consistently, with reported concerns in both community-based housing and host homes. This included structural or maintenance-related problems with housing, issues related to drug use and crime, and heightened risk for abuse in underregulated host home settings.

Quality of care in host home settings was discussed as well. A few stakeholders reported positive experiences in host homes while others described problems such as inadequate choice and autonomy for residents or serious safety concerns. Many noted that the current system for

ensuring safety of host homes was inadequate and cited a few widely publicized cases of abuse or neglect.

Affordability and accessibility were frequently mentioned as tandem issues. Stakeholders noted that disability and accessibility are often absent from the Boulder County dialogue about affordable housing and many feel that housing rules and regulations were created without consideration of the IDD population. For example, city regulations regarding the number of unrelated individuals who can live together may prevent people with IDD from accessing certain alternative housing solutions. Stakeholders recommended that systems examine regulations from an IDD lens and make needed exceptions to increase available housing options. As one family member noted: *"My daughter and her best friend couldn't live together because the services that they get would not be paid for under the current regulations."*

Recommendations: Housing

- Monitor and participate in policy initiatives and collaborations to increase local affordable and accessible housing options in general, and for individuals with IDD specifically.
- Consider funding to enhance safety mechanisms for current host home model in Boulder County. Guidelines and requirements for host homes exist but ongoing regulation and inspections are currently inadequate.
- Consider funding innovative pilot approaches to housing or family support grants that can go toward the establishment of shared family housing.

Systems Navigation, Case Management and Advocacy

Across data sources and stakeholder groups, systems navigation, case management and advocacy consistently emerged as central themes, second only to housing. Although these are often described as distinct services, many stakeholders reflected on the relationships between them and referenced them interchangeably. Many noted that addressing service shortages or gaps within one of these areas could potentially resolve an overarching service gap across all areas.

Supplementing case management services with systems navigation and advocacy services was repeatedly mentioned by stakeholders across groups. Many stressed a need to reexamine the idea of a single-entry point or "one stop shop" as few know families who have had that experience as it was intended. Many stressed that the current system and workforce simply does not have the capacity to help families navigate through complex eligibility determination processes and access needed services.

One family member described, *"We need just general systems navigation…If you don't have the right buzzword, you get sent down the wrong alley…Oftentimes, people are turned away from funding resources when really, they should have been just essentially led to a different door."*

> *"It's not just connecting someone to services as a case manager does; it is making all of the logistical pieces come together. If you have a really complex health condition, somebody's job is to say: 'Did you know that you qualify for X? Did you know that you can do X?' And then they help piece it all together…that is a navigator."*
>
> -Family Member

Many stakeholders also noted that Colorado's shift to conflict-free case management will inevitably impact the current structure of Boulder County IDD services overall (see 'Potential Medicaid Shifts and Recommendations' for more information). Although many of the key variables and resultant impacts of this shift are yet to be determined, Boulder County can be proactive in addressing existing gaps leading up to and throughout the implementation process. Some stakeholders also suggested the possibility of capitalizing on family member knowledge and experience by recruiting and training and compensating family members to provide navigation and advocacy services. As one family member participant explained, *"We talked about funding for community navigation services, because again, all of us spoke as parents. We're already providing these navigation services to others just because we happen to know the system, but if someone doesn't stumble along one of us, they may not be provided with services."*

Provider workforce issues such as staff turnover and low wages also surfaced in survey findings as well as stakeholder dialogue. A lack of benefits and affordable housing for direct service providers was also emphasized. Some stakeholders suggested creative approaches to enhancing benefits for staff such as partnering with community organizations and businesses to offer specific

wellness benefits. One community member commented, *"As a community, it would be so great to be like, 'We've got 20% off for all direct support workers at a massage place.'"*

Provider training gaps were also noted by many stakeholders. Although survey respondents largely reported positive overall experiences with case managers, many stakeholders also perceived that a lack of overall knowledge exists. Some noted inconsistency in their experiences over time, indicating that they had received differing information, accommodations and services depending on the case manager. Additionally, several stakeholders noted that specific best practices such as person-centeredness requires significant funding to ensure it is consistently and effectively practiced.

A clear, fair and comfortable process for switching providers and/or resolving provider complaints was also raised by stakeholders. Some shared that the current process for complaints is to file with the agency from which the services are received. Several noted that people have had to face providers directly to share reasons for wanting to change to another provider. As one systems professional stated, *"People/clients should simply be able to choose Safeway over King Soopers and switch providers without having to explain why."*

Recommendations: Systems Navigation, Case Management and Advocacy

- Consider building Boulder County case management capacity proactively through expanding options for case management (see 'Potential Medicaid Shifts and Recommendations' for more detail)
- Direct funding for specific systems navigation and/or advocacy efforts (temporarily, at a minimum). Although these services are often utilized to address systems-level problems, stakeholders agreed that they will remain a vital service for people with IDD and their families, regardless of how efficient or inefficient any "no wrong door" or "single entry point" models are functioning. Systems navigation and advocacy not only increase individual capacity for self-advocacy and foster health systems literacy, they also cross systems and address complexities related to multi-system involvement that most people with IDD need. Further, investments in building systems literacy within the IDD community do not end with the turnover of a case manager but are sustained throughout the course of an individual's lifetime involvement in services. These funds could be critical for managing gaps during upcoming systems changes and shifts to conflict-free case management, ongoing policy changes and processes, and natural age-related transition periods that continue to be a challenge for people with IDD and their families.
- Consider funding programs to recruit and train paid family advocates who have acquired critical lived experience and systems navigation expertise. Tapping into the wealth of knowledge in existing, natural supports is not only a smart financial investment, but also fosters family representation and leadership within the community. Many family leaders already work within their communities, compiling and

sharing information, and serving as a vital resource to other families. Formalized approaches to employing and compensating family advocates have also been successful as some community organizations have recruited and trained family advocates to assist with both systems navigation and advocacy needs.

- Explore opportunities to expand upon existing resources and tools to create a comprehensive, centralized online repository for IDD-related information. Compile existing resources as many have already been developed by providers, advocacy groups and family members. Stakeholders repeatedly emphasized needing a centralized method to search for agency/program information as well as information about eligibility, service access and advocacy resources. While providers may feel this already exists, families and other community stakeholders do not feel it is sufficient.

Mental Health

A need for improvements to mental health services for people with IDD was clearly acknowledged across individuals with IDD, family members and providers.

Access to qualified providers was the most common theme that surfaced related to mental health. One stakeholder with IDD shared about the number of steps it took to receive a mental health diagnosis, proper medication and ongoing mental health treatment. Another participant with IDD articulated the dangers that many in her community face when they are not easily identified as a person with IDD: "*You have marginalized people with mental health issues going to their Medicaid general practitioner for a mental health and/or IDD diagnosis…If you are not trained to recognize IDD as a therapist, you cannot recommend things for people who don't have the same neuro functioning [as a person without IDD].*" Stakeholders also shared how many individuals with IDD don't necessarily present immediately with intellectual disabilities but rather in behavior that is not as easily recognized.

Recommendations: Mental Health (see 'Potential Medicaid Shifts and Recommendations' for additional recommendations)

- Work to expand training and development of the mental health workforce to increase the availability of providers qualified to serve individuals with IDD
- Consider expanding Boulder HHS High Fidelity Wraparound services to people with IDD to help navigate mental health services

Self-Advocacy, Community Engagement and Social Connectedness

Research promotes inclusion and community engagement to address social isolation, which is associated with poor health outcomes.[2] Investment in community engagement and social connectedness efforts for individuals with IDD also aligns with best practices regarding inclusiveness, stakeholder involvement and recognition of lived experience as critical to decision-making about services and supports. Social connectedness is a clear national trend and federal guidance sugge sts that all waivers should contain services/elements to address this key issue (see Potential Medicaid Shifts and Recommendation for more detail). Survey data as well as stakeholder dialogue clearly indicated a need for increased community engagement, inclusion and social connectedness for people with IDD, both among peers and within the community at large. This included:

"There should be nothing about us without us. People need to be at the table. Promoting, supporting and empowering citizen experts and self-advocates. We can't understand why this fight is still being fought. Boulder is wealthy. There are lots of regions doing a lot more with a lot less because they are prioritizing it. This has to become a priority."

- Self-Advocate

Self-advocacy training and events to build skills related to leadership, communication and advocating for one's needs. Many stakeholders commented that this type of training provided them with tools and skills to seek needed services, engage with larger community and advocacy efforts and even protect themselves from mistreatment in the workplace, or by providers and community members.

Opportunities for community engagement and representation and having the voices of people with IDD and their families heard and prioritized in decision-making processes.

Access to social and recreational activities which include options for peer-only activities as well as activities and events for the general public that are open and accessible for people with IDD and their families. One family member shared a desire for all families to have access to arts, theater and cultural events just as typical families do: *"We all deserve more than taking*

"The strongest predictor of lifespan is not diet or exercise. It is actually social integration. Having at least 3 friends you can confide in and speak with on a regular basis."

-Community Member with Autism

[2] Cornwell, E. Y., & Waite, L. J. (2009). Social disconnectedness, perceived isolation, and health among older adults. *Journal of health and social behavior*, *50*(1), 31-48.

our family member to a rehearsal or a kid's event. We need the real deal. Just let everyone know at the event welcome speech – set the expectation that this is okay for people to be there. We just need help training staff and hands on training for volunteers, ushers, etc. They just need peace of mind that they are covered and we need to be educating community about how to do this well."

Recommendations: Self Advocacy, Community Engagement and Social Connectedness

- Create a formal process for seeking and promoting consultation from leaders and self-advocates with IDD and for promoting their meaningful engagement in service design and program implementation ongoing.
- Increase funding for self-advocacy training to promote self-advocacy at the individual level, cultivate leadership skills for people with IDD and foster their involvement in community groups, civic engagement opportunities and decision-making processes. Consider local advocacy groups as well as statewide groups such as the Colorado Cross-Disability Coalition that have developed self-advocacy training models that could be replicated or expanded.
- Increase funding for social and recreational programming such as those specifically for people with IDD, including funding for transportation and/or with careful consideration of existing transportation accessibility. Funding could go to current highly attended EXPAND recreation programs that provide opportunities for individuals with IDD to participate in sports or other activities with their peers in a comfortable space or those that provide "inclusion support" for staff to support individual participation in a standard activity open to the whole community. Stakeholders with IDD clearly expressed that it is critical to provide options of inclusion support as well options for activities with peers with IDD only, as preferences for participation are highly individual.
- Funding could also be increased to promote opportunities for people with IDD and their families to engage with community in forums/environments that are often harder to access such as arts and cultural activities, etc. For example, one Boulder County family member created a program that trains and partners with local arts venues to make specific event dates open and accessible to both the general public and people with IDD and their families.

COMMUNITY EDUCATION AND IDD AWARENESS

Many stakeholders surfaced the need for increased community education and awareness about IDD. This was a particularly strong theme for individuals with IDD who expressed a desire to be seen, understood, included and valued as part of their community. Advocacy groups and small community organizations also emphasized community education and awareness as a vital

component to a long-term, sustainable and holistic approach to supporting people with IDD as part of their communities. It is viewed as a strong and essential component to fostering inclusion, building protective factors (e.g., supports against abuse and social isolation) and building community-based supports for people with IDD that can supplement services.

Community trainings for key groups such as first responders, legal services, victim service centers, senior and recreational centers who don't understand the needs of the IDD population was commonly discussed. Key training elements would include how to recognize people with IDD, communication strategies and guidance for how to connect people to needed services if needed. A few individuals with IDD talked about going into schools to educate people from a young age about IDD, to shift attitudes and increase community inclusion.

"Community is anywhere that anybody has gone; the tiny corners of community. We need to expel the myth that people with disabilities are served only by IDD organizations. We need to start letting people see people for people. People are excited about that and want to welcome people. But they don't even know that they can welcome people or how to do so sometimes."
-Service Provider/Advocate

Collaborations to address confidentiality issues between systems and enhance information sharing efforts were also raised by a few community members to enhance the ability to refer individuals with IDD to needed services. As one community member shared, "*I have a wealth of information about individuals in our community with intellectual and developmental disabilities, who are probably without services, who are in need of services, and I can't tell anyone about them. That's probably the single-most frustrating thing that I have, is the confidentiality rules that are there."*

Recommendations: Community Education and IDD Awareness

- Invest in targeted training and specific referral processes for key systems and community organizations including emergency response and crisis systems, local homeless shelters, mental health providers, law enforcement, etc.
- Consider a more general disability awareness training that can be tailored for local businesses and other community spaces.

ONGOING MONITORING AND EVALUATION

Community stakeholders, literature sources, local and state-level systems, and national groups all identify a critical need for ongoing monitoring and evaluation of needs, programs and services, as well as the larger policy context that influences local systems and service structures. Key issues raised included the following:

Collecting ongoing data about incidence and type of disabilities among community members and corresponding service needs over time to inform service planning, funding and improvements.

Increasing accountability measures including transparency about funding and program expenditures so that the system and its providers are protected and the public is well-informed about the use of mill levy dollars. Several stakeholders noted the importance of collecting data such as numbers served, wait list information, participant satisfaction and intended program outcomes for participants. These data can be used to inform program improvements and to prepare for Federal increases in accountability measures.

Monitoring changes in policy and analysis of their implications for local service delivery structures. Stakeholders emphasized that the policy landscape will remain complex and variable, requiring ongoing monitoring and analysis to ensure local responsiveness and preparations for change.

Recommendations: Ongoing Monitoring and Evaluation

- Invest in ongoing data collection about disability and service needs at the community level. While county and state systems currently collect data on individuals receiving services, these data are not inclusive of community members outside of those systems. Ensure that local census efforts and community surveys include information about disability that allows for self-identification and ensures individual anonymity.
- Further define Mill Levy funding guidelines (see 'Potential Medicaid Shifts and Recommendations' for more detail).
- Increase transparency measures for funding expenditures and reporting (see 'Potential Medicaid Shifts and Recommendations' for more detail).
- Increase evaluation reporting requirements for all funded programs in the areas of client satisfaction and perceptions regarding the responsiveness of services; program outcomes such as participant improvements in health, mental health, social/behavioral areas of life, adaptive functioning, etc. When possible, utilize, existing participant data available through the larger state and federal reporting systems that providers currently utilize.
- Develop a community advisory council for fiscal decision-making and monitoring of efforts funded that includes individuals with disabilities and their families as a central part of decision-making processes. This group should provide input and oversight in the following areas:
  - Ongoing review and assessment of community needs and disability-related data, as well as policy-related information that has implications at the county-level.
  - Project funding decisions and rationale for funding, key groups and expected numbers served, as well as projected plans for spending over time.
  - Communications to the public about funding decisions and outcomes of projects.

- Ensure ongoing monitoring of state and national policy initiatives and changes, with analysis of implications at the county-level, collaborating with core policy advisory or implementation groups as appropriate. (see 'Potential Medicaid Shifts and Recommendations' for more detail).

National Context: Service Delivery Approaches and Evaluation

To effectively contextualize and evaluate local needs, it is important to understand the national landscape and context related to service provision for the IDD community. Thus, the needs assessment also included a review of literature and publicly available information as well as informational interviews with local and national service providers. Part of this work aimed to explore broad national trends in IDD service provision, as well as data collection and evaluation efforts to monitor the quality of services and costs of programming.

MOVEMENT TOWARD COMMUNITY-BASED, PERSON-CENTERED SERVICES

Since the deinstitutionalization movement of the 1970s, there has been a gradual, but consistent trend toward more integrated, community-based services and supports for individuals with IDD, although the extent to which individual states and communities provide true community-based services varies. The movement is guided, in part, by a range of federal policies[3] which include the following:

- In the 1980s, Medicaid began administering waivers under Home and Community Based Services HCBS to promote de-institutionalization and community-based services[4]
- The Individuals with Disabilities Education Act was reauthorized and renamed from prior legislation in 1990 and states that students are entitled to a free appropriate education tailored to their individual needs and an individualized education program, and that students must be educated in the least restrictive setting[5].
- The 1990 American with Disabilities Act (ADA) also defined unnecessary institutionalization as a form of discrimination[6].
- The 1999 Supreme Court's Olmstead decision reinforced the ADA, making explicit the right for people with disabilities to receive community-based care. President Obama later issued a proclamation for the "Year of Community Living" in 2009, with direction to

[3] Li, S. (2014). *Community-based residential alternatives for persons with intellectual and developmental disabilities: Current practices, trends, and issues.* Retrieved from http://www.ancor.org/sites/default/files/news/gwu_residential_report.pdf.
[4] Williamson, H.J., & Perkins, E.A. (2014). Family caregivers of adults with intellectual and developmental disabilities: Outcomes associated with U.S. services and supports. *Intellectual and Developmental Disabilities*, *52* (2), 147-159.
[5] Colorado Department of Education. (2018). Special Education Rules and Regulations. Retrieved from https://www.cde.state.co.us/spedlaw/rules
[6] National Council on Disability (NCD). (2017). National disability policy: A progress report. Retrieved from https://www.ncd.gov/progressreport/2017/national-disability-policy-progress-report-october-2017.

substantially increase enforcement of the Olmstead ruling and the integration mandate of the ADA[7].

Additionally, federal policy and IDD advocacy movements now emphasize the best practice of designing services around individual needs, strengths and desires.

- The core values of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 are self-determination, independence, productivity, and inclusion[8].
- The President's Committee for People with Intellectual Disabilities provided a series of recommendations in 2016 which included that federal agencies promote self-determination and supported decision-making for individuals with IDD[9].
- The 2014 Medicaid Final Rule requires a person-centered service plan for key waivers. Person-centered planning involves planning driven by the individual, includes people chosen by the individual, and is timely and convenient for the person receiving services. It reflects the individual's goals, desires and needs, is culturally relevant, and provides choices and mechanisms for receiving information and resolving disagreements.[10]

Federal policy around service provision for the IDD community is continuously evolving and requires substantial resources to monitor implications at the local level. The 'Medicaid Funding Trends and Potential Shifts' section of this report provides key current trends to monitor as well policy-related recommendations for Boulder County to consider in service planning and funding decisions.

OPPORTUNITIES AND LIMITATIONS OF IDD DATA AND EVALUATION

In addition to monitoring policy and national trends in service provision, it will be important for Boulder County to invest in ongoing monitoring and evaluation of local service needs and program costs. A key first step in this process is understanding national data collection efforts and challenges associated with gathering reliable data about the IDD populations and services. There are some national sources of data about IDD population demographics, service provision, and

[7] President's Committee for People with Intellectual Disabilities (PCPID). (2016). Strengthening an Inclusive Pathway for People with Disabilities and their Families: Report to the President. Retrieved from https://www.acl.gov/sites/default/files/programs/2017-03/PCPID-Report-2016.pdf.
[8] Administration on Intellectual and Developmental Disabilities (AIDD). (n.d.). Biennial report to Congress, the President, and the National Council on Disability Fiscal Years 2011 and FY 2012. Retrieved from https://www.acl.gov/about-acl/reports-congress-and-president.
[9] President's Committee for People with Intellectual Disabilities (PCPID). (2016). Strengthening an Inclusive Pathway for People with Disabilities and their Families: Report to the President. Retrieved from https://www.acl.gov/sites/default/files/programs/2017-03/PCPID-Report-2016.pdf.
[10] enters for Medicare and Medicaid Services (CMS). (n.d.). Final Rule Medicaid HCBS webinar. Retrieved from https://www.medicaid.gov/medicaid/hcbs/guidance/hcbs-final-regulation/index.html.

program costs that can be used to deepen understanding of outcomes and costs for particular services. Most available information is from state IDD agencies and federal sources. Information is typically reported at a high-level (i.e., encompasses large service areas such as "employment services") and relies heavily on data provided by state IDD agencies funded through Medicaid HCBS waiver funds. Further, definitions of IDD differ across data sources and are dependent upon factors such as funding streams and reporting requirements.

Data about particular service delivery models, best practices, and associated costs and outcomes, are much more limited. This is largely due to variations in services and funding structures across states. First, the demographics and needs of IDD communities vary across states and thus affect the cost of service provision (Li 2014 p.9, NCD 2012a). Second, each state has a different funding structure for IDD service provision and there are a wide number of funding sources from which states can draw upon to create the overall funding structure. Finally, states also have a range of approaches to waiver administration, including populations served and services provided (Anderson et al. 2016 p.12). The inherent variability and complexity in funding structures makes it difficult to compare data across states (Anderson et al. 2016 p.12, NCD 2012a). Table 4 below outlines numerous data collection efforts related to IDD services.

Table 4. Key Data Collection Efforts for IDD Services

Source	Description
Access to Integrated Employment project at Institute for Community Inclusion at UMass Boston	Tracks data on employment and day services since 1988. Partially funded by AIDD as a Project of National Significance and includes many of the sources below
National Survey of State IDD Agencies' Day and Employment Services	Information on community-based and facility-based employment and day services, funding sources and allocation, and waiting lists
The National Survey of Community Rehabilitation Providers	Survey conducted every 5 years and includes information on CRP characteristics, employment outcomes, and service distribution
State Agency and Community Rehabilitation Provider (CRP) promising practices (part of the Access to Integrated Employment project)	Collection of federal data and other sources regarding employment; users can generate state-level figures for indicators and trends
State of the States in Intellectual and Developmental Disabilities	Funded by AIDD, U.S. Dept of Health and Human Services, University of Colorado School of Medicine, Dept. of Psychiatry; users can access nationwide and state-level longitudinal financial and programmatic trends in IDD
AIDD Project of National Significance.	Includes data on spending for groups of services (e.g., family support and supported living), and cost of care for certain types of services
National Core Indicators	Voluntary surveys administered by National Association of State Directors of Developmental Disabilities Services (NASDDDS) member offices. Surveys of adults receiving services, their families, and families with children receiving services, as well as staff.
Residential Information Systems Project (RISP) and Supporting Individuals and Families Systems Project (FISP)–	RISP data provides data on current residential status of IDD population at national and state levels. Includes information on ages of I/DD population, type of residence, and number of I/DD AIDD Project of National Significance and Institute on Community Integration. Includes state agency caseload information and public funding information of residential services. Data from wide variety of sources including government reports and offices, articles published about Medicaid spending, and other academic articles.

Given the local factors shaping service implementation and cost, as well as the limited data about best practices for particular service delivery models, local contextual information (NCD 2012a) and input from practitioners (where available) is critical for determining and framing funding and service implementation decisions.

Boulder County Service Delivery

The needs assessment also included a review of service delivery structures and Medicaid data at the state and county level. Publicly available information was reviewed and informational interviews conducted with state and local systems professionals to inform the summary of service delivery structures and Boulder County providers below. Additionally, Keystone Policy Center completed an analysis of Boulder County IDD Medicaid utilization and costs relative to the state and to the neighboring Larimer County.

ELIGIBILITY AND SERVICE DETERMINATION

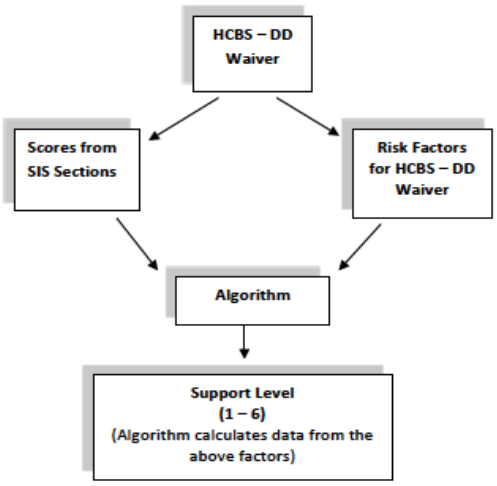
State Eligibility

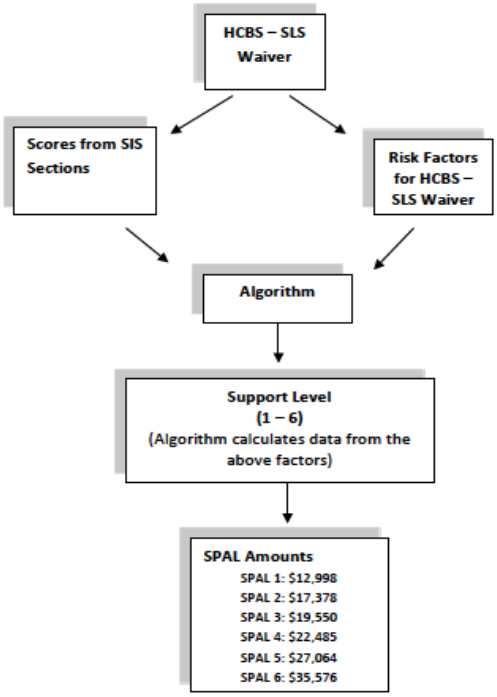
Home and Community-Based Services (HCBS) in Boulder County are made available to individuals with IDD by the State of Colorado through several funding programs overseen by the Community Living Office and administered by the Boulder County Community Centered Board Imagine! Colorado. There are three primary waivers for individuals with IDD although some individuals may also meet the targeting criteria for other waivers not listed below (e.g., Elderly Blind and Disabled Waiver administered by HCPF).

The Home and Community-Based Services Waiver for Persons with Developmental Disabilities (DD) provides access to 24-hour, seven days a week supervision through Residential Habilitation and Day Habilitation Services and Supports. The service provider is responsible to support individuals, in services, to find living arrangements.

The Home and Community-Based Services -SLS waiver (HCBS-SLS) provides necessary services and supports for individuals with intellectual or developmental disabilities so they can remain in their homes and communities with minimal impact to individuals' community and social supports. The HCBS-SLS waiver promotes individual choice and decision-making through the individualized planning process and the tailoring of services and supports to address prioritized, unmet needs.

The visual below provides a high-level overview of these two core IDD waiver processes (DD and SLS).





The Children's Extensive Support Waiver (HCBS-CES) helps children and families with intellectual or developmental disabilities by providing services and supports that will help children establish a long-term foundation for community inclusion as they grow into adulthood.

Services Allocation: Level of Care for Waivers

Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF-IID) level of care as determined by the functional needs assessment (as defined in 42 CFR 440.150). There are six levels of care with one being the lowest level of need and six being the highest.

Waitlist

There are 2,808 individuals on the "as soon as available" waiting list for HCBS-DD as of August 31, 2018.

People Not Eligible for Waiver Services

The primary source of funding for these services is the mill levy at the local levels. There are currently two state-only funded programs that serve people who do not qualify for waiver services:

- The State-funded Supported Living Services (State SLS) program provides funding assistance to individuals who can live independently with limited supports, or if they need extensive supports, are receiving those supports from other sources. (25.5.10.200)

- The Family Support Services Program (FSSP) provides support for families who have children with developmental disabilities or delays with costs that are beyond those normally experienced by other families. "The primary purpose of the FSSP is to support children with developmental disabilities or delays remaining within their own nurturing family setting and prevent out-of-home placements" (HCPF website). Families are offered grants based on available funds in a given fiscal year. These grants can be used for approved services for the family member with an Intellectual or Developmental Delay/Disability including Respite Care, Therapy Services, Medical, Dental, Vision Transportation, Assistive Technology, Home Modifications, Homemaker Services, Child Care, and Family Assistance. Individuals must apply for funds through the CCB and are only eligible for grants if they are already receiving services from Imagine!

SERVICE DELIVERY STRUCTURES IN BOULDER COUNTY

As described in the 'Eligibility and Service Determination' section above, Boulder County's Community Centered Board Imagine! administers IDD Medicaid waivers, contracts with service providers, provides direct services, and provides case management services to Boulder County residents with IDD. In addition to Medicaid funding, Imagine! has historically received the majority of Boulder County's mill levy funds for its services such as:

- Education and therapy
- Work opportunities in the community
- Recreational learning and leisure activities
- Facilitation of independent and group living
- Support for families that care for their children at home
- Guidance in everyday living

Several other key IDD service providers in Boulder County have also received small mill levy funding allocations in recent years for specific types of programming:

- The Association for Community Living Boulder (ACL) aims to "build inclusive communities and enhance the lives of people with intellectual and developmental disabilities through advocacy, training, and support" (ACL Boulder, 2018).
- The Center for People with Disabilities (CPWD) works to "provide resources, information and advocacy to assist people with disabilities in overcoming barriers to independent living" (CPWD, 2018).
- EXPAND/Play Boulder Foundation supports individuals with IDD in recreational activities through their mission of "creating excellence in parks and recreation by mobilizing community support through education, philanthropy and advocacy" (Play Boulder, 2018).

Imagine! also manages contracts with approximately 150 providers who offer services to Boulder County community members with IDD. These vendors offer services in the following general areas:

- Auditory Services
- Behavior Therapy
- Chiropractic
- Cleaning and homemaking services
- Education and Tutoring services
- Hippotherapy
- Nutrition and Wellness
- Massage
- Music Therapy
- Occupational and Physical Therapy
- Psychotherapy
- Speech Language Therapy
- Visual Impairment Therapy

For a complete list of Boulder County service delivery providers along with contacts and general service information, contact BCDHHS. OMNI utilized vendor information provided by Imagine! and completed additional searches to compile any publicly available information, grouping providers into the categories listed above as appropriate.

MEDICAID UTILIZATION DATA

Keystone Policy Center analyzed Boulder County IDD Medicaid services utilization and costs and compared it to the state as a whole and Larimer County. According to Colorado Population Estimates by County on the Department of Local Affairs website11, Larimer County is Colorado's sixth most populous county with 343,853 residents as of July 2017 compared to Boulder County, Colorado's eight most populous county with 322,854 residents as of July 2017.

In Boulder County, 179 individuals are served on the CES waiver (ages 0-17), 377 on the DD waiver, and 379 on the SLS waiver. A majority of the individuals (approximately 94%) served are under the age of 65.

The proportion of individuals in the DD and SLS waivers in each of the six severity/support levels and the mean costs have remained consistent between 2015 and 2017.

Boulder County costs are consistent with the mean costs of the State. On average, Boulder County serves 6-8% of the total State population being served through these waivers.

[11] https://demography.dola.colorado.gov/population/population-totals-counties/

Table 5. Waiver Support Levels and Mean Costs per Client

Support Levels (2017)	DD	Mean cost	SLS	Mean cost
1	38	$ 38,827.06	155	$ 5,370.19
2	64	$ 46,065.02	109	$ 9,170.73
3	49	$ 56,527.56	33	$ 12,072.38
4	68	$ 70,172.73	31	$ 12,770.28
5	77	$ 75,453.25	31	$ 15,764.06
6	77	$ 102,638.80	*	$ 22,589.61

** Numbers less than 30 are not reported*

Table 6. Top DD and SLS Waiver Services

DD WAIVER	SLS WAIVER
Age 18-64 ▪ Residential Habilitation ▪ Day Habilitation ▪ Supported Employment ▪ Non-Medical Transportation ▪ Behavioral Services ▪ Prevocational Services ▪ Vision Services ▪ Specialized Medical Equipment and Supplies	**Age 18-64** ▪ Day Habilitation ▪ Respite ▪ Non-Medical Transportation ▪ Personal Care ▪ Supported Employment ▪ Homemaker ▪ Behavioral Services ▪ Prevocational Services ▪ Mentorship ▪ Professional Services ▪ Vision Services ▪ Home Modifications ▪ Specialized Medical Equipment and Supplies ▪ Assistive Technology ▪ Vehicle Modifications ▪ Personal Emergency Response System (PERS)
▪ **Age 65+** ▪ Residential Habilitation ▪ Day Habilitation ▪ Non-Medical Transportation ▪ Supported Employment ▪ Behavioral Services ▪ Prevocational Services ▪ Specialized Medical Equipment and Supplies ▪ Vision Services	**Age 65+** ▪ Day Habilitation ▪ Personal Care ▪ Non-Medical Transportation ▪ Homemaker ▪ Prevocational Services ▪ Mentorship ▪ Supported Employment ▪ Respite

Table 7. Individuals on Wait List in Boulder County (September 2018)

Support Level	*Clients*	*Age Group*	*Clients*
1	77		
2	79	Age 18-64	330
3 & 4	44		
5 & 6	34	Age 65+	5
Not identified	101		

Each fiscal year, the Department maintains a statewide waiting list for the Home and Community Based Services for Persons with Developmental Disabilities (HCBS-DD) Waiver. The Community Contracts Management System (CCMS) serves as the statewide repository for waiting list data including individuals' needs and preferences as entered into the system by CCB case managers. Individuals waiting for services have a status of "Yes-Waiting" with one of the following timelines:

- As Soon As Available (ASAA) – The individual has requested enrollment as soon as available.
- Date Specific – The individual does not need services at this time, but has requested enrollment at a specific future date. This category includes individuals who are not yet eligible due to not having reached their 18th birthday.
- Safety Net – The individual does not need or want services at this time, but requests to be on the waiting list in case a need arises at a later time. This category includes individuals who are not yet eligible due to not having reached their 18th birthday.
- Internal Management – Individuals who have indicated interest in HCBS SLS waiver services and are in the enrollment process are listed in CCMS with a status of "Internal Management."

CCB case managers are required to verify and update the waiting lists record of eligible individuals within their respective catchment areas at least semi-annually for Medicaid waivers. The prioritization for the waitlist starts with:

1. Children 18-21 Transitions (children transitioning from foster care or the HCBS-CES waiver)
2. Emergency, defined in Colorado as:
   - Homeless: does not have a place to live or is in imminent danger of losing place of abode;
   - Abusive or neglectful situation;
   - Danger to others: the person's behavior or psychiatric condition is such that others in the home are at risk of being hurt by him/her. Sufficient supervision cannot be provided by the current caretaker to ensure safety of the person in the community;

- and/ or a Danger to self: a person's medical, psychiatric or behavioral challenges are such that the person is seriously injuring/harming self or is in imminent danger of doing so.

3. Deinstitutionalization
4. Legislative criteria for appropriations

There is reserved capacity for children ages 18-21 aging out of state foster care or the HCBS-CES (estimated at 125 people per year), people meeting the emergency criteria (estimated at 150 people per year), and for deinstitutionalization (estimated at 48 people per year) according to the approved waiver application CO.007.R07.01. In April 2017, of the individuals waiting for enrollment in the HCBS-DD Waiver with a Medicaid ID number, 78% were currently enrolled in one of the state's other HCBS waivers (for example, the Elderly Blind and Disabled Waiver).

Utilization Conclusions

In general, the utilization research completed by Keystone Policy Center did not reveal any noticeable concerns or recommendations. While Boulder County serves more children than Larimer County and serves roughly 50 additional clients per waiver, spending levels, breakdown by severity and overall averages are fairly similar. Boulder County's costs are slightly higher for clients in Level 6 support.

Medicaid Funding Trends and Potential Shifts

Keystone Policy Center also reviewed the following key areas to better understand the broader policy context that may have implications for local IDD service delivery:

- Medicaid funding trends and general information
- Potential Medicaid shifts and recommendations

MEDICAID FUNDING TRENDS AND GENERAL INFORMATION

To inform Boulder County's understanding of and planning for future IDD services, Keystone compiled Medicaid trends to monitor over time. Recommendations based on these scenarios are not offered at this time, as the impacts will be outside of Boulder County's control. Each trend also contains relevant information about: status/timing; potential effects on the availability of services; and cost implications as appropriate. The following trends are further detailed below:

- Waiver Simplification
- Employment
- Settings Rule
- Employment First
- Hospital Transformation Program
- Cost Control Bill

Waiver Simplification

As described in the Concept Paper for Waiver Simplification in Colorado, Colorado has historically been a leader among states providing supportive services to people with all types of disabilities, enabling them to live in the least restrictive settings possible. Shortly after 1915(c) waivers became available, Colorado obtained approval for individuals with developmental disabilities and individuals who are elderly, blind, or disabled. In the early 1990s, Colorado became one of the first states to implement a Single Entry Point (SEP) system to determine eligibility for Medicaid and functional eligibility for most of its waivers. While Colorado continues to be a model of community long-term services and supports (LTSS), the waiver system has become excessively complex with 10 waivers offering different service packages for adults and children. The system is complicated for families and caregivers to navigate and the state to administer.

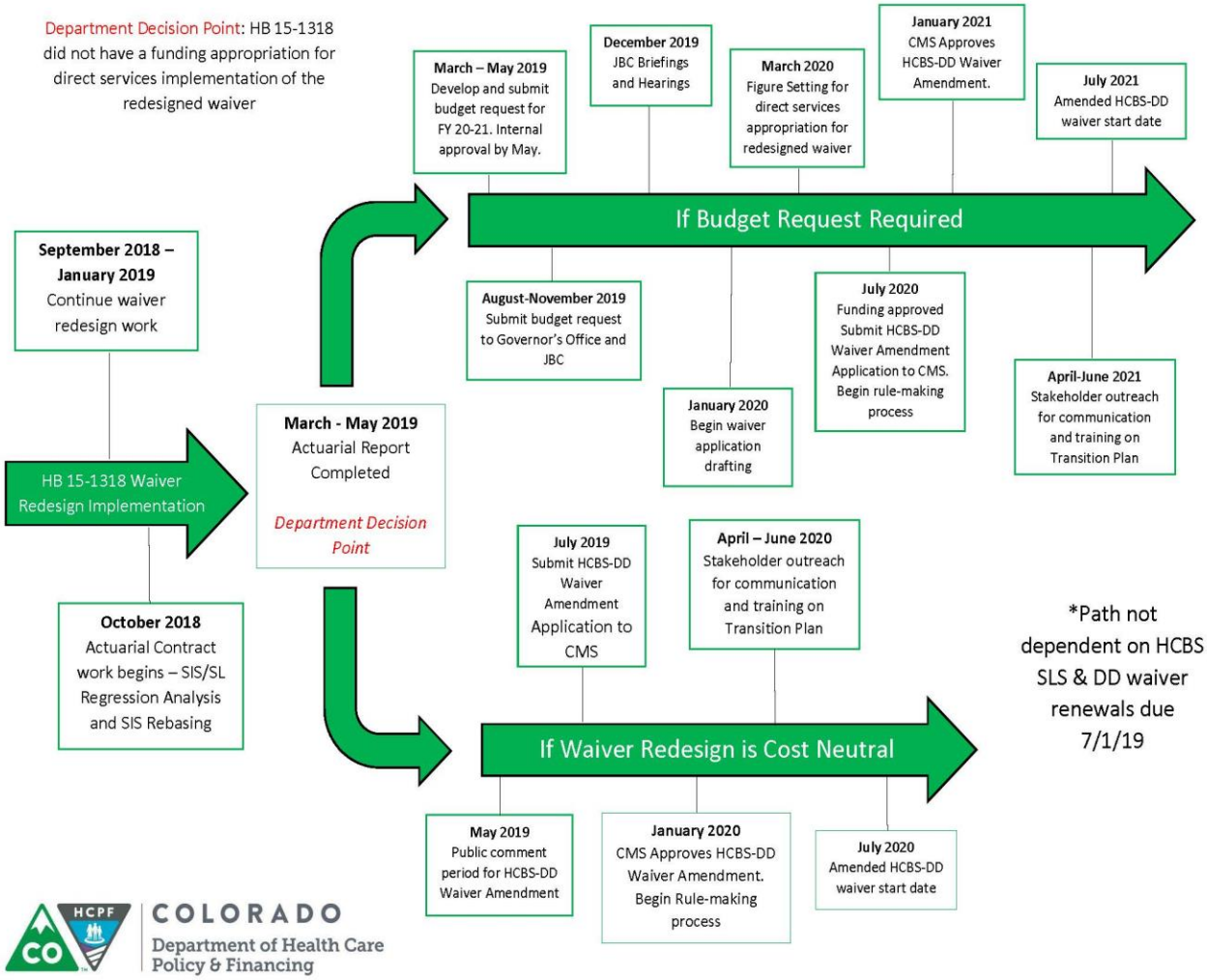
In response, the Waiver Redesign Workgroup was established in 2013 and charged with recommending an array of long-term services and supports to the Community Living Advisory Group (CLAG) including definitions constructed so as to minimize restrictions on an individual to live life while supporting health and safety. In 2015, the Workgroup's recommendations and

statewide stakeholder input were captured in a comprehensive Summary and Recommendation Report and Addendum.

In 2016, the Waiver Redesign Workgroup transitioned into the Waiver Implementation Council (WIC) which currently provides guidance and advice to HCPF on the design and implementation of a redesigned Home and Community-Based Services (HCBS) waiver to serve adults with Intellectual and Developmental Disabilities (IDD). The redesigned waiver will offer an array of services and supports that are flexible to the needs and preferences of the individuals who receive them, are available when and where they are needed, and incorporate the following principles:

- Freedom of choice over living arrangements, social, community, and recreational opportunities
- Individual authority over supports and services
- Support to organize services in ways that are meaningful to the individual receiving services
- Health and safety assurances
- Opportunity for community contribution
- Responsible use of public dollars

Status/Timing In June of 2018, the Department expanded the membership of the WIC to 30 members. The Department and the WIC will meet at least quarterly between July 2018 and June 2019. The workgroup is consulting and advising the Department's design and implementation of a consolidated waiver. If the redesign is cost neutral, the new consolidated waiver will begin in July 2020; if it is not budget neutral, then the consolidated waiver will begin in July 2021. The timeline is illustrated below.



<u>Effect on Availability of Services</u>

Effect on services will depend on the final recommendations of the WIC, HCPF's decisions and what is accepted by CMS.

<u>Cost Implications</u>

The actuarial analysis will be done between March – May of 2019.

No Wrong Door

According to HCPF's website, "the purpose of the three-year No Wrong Door (NWD) implementation grant, secured with funding from the federal Administration on Community Living (ACL) in September 2015, is to develop a model for implementing NWD statewide to address many of the major challenges currently experienced by long term services and supports (LTSS) consumers (LTSS are a range of supportive services for people with physical, cognitive or mental disabilities or conditions that limit their ability to care for themselves; services range from

personal and homemaker services to skilled nursing care). Model implementation will be developed by monitoring four regional pilot sites and testing and refining various tools and approaches to carry out the functions of a NWD system as articulated by the ACL."[12]

Status/Timing

These regional pilot sites launched in summer 2017, through contracts awarded to the following agencies and counties:

- Colorado Access (serving Adams, Arapahoe, Denver and Douglas counties)
- Larimer County Department of Human Services
- San Juan Basin Area Agency on Aging (serving Archuleta, Dolores, La Plata, Montezuma, and San Juan counties)
- Senior Resource Development (serving Pueblo county)

The Department is working with the regional pilot sites to test the proposed Regional No Wrong Door Entity model for the purpose of streamlining access to LTSS for all people in need regardless of age, disability or pay source.

The Department has contracted with the Center on Network Science (CNS) from the University of Colorado-Denver, School of Public Affairs to serve as the No Wrong Door project evaluator. The CNS's work will include evaluation of the NWD regional pilots' ability to carry out the six functions of a No Wrong Door system. CNS will also help to determine how to implement NWD statewide upon the conclusion of the pilot phase.

Effect on Availability of Services

When fully implemented, the regional entities model assumes existing LTSS entry point agencies will be replaced or reorganized.

Cost Implications

CNS will work with the pilot sites, their customers and referral sources to collect quantitative and qualitative data measuring the sites' effectiveness and cost.

Employment

Meaningful employment contributes to self-sufficiency, builds self-esteem, improves social and financial capital, and contributes to the socio-economic well-being of communities. Employment provides people the opportunity to support themselves in the full expression of the rights and responsibilities of citizenship. While expressing an ability, desire and willingness to work in the community and contribute to the economy, many adults and youth with disabilities experience significant barriers to employment.

[12] https://www.colorado.gov/pacific/hcpf/no-wrong-door-implementation-grant

Despite progress made since the passage of the Americans with Disabilities Act of 1990 (ADA) and comparable equal opportunity and nondiscrimination laws passed by most states, the percentage of people with disabilities participating in our workforce is far below the rate for people without disabilities. As documented in the state plan for Colorado, there are just over 300,000 Coloradans with disabilities, representing 8.9 percent of the State's population; 41.6 percent of these individuals are employed compared to 79.1 percent of Coloradans who do not have a disability. There is still significant work to be done to improve the employment prospects of individuals with disabilities in Colorado, including encouraging participation through increased understanding of the supports available to promote their success, and ensuring those who seek to work have opportunities to do so in competitive integrated employment.

SB18-145 was signed by the Governor in May of 2018 and requires the Department of Labor and Employment and the State Medical Services board in the Department of Health Care Policy and Financing to promulgate rules that require all providers of supported employment services for persons with disabilities to obtain a nationally recognized supported employment training certificate or earn a nationally recognized supported employment certification relating to supported employment services.

It also requires that the Department of Labor and Employment's fee schedule for rehabilitation services include the discovery process as an alternative comprehensive assessment if appropriate for persons with disabilities.

Status/Timing

The rules must specify time frames for completion of the training or certification. The time frames must provide for training to be completed over a five-year period, subject to appropriations for reimbursement of vendors.

Settings Rule

In January 2014, the Centers for Medicare & Medicaid Services (CMS) published a rule to ensure that the provision of Home and Community Based Services (HCBS) occurs pursuant to a person-centered planning process and in settings that meet certain criteria (79 Fed. Reg. 2948 January 16, 2014). The rule went into effect in March 2014 giving states five years to comply until the rule was again amended. Now states have until March 2022 to ensure that their HCBS settings are compliant with the rule. The new regulations ensure that participants in HCBS programs have access to the benefits of community living, and that services are true alternatives to services provided in an institutional setting and are delivered in the most integrated setting possible.

The final rule requires that all HCBS settings meet specific criteria, including that they:

- Be integrated in and support full access to the greater community
- Be selected by the participant from among setting options

- Ensure individual rights of privacy, dignity, and respect, and freedom from coercion and restraint
- Optimize autonomy and independence in making life choices
- Facilitate choice regarding services and who provides them

In addition, provider-owned or provider-controlled residential settings must meet additional criteria, including that they:

- Have a lease or other written agreement providing similar protections for the client that address eviction and appeals processes
- Ensure privacy in the client's unit including lockable doors, choice of roommates, and freedom to furnish and decorate the unit
- Ensure that individuals have freedom and support to control their own schedules and activities, and have access to food at any time
- Protect individuals' abilities to have visitors of their choosing at any time
- Be physically accessible

The HCBS Settings Rule affects the following Colorado HCBS waivers:

- Elderly, Blind, and Disabled (EBD)
- Persons with Brain Injury (BI)
- Persons with Spinal Cord Injury (SCI)
- Community Mental Health Services (CMHS) for Persons with Major Mental Illnesses
- Persons with Developmental Disabilities (DD)
- Supported Living Services (SLS)

Status/Timing

The Department has developed a Statewide Transition Plan (STP) for bringing Colorado's Home-and-Community-Based Services into compliance with the Final Settings Rule. The STP outlines the Department's process and timelines for working with interested parties to implement requirements of the rule for all HCBS. The STP is a detailed project plan of Colorado's road to compliance, and it is required by CMS to be subject to public input, be regularly updated, and be submitted for CMS approval and guidance. According to the STP, "since the implementation of the HCBS Settings Rule, the Department has been working with stakeholders to ensure that Colorado is fully compliant. The Department has convened an interagency group, which includes the Colorado Department of Human Services (CDHS) and the Colorado Department of Public Health and Environment (CDPHE), to assist in preparing and taking Action Steps. The Department has solicited waiver participants, providers, and other stakeholders to assist with onsite technical assistance, participation in web-based trainings, and stakeholder workgroups, as well as presentations at various committees and boards to educate and engage in conversation regarding the HCBS Settings Rule."

The Department maintains a website for educational materials, Department communications, and CMS communications. The Department will continue to provide trainings to stakeholders regarding the HCBS Final Settings Rule to ensure that participants, providers and other stakeholders understand the HCBS Final Setting Rule and its implementation. The Department has completed a crosswalk that systemically assesses current state statutes, regulations, and waivers and identifies where changes may be necessary; this crosswalk is incorporated by reference into the STP. The Department has begun conducting site visits and collecting provider transition plans (PTPs).[13]

Employment First

Recognizing the benefit of employment, the Colorado Legislature in 2016 created an Employment First Advisory Partnership (EFAP) that was directed to make recommendations to the General Assembly about improving access to employment for people with disabilities. Employment First also seeks to ensure individuals with disabilities are working in integrated settings at competitive wages.

Employment First is a philosophy that all people, including people with the most significant disabilities, are capable of full participation in employment and community life. Advocates for Employment First believe that all people should be given meaningful, individualized, integrated opportunities to explore the world of work, to discover how they might contribute, and to chart a course to employment and greater prosperity.[14]

Status/Timing

In June 2016, Governor Hickenlooper signed Senate Bill 16-077 into law making Colorado the latest in a group of 19 states to adopt an Employment First paradigm. The law establishes the EFAP, a collaboration between the Colorado Department of Education, the Colorado Department of Health Care Policy and Financing, the Colorado Department of Higher Education, Colorado Department of Human Services and the Colorado Department of Labor and Employment through September 2021. The collaboration also includes representatives with disabilities seeking supported employment, representatives of families of people with disabilities, representatives of those advocating for people with intellectual disabilities as well as others focused on cross-disability interests. The State Rehabilitation Council was assigned lead agency responsibility for developing, convening and administering the Employment First Advisory Partnership.

Members have met monthly since January 2017 for the purpose of developing recommendations to be reported to the General Assembly between November 2017 and January 2018. The

[13]https://www.colorado.gov/pacific/sites/default/files/Statewide%20Transition%20Plan-December%2016%202016.pdf
[14] https://www.colorado.gov/pacific/dvr/employment-first-advisory-partnership

Advisory Partnerships continues to meet the third Tuesday of the month, and their work can be found here.

Effect on Availability of Services

In order to fully implement Employment First recommendations, HCPF would need to create a buy-in for all adult waivers. A buy-in only exists for two waivers - the Elderly, Blind and Disabled (EBD) and Community Mental Health CMHS) Waivered Services.

Cost Implications

To fully implement the Employment First Recommendations or provide supported employment for those within the IDD waiver would require approval from CMS and additional funding. The right supports are needed to implement this in a way that really supports individuals with IDD:

- Making employment processes more person-centered
- Ensuring that the discovery phase of supported employment starts earlier and continues throughout employment to ensure job and career growth and increased satisfaction
- Developing and expanding use of benefits counseling to allow individuals with disabilities to understand their earning potential and benefits implications

Hospital Transformation Program (HTP)

The Hospital Transformation Program (HTP) is a five-year reform initiative that builds upon the existing hospital supplemental payment program to incorporate value-based purchasing strategies into existing hospital quality and payment improvement initiatives. Under the HTP, hospitals will be required to implement quality-based initiatives to receive supplemental payments and demonstrate meaningful community engagement and improvements in health outcomes over time.

Status/Timing

Planning Period – August 2017 – October 2018
Ramp-up Period – October 2018 – October 2019 - Community and Health Neighborhood Engagement and waiver development
Program Implementation – October 1, 2019

Effect on Availability of Services

The Hospital Transformation Program will support hospital-led infrastructure development, partnerships, data sharing, and operational changes needed to ensure that the state's acute care hospitals are in line with other ongoing reform efforts.

- Improve patient outcomes through care redesign and integration of care across settings;
- Improve the patient experience in the delivery system by ensuring appropriate care in appropriate settings;

- Accelerate hospital's organization, operational and system readiness for value-based payment;
- Increases collaboration between hospitals and other providers, particularly Accountable Care Collaborative (ACC) participants, in data sharing and analytics and evidenced-based care coordination and care transitions, integrated physical and behavioral care delivery, chronic care management, and community-based population health and disparities reduction efforts; and
- Add value to the system through an evidence-based and quality measure-driven approach.

Cost Implications

The program will operate as a five-year demonstration and require a federal waiver under section 1115 of the Social Security Act. The Hospital Transformation Program will use delivery system reform incentive payments (DSRIP) to support hospital-led projects to lower Health First Colorado (Colorado's Medicaid Program) costs through reductions in avoidable care. For the incentive payments, the state will leverage hospital supplemental payment funding generated through existing hospital provider fees authorized under the Colorado Health Care Affordability Act of 2009.

Cost Control Bill (SB 18-266)

SB 18-266 "Controlling Medicaid Costs" directs the Department of Health Care Policy & Financing to pursue cost-control strategies in Medicaid. The bill dedicates permanent staff to pursue cost-control, value-based payments and other approaches; makes available expenditure, quality of medical services, and pharmaceuticals information to providers; and utilizes technology to further review claims prior to payment to prevent improper payments. The bill also creates an evidence-based hospital review program to ensure appropriate utilization of hospital services.

In the Health Care Policy & Financing FY 2018-19 Performance Plan, HCPF highlights the following cost reduction programs:

Hospital Review Program

In recognition that hospitals are responsible for about 30 percent of Colorado Medicaid spending and 10 percent of the state's budget, the Hospital Review Program provides inpatient utilization review through pre-admission certification and continued state review using evidence-based guidelines. Targeted for implementation January 1, 2019, the program will notify the Regional Accountable Entities (RAEs) of member diagnosis and treatment plans and highlight opportunities for discharge planning care coordination and case management of patients who are at risk for readmission. The program will also allow the RAEs to invite patients into population health and disease management programs. Last, it includes a complex claim prepayment review to ensure proper coding and payment.

Health Care Cost Control Roadmap

HCPF is leading a collaborative process to devise a three to five plus year Cost Control Roadmap for the State of Colorado. The Roadmap is intended to frame policy and drive actions that reduce health care prices to the benefit of employers, consumers and other payers. The comprehensive Roadmap will cover areas including:

- Provider practice patterns and changing norms
- Members such as seniors, individuals in rural areas and children
- Innovations by local business to solve challenges
- Benefit areas such as hospital, primary care and pharmacy
- Value based payments and other alternate payment methodologies
- Lifestyle and population health influencers such as tobacco use, addiction and excess weight

Provider Cost and Quality Tools

HCPF will roll out a suite of powerful cost and quality assessment capabilities to the seven RAEs as well as hospitals and primary care medical home (PCMH) providers to identify potentially avoidable costs on member care, individuals, PCMHCs, specialists and hospitals. Ultimately the tool will enable providers to improve their referral patterns toward more cost-effective higher quality physicians and hospitals, enable hospitals to identify and self-correct inefficient, lower quality care delivery or affiliated providers, and allow RAEs to target members for care management. HCPF will also direct members seeking provider locator services to higher performing providers.

Status/Timing

The various pieces of the Cost Control bill have different timelines, though the overall philosophy has definitely been embraced by the Department already.

Cost Implications

The major implication of Controlling Medicaid Cost Initiatives is that the department will continue to scrutinize all costs and all savings mechanisms available.

POTENTIAL MEDICAID SHIFTS AND RECOMMENDATIONS

Recommendations are provided for the following scenarios in which Boulder County's plans and actions have implications for outcomes. These include:

- Collaboration with Regional Accountable Entities (RAEs)
- Social Connectedness
- Conflict-Free Case Management
- Mill Levy recommendations

Each area also contains relevant information about: status/timing; potential effects on the availability of services; and cost implications as appropriate.

Regional Accountable Entities (RAEs)

RAEs are responsible for coordinating members' care, ensuring they are connecting with primary and behavioral health care, developing regional strategies to serve Health First Colorado members, and monitoring data and metrics to ensure quality care. They are designed to influence, through contractually defined incentives and deterrents, the behaviors of providers and clients and increase integration of physical and behavioral health care. The new contracts require that RAEs work with counties and social services partners to coordinate care, particularly around transitions of care.

Status/Timing

The RAE contracts were executed in April 2018 and the map and list of selected RAEs is posted on https://CO.gov/HCPF/ACCPhase2. Starting July 1, 2018, Health First Colorado contracted with one organization in each region of the state to manage both physical and behavioral health care.

Effect on Availability of Services

While the aim is to eventually improve care, many changes are largely administrative and behind the scenes, and RAEs are attempting to launch their programs without disrupting services for members.

Each RAE is responsible for its own network and they have to demonstrate network adequacy to the Department. The RAE contracts require adequate access to behavioral health services included in the Capitated Behavioral Health Benefit, which includes meeting the network adequacy standards. Each RAE can still place their own limitations on networks. The Department has also engaged an external quality review vendor who will help determine and monitor networks to make sure they meet the proper adequacy standards. Additionally, the new managed care regulations require the RAE to notify the Department if a provider is leaving the network and if that will make it hard for members to receive certain services. There are also opportunities for single-case agreements for established relationships and specialty providers outside of network that the RAE can arrange.

Behavioral Health

Each RAE also has to develop a statewide network of behavioral health providers. Previously, BHOs reviewed behavioral health providers and allowed those it approved to bill for services. The process is called credentialing. Many smaller or independent providers felt shut out of Health First Colorado because they could not get credentialed. Now RAEs are in charge of credentialing in their regions.

Recommendations: Behavioral Health

Work to identify the number of people with IDD in Boulder County that need access to mental health services to better understand the provider gap.

Cost Implications

Phase Two of the Accountable Care Collaborative aims to control costs in the state government's largest agency while helping Medicaid members improve their health through integrating primary care and behavioral health, which includes mental health and substance use disorder services. So far, the ACC has shown incremental savings each year and is credited with cutting $161 million in costs by coordinating patient care and connecting members with primary care.[15]

Recommendations: Regional Accountable Entities (RAEs)

Work to facilitate the partnership between CCHA, the RAE for Region 6, and providers relative to the RAE contract sections:

- 11.3.6 (Care Coordination for LTSS and HCBS waivers and other programs designed for special populations)
- 11.3.10 (Care Coordination for Members transitioning between settings including Members receiving LTSS services)
- 11.3.11 (Assisting Members' with IDD to locate appropriate services)

Social Connectedness

One of our key informants said that all waivers for all populations should have some capacity for social connectedness. Social isolation is a common secondary condition associated with any primary disability. In other words, the primary disability may lead to less contact and connectedness with other people. Social isolation has been found to leave individuals with disabilities vulnerable for psychological and other health problems. People with disabilities may be more vulnerable to stress if they lack social support.

One option, suggested in a report on increasing access and equality for individuals with developmental disabilities in Washington to build additional support in communities is to encourage local organizations such as peer support networks. These are voluntary associations of people with disabilities, their families, or some combination of the two that unite to address common needs through mutual support and joint action. A staff person is typically required to advise and organize the network, though it should ultimately be shaped by the needs and preferences of its members.

[15] Colorado Department of Health Care Policy and Financing (2017). "FY2018-19 Joint Budget Committee Hearing (Dec. 13, 2017)." P. 46. Retrieved from https://www.colorado.gov/pacific/sites/default/files/2017%20Health%20Care%20Policy%20and%20Financing%2C%20EDO%20Hearing%20Responses.pdf October 2018.

Funding development and staffing to foster these local networks would provide greater support to people receiving limited services and their families as well as those waiting to receive state services. Peer support networks can be organized by self-advocacy groups, local Arc Chapters, and other family or advocacy-oriented organizations. The Oregon Office of Developmental Disability Services has worked with the Oregon Council on Developmental Disabilities to develop the Oregon Consortium of Family Networks, an association of networks that support the families of people with disabilities.[16]

Rocky Mountain Human Services, Denver's CCB, seeks mill levy-funded projects that would increase the service options and provider base to benefit Denver residents with intellectual and developmental disabilities. This includes funding for programs that increase opportunities and access to social and recreational activities. A list of funded projects can be found here.
Some examples:

Agency/Project Name	Description	Ages
Activity Options: Project World	Facilitates access to diverse community and social activities as well as overnight travel. Past activities have included attending local sporting events and concerts.	18 & up
Connect Us: Social Inclusion Project	Offering age-based play groups, inclusive recess facilitation, parent support, and summer camp.	3 to 13
Jewish Family Service: Arts and Community Exploration (ACE)	Offers vibrant and creative art projects, group and individual music therapy, cultural and holiday explorations, and recreation. Empowers individuals to choose volunteering and participating at local art galleries/studios, museums, nature walks, recreation centers, and citywide adventures.	18 & up
StellarCare Vacations	Increased access to personalized and/or group travel opportunities, including out of state travel.	18 & up
The Wayfaring Band	All-inclusive, multi-day trip packages that focus on getting participants off the beaten path. In addition to road trips and far-flung adventure travel, TWB offers leadership development programming, community education workshops, and advocacy.	18 & up

Recommendations: Social Connectedness

Consider developing a Request for Proposal for community organizations to engage in programs and opportunities related to Social Connectedness and integrated activities (see above).

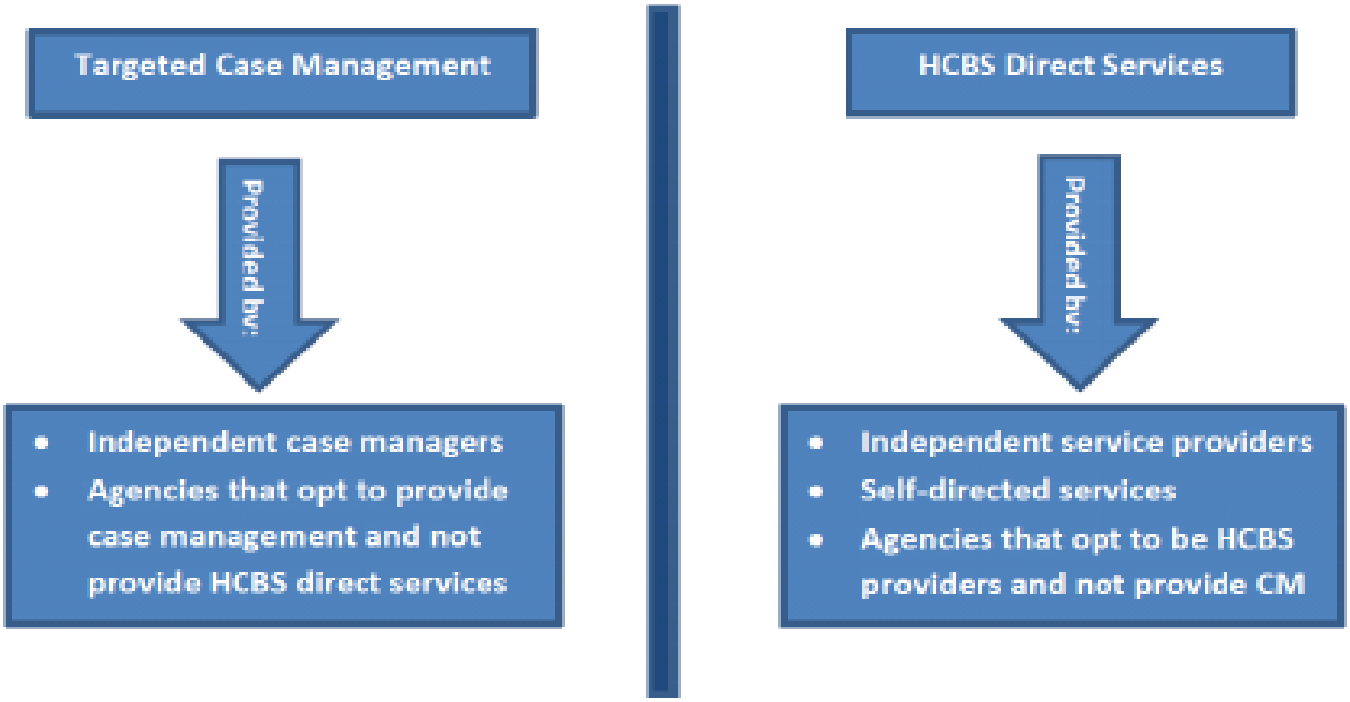
[16] http://www.sao.wa.gov/state/Documents/PA_DevDisabilities_Access_ar1009938.pdf

Conflict Free Case Management

Conflict Free Case Management prohibits the delivery of Case Management Support and Home and Community Based Direct Services by the same agency or entity. The federal Centers for Medicare & Medicaid Services passed a final rule (42 CFR § 441.301(c)(1)(vi)) in March 2014 requiring separation of case management and direct services.

In March 2014, the Centers for Medicare and Medicaid Services (CMS) implemented a final rule requiring states to separate case management from service delivery functions to reduce conflict of interest for services provided under home and community-based services (HCBS) waivers. This rule addresses conflicts of interest that may arise when one entity is responsible for both performing case management functions and providing direct services. As a result of these federal regulations, Colorado's existing system for its waivers supporting individuals with IDD is no longer compliant because case managers and direct service providers are currently part of the same organization. Colorado must comply with this rule to continue receiving these funds.

Source: Task Group on Conflict Free Case Management



In addition, House Bill 17-1343 required the Department to develop qualifications for Case Management Agencies and case managers.

Some key qualifications in this redesign for entities and case managers:

- Must have a physical location in Colorado and meet all required case management activities for the areas in which the agency serves;
- Demonstrate proof the agency has employed staff that meet case manager qualifications;

- Meet the staffing patterns indicated within regulations;
- Have established community referral systems and demonstrate linkages and referral ability to make community referrals for services with other agencies;
- Must have one month reserved financial capacity to maintain operations;
- Must demonstrate ongoing financial sustainability reserves that match one month of expenditures associated to the number of individuals expected through that catchment area and provide stability for case managers, clients and service providers;
- Case Managers must complete the following within 6 months of hire date - Completion of Department approved case management training and certification

Imagine! and other CCB's must choose to:

1. CCBs operate as a case management agency only (i.e., divests itself of direct services)
2. CCBs operate as a direct service provider only (i.e., divests itself of TCM services)
3. CCBs continue to provide both TCM and direct services, but never to the same individual
4. CCBs discontinue providing services and TCM to Medicaid I/DD waiver individuals

Status/Timing

All individuals receiving HCBS must be enrolled in a conflict-free system by 2022.

Effect on Availability of Services

In order to meet the intent, Boulder County and HCPF needs to actively work to recruit new case management agencies and direct service providers to increase individual choice between existing and new case management agencies and providers. Capacity building will be key in order to ensure intent is met.

Cost Implications

Boulder County could consider using Mill Levy to build capacity.

The original intent of Boulder's CCB was to provide both case management and direct services for Boulder residents. Imagine! will now have to choose to focus on only one service component per client. Boulder residents will also no longer be required to receive case management from Imagine!. They can receive case management wherever they choose, as the geographic boundaries of the CCB structure will no longer follow CMS rules. Therefore, mill levy funding for case management for Boulder residents should not be given to one specific entity; doing so would almost certainly ensure that mill levy funds would be linked to non-Boulder residents.

Recommendations: Conflict Free Case Management

Boulder County should undertake a provider capacity and availability study for case management agencies and direct service provider supply in the County.

Boulder County should help facilitate transition to conflict free case management. Use an RFI to direct Mill Levy resources to new Boulder County case management agencies to cover needed reserve requirements to be paid back as entity builds own reserve, cover salary costs and have those reduce over time, and/or cover costs of required training and certification by HCPF.
Note: Funds should be used to build case management capacity for serving in Boulder County and not building statewide capacity of a case management entity.

Mill Levy Accountability and Reporting

The recommendations that follow are based on best practices implemented in Denver following their audit, and seek to protect Boulder County, grantees receiving dollars from the Mill Levy, and most importantly individuals with intellectual and developmental disabilities being served by these tax dollars. These recommendations seek to ensure that funds continue to support and meet the needs of Boulder residents with intellectual and developmental disabilities.

Boulder County needs better definition of contract terms to ensure a better understanding of what is an allowable expense. The lack of definition around "facilities and services" has created some vagueness with how dollars should be spent and hinders the ability of the County to ensure that mill levy funds are going towards providing services and support as intended by the voters. In addition, Boulder County should limit the amount of the Mill Levy that goes to administrative expenses as its intent was for services and facilities. Denver County has allowed for 15% of those targeted expenditures to include reasonable administrative cost actually incurred for the provision of services. Denver County adopted the definition of administrative expenses as costs incurred by an organization for a common objective that cannot be easily attributed to a single program or cost area. The Financial Accounting Standards Board (FASB) and The Office of Management and Budget (OMB) provides a list of examples of common administrative expenses, which can include general recordkeeping, budgeting, financing, management, executive salaries, and oversight – they should not include fundraising expenses. Boulder County should request source documentation to validate that administrative expenses do not exceed 15% on all future invoices from grantees.

Additionally, Mill Levy funds should support the development and distribution of informational materials, holding forums and other communication efforts designed to reach the Boulder community for the purposes of informing and/or educating the public about the conditions of developmental disabilities, how to apply for service, and the types of services and supports that are offered through Imagine!, and its provider network, and other grantees.

Recommendations: Mill Levy Accountability and Reporting

Boulder County should develop a Community Advisory Council to leverage community engagement and participation related to the needs and gaps for people with IDD with individuals with IDD and their families as a central part of decision-making processes. This group should provide input and oversight in the following areas:

- Ongoing review and assessment of community needs and disability-related data, as well as policy-related information that has implications at the county-level; Boulder County could request information and feedback from the Council specific to the needs of Boulder residents with IDD during its continuous assessment of needs
- Input on project funding decisions and rationale for funding, key groups and expected numbers served, projected plans for spending over time
- Communications to the public about funding decisions and outcomes of projects
- The Advisory members would be encouraged to provide data, anecdotal information, and/or represent personal and professional experience. Rocky Mountain Human Services (RMNS), Denver's CCB, has created a similar structure for the oversight of their mill levy dollars.

Boulder County should create definitions for eligible and allowable expenses under the Mill Levy.

- The ballot language identifies monies "allocated for facilities and services for people with DD."
- Boulder County should amend the contract exhibits to specify what constitutes an allowable cost to ensure appropriate funding of the Mill Levy in the future.
- Boulder County should amend contract reporting to focus on systemwide metrics.
- Boulder County should limit and verify that administrative expenses do not exceed 15%, and require grantees classify executive salaries as administrative expenses. Finally, Boulder County needs to be clear that fundraising expenses are not allowable expenses.
- Boulder County should require any communications or outreach expenses to be for the sole purpose of IDD programs.

Boulder County should require more formalized reporting for all recipients of funds.

- Develop a monitoring tool that would ensure adherence to explicit contract requirements and provide a transparent process for oversight (and understanding how funds are spent).
- The reporting should include Non-Medicaid reimbursed activities, percent of use by participants and Medicaid-reimbursed activities, percent of use by Medicaid participants.

Prioritized Recommendations and Opportunities

Recommendations and opportunities summarized in this section include those outlined by both OMNI and Keystone earlier in the report. All recommendations were selected with careful consideration of stakeholder feedback, along with the larger policy and literature context related to IDD service funding and provision. They are intended to provide a broad range of options; some would build upon existing programs or infrastructure while others would serve as new innovations or pilot efforts. Each recommendation includes: 1) the policy and/or stakeholder context that informed it; 2) benefits; 3) general cost information and resources needed; and 4) a rough timeframe and/or phase in which the recommendation could be implemented (these phases reflect initial work by Boulder County to sequence the recommendations and timing may evolve over time). Recommendation areas align with each core priority identified by key stakeholders and include the following:

HOUSING				
Investment Area	**Policy, Literature, and/or Stakeholder Context**	**Benefits**	**General Cost Information/ Resources Needed**	**Phase** Phase 1: up to 6 months Phase 2: 6-18 months Phase 3: 18-36 months.
Recommendation Monitor and participate in policy initiatives and collaborations to increase local affordable and accessible housing options in general, and for individuals with IDD specifically	Housing identified as a top priority by all stakeholder groups	Ensures that BCDHHS remains current on Boulder County systems related to housing and policy context, and that any investments made are informed by and complementary to existing efforts	Low Requires staff time for ongoing monitoring and assessment work as well as participation in local collaboratives as appropriate	Phase 1 Work with BCDHHS Housing Group to ensure integration of special populations into the plan (request that the Regional Affordable Housing plan considers language in plan to address IDD population and representation)
Recommendation Explore current regulatory issues, inspection protocols and records to determine effectiveness of current host home system in Boulder County If need is determined, allocate funding to enhance safety mechanisms	Housing identified as a top priority by all stakeholder groups; guidelines and requirements for host homes exist in Boulder County but ongoing regulation and inspections need improvement	Works to bolster and strengthen an existing program that is currently well-utilized	Low-Medium Current infrastructure exists and could be supplemented; initial investment needed to assess gaps in current regulatory and inspection structures and processes, followed by funding for additional staff positions as necessary	Phase 1 Further explore host home regulation needs Phase 2 Setup protocol to track changes after formation of Advisory Council (see Ongoing Monitoring and Evaluation)
Opportunity Consider approaches to housing and family support funds for housing in context of the Regional Affordable Housing Plan, with a focus on IDD accessibility	Housing identified as a top priority by all stakeholder groups, with 'access to a variety of options' particularly emphasized. Funding dependent upon local pilot programs available, proposed costs, and/or evolving local context which may suggest better options over time	Opportunity to explore new models with potential for increasing available options to the community over time Family support funds specifically, give autonomy to families to decide how to best utilize and/or pool resources for other families for community housing	High Dependent upon specific program costs; proposals for pilot housing approaches and/or family support grants for housing should all include annual costs per person	Phase 2 Plan process Phase 3 Launch

CASE MANAGEMENT, NAVIGATION, AND ADVOCACY				
Investment Area	**Policy, Literature, and/or Stakeholder Context**	**Benefits**	**General Cost Information/ Resources Needed**	**Phase** Phase 1: up to 6 months Phase 2: 6-18 months Phase 3: 18-36 months.
<u>Recommendation</u> Direct funding for specific systems navigation and/or advocacy efforts for individuals (temporarily, at a minimum) <u>Related Opportunity</u> Consider funding programs to recruit and train paid family advocates who have acquired critical lived experience and systems navigation expertise	Stakeholders emphasized the need for navigation support, regardless of how well "no wrong door" or "single entry point" models are believed to be functioning Funds could be particularly critical for managing gaps during upcoming systems changes and shifts to conflict-free case management and ongoing policy changes and processes The opportunity to recruit and train paid family advocates to meet navigation and advocacy needs suggested by multiple stakeholder groups and has been a successful model in other settings; implementation would depend upon the availability and interest of local family advocates	Systems navigation and advocacy increase individual capacity for self-advocacy, foster health systems literacy, address complexities related to multi-system involvement and assist and natural age-related transition periods Investing in building systems literacy within the IDD community are sustained throughout the course of an individual's lifetime involvement in services, rather than ending with staff turnover Training family members as advocates/navigators taps into the wealth of knowledge in existing, natural supports and is smart financial investment (many family leaders already work within their communities, compiling and sharing information, and serving as a vital resource to other families); it also fosters family representation and leadership within the community Formalized approaches to employing and compensating family advocates have also been successful as some community organizations have recruited and trained family advocates to assist with both systems navigation and advocacy needs	<u>Medium</u> Requires additional paid staff positions or grants specifically for navigation and advocacy. Consider: Building on Boulder County wraparound/case management for navigation Awarding funds through an RFP process to outside entities for navigation and/or advocacy, including the possibility of training and employing family advocates	<u>Phase 1</u> Mapping: Explore co-locating BCDHHS navigator, navigation resources, and application of navigation model within I/DD, cultural competence, etc. <u>Phase 2</u> RFP

CASE MANAGEMENT, NAVIGATION, AND ADVOCACY				
Investment Area	**Policy, Literature, and/or Stakeholder Context**	**Benefits**	**General Cost Information/ Resources Needed**	**Phase** Phase 1: up to 6 months Phase 2: 6-18 months Phase 3: 18-36 months.
Recommendation Undertake a provider capacity and availability study for case management agencies and direct service provider supply in the County so that Boulder county can help facilitate transition to conflict free case management Use an RFI to direct Mill Levy resources to new Boulder County case management agencies to cover needed reserve requirements; could be paid back as entity builds own reserve, cover salary costs and have those reduce over time, and/or cover costs of required training and certification by HCPF	Review of other county needs assessment processes and stakeholder interviews with systems professionals	All individuals receiving HCBS must be enrolled in a conflict-free system by 2022 and Boulder County efforts could increase individual choice between existing and new case management agencies; capacity-building will be critical in this transition	Medium – High Cost of capacity study as well as needed investments to build capacity	Phase 1 Mapping and exploring Phase 2 RFP

CASE MANAGEMENT, NAVIGATION, AND ADVOCACY				
Investment Area	**Policy, Literature, and/or Stakeholder Context**	**Benefits**	**General Cost Information/ Resources Needed**	**Phase** Phase 1: up to 6 months Phase 2: 6-18 months Phase 3: 18-36 months.
<u>Recommendation</u> Work to facilitate the partnership between CCHA, the Regional Accountable Entity (RAE) for Region 6, and providers relative to the RAE contract sections: *11.3.6 (Care Coordination for LTSS and HCBS waivers and other programs designed for special populations); 11.3.10 (Care Coordination for Members transitioning between settings including Members receiving LTSS services); 11.3.11 (Assisting Members' with IDD to locate appropriate services)*	Accountable Care Collaborative (ACC) 2.0 implementation is a high priority for the Department of Health Care Policy and Financing RAE contracts were effective July 1, 2018, meaning CCHA took responsibility for services delivered to Boulder County's IDD population as of that date Potential collaboration to support the community should be defined and documented for consumers and providers to have clarity regarding accountable parties	Boulder County, CCHA and providers can likely identify both gaps and areas of overlap with regard to care coordination for LTSS and HCBS	<u>Low</u> By providers contracting with RAE ensures mill levy funds are better leveraged	<u>Phase I</u> Tie into Medicaid work <u>Phase II</u> BCDHHS meet with CCHA leadership to make plan that serves special population in context of ACC 2.0
<u>Opportunity</u> Explore opportunities to expand upon existing resources and tools to create a comprehensive, centralized online repository for IDD-related information; compile existing resources as many have already been developed by providers, advocacy groups and family members.	Identified medium priority as navigation investments may address the issue Stakeholders shared the need for a more centralized method to search clear information about eligibility, services and advocacy resources; although some of this information exists, many stakeholders do not feel it is sufficient in its current form	Aims to enhance access to information for individuals with IDD and their families	<u>Low-Medium</u> Dependent upon the state of existing resources and identified accessibility needs; will either need to be compiled and merged or content generated. Existing info should be utilized to minimize IT costs at this time.	<u>Phase 3</u> Phase III: Advisory group work

MENTAL HEALTH				
Investment Area	**Policy, Literature, and/or Stakeholder Context**	**Benefits**	**General Cost Information/ Resources Needed**	**Phase** Phase 1: up to 6 months Phase 2: 6-18 months Phase 3: 18-36 months.
Recommendation Work to identify the number of people with IDD in Boulder County that need access to mental health services to better understand the provider gap Explore expanding Boulder HHS wraparound services to people with IDD to help navigate mental health services	Identified as key priority by stakeholders and in policy trends	Aims to better understand the provider capacity and concerns related to serving people with IDD and mental health needs	Medium Staff time and service provider investment Explore opportunities for data collection and analysis (e.g., through service providers) to better understand service gaps Examine past claims/ utilization data from Mental Health Partners and Imagine! as part of the process	Phase 1 Identify data sources and analysis needed Phase 2 Depending on available data, complete analysis and explore findings

SELF ADVOCACY, COMMUNITY ENGAGEMENT AND SOCIAL CONNECTEDNESS				
Investment Area	**Policy, Literature, and/or Stakeholder Context**	**Benefits**	**General Cost Information/ Resources Needed**	**Phase** Phase 1: up to 6 months Phase 2: 6-18 months Phase 3: 18-36 months.
Recommendation Create a formal, recommended process and key considerations for Boulder County organizations to seek and promote consultation from leaders and self-advocates with IDD	Stakeholders and best practices emphasize that ongoing consultation from people with IDD and their families on service design and implementation is essential	Creating a formal process with recommended steps and guidance for engagement, supports more meaningful and sustained engagement over time	Medium Utilize existing guidance from local, state and national advocacy organizations regarding inclusion and meaningful engagement for people with IDD	See 'Ongoing Monitoring and Evaluation' recommendations for more information about formation of a formal Advisory Council; share learnings from this process with other local groups to foster engagement and inclusion
Recommendation Provide funding for self-advocacy training to promote self-advocacy at the individual level, grow leadership skills for people with IDD and foster their involvement in community groups, civic engagement opportunities and decision-making processes Consider funding local advocacy groups and/or statewide groups such as the Colorado Cross-Disability Coalition that have developed self-advocacy training models that could be tailored, replicated or expanded	Self-advocacy skills were emphasized by stakeholders and in literature as critical to promoting community engagement and social connectedness Self-advocacy training fosters skills to advocate for key issues such as personal safety, fair treatment in the workplace, adequate and appropriate services, etc.	Aims to build advocacy and leadership skills for people with IDD, as well as to foster their involvement in community groups, civic engagement opportunities and decision-making processes	Medium Utilize existing local advocacy groups and/or statewide groups with established trainings and infrastructure to minimize or eliminate training development costs	Phase 1 Train-up existing providers, individuals with IDD and families to provide self-advocacy trainings Phase 2-3 Move to maintenance plan

SELF ADVOCACY, COMMUNITY ENGAGEMENT AND SOCIAL CONNECTEDNESS				
Investment Area	**Policy, Literature, and/or Stakeholder Context**	**Benefits**	**General Cost Information/ Resources Needed**	**Phase** Phase 1: up to 6 months Phase 2: 6-18 months Phase 3: 18-36 months.
Recommendation Boulder County should consider developing a Request for Proposal for community organizations to engage in programs and opportunities related to Social Connectedness and integrated activities Related Opportunity Consider funding to promote opportunities for people with IDD and their families to engage with community in forums/environments that are often harder to access such as arts and cultural activities, etc.; for example, one Boulder County family created a program that trains and partners with local arts venues to make specific event dates open and accessible to both the general public and people with IDD and their families Related Opportunity Consider increased funding for social and recreational programming such as those specifically for people with IDD, including funding for transportation and/or with careful consideration of existing transportation accessibility Funding could be directed to current highly attended EXPAND recreation programs that provide opportunities for individuals with IDD to participate in sports or other activities with their peers in a comfortable space or those that provide "inclusion support" for staff to support individual participation in a standard activity open to the whole community Related Opportunity: Encourage and support local organizations such as peer support networks.	Suggested by HCPF staff and based on best practices from Denver County Stakeholders with IDD clearly expressed that it is critical to provide range of options for inclusion support as well as options for activities with peers with IDD only, as preferences for participation are highly individual	Supports the best practice of inclusion and social connectedness	Medium RFP process defined/developed Mill Levy funds allocated	Phase I Assess existing community organization programs and determine where IDD accessibility and programming could be integrated or modified Phase II Plan for awareness for existing community events and RFP for any gaps

COMMUNITY EDUCATION AND IDD AWARENESS				
Investment Area	**Policy, Literature, and/or Stakeholder Context**	**Benefits**	**General Cost Information/ Resources Needed**	**Phase** Phase 1: up to 6 months Phase 2: 6-18 months Phase 3: 18-36 months.
Recommendation Invest in targeted training and specific referral processes for key systems and community organizations including emergency response and crisis systems, local homeless shelters, mental health providers, law enforcement, etc.	Identified as key priority by stakeholders and indicated as best practice in literature review	Aims to increase community capacity to serve and refer people with IDD for services	Medium Utilize existing local advocacy groups and/or statewide groups with established trainings and infrastructure to minimize or eliminate training development costs	Phase 2 or 3 Consider phasing after the self-advocacy training so that self-advocates could participate and share learnings
Recommendation Consider a more general disability awareness training that can be tailored for local businesses and other community spaces	Reassess once other investments have been made	Increases capacity for local businesses to employ people with IDD and promote community inclusion in other community spaces	Medium Utilize existing local advocacy groups and/or statewide groups with established trainings and infrastructure to minimize or eliminate training development costs	Phase 2 or 3 Consider phasing after the self-advocacy training so that self-advocates could participate and share learnings

ONGOING MONITORING AND EVALUATION				
Investment Area	**Policy, Literature, and/or Stakeholder Context**	**Benefits**	**General Cost Information/ Resources Needed**	**Phase** Phase 1: up to 6 months Phase 2: 6-18 months Phase 3: 18-36 months.
Recommendation Develop a Community Advisory Council to leverage community engagement related to the needs and gaps for people with IDD, with individuals with IDD and their families as a central part of decision-making processes. This group should provide input and oversight in the following areas: • Ongoing review and assessment of community needs and disability-related data, as well as policy-related information that has implications at the county-level; Boulder County could request information and feedback from the Council specific to the needs of Boulder residents with IDD during its continuous assessment of needs • Project funding decisions and rationale for funding, key groups and expected numbers served, projected plans for spending over time • Communications to the public about funding decisions and outcomes of projects • Advisory Council members would be encouraged to provide data, anecdotal information, and/or represent personal and professional experience. Rocky Mountain Human Services (RMNS), Denver's CCB, has created a similar structure for the oversight of their mill levy dollars.	Policy and Stakeholder priority; aligns with best practices re: inclusiveness, stakeholder involvement and recognition of lived experience as critical to decision-making.	Utilizes stakeholder expertise to inform the allocation of Mill Levy dollars and generates stakeholder buy-in regarding funding decisions Increases overall accountability for where and how funds are allocated	Low Development of process for recruiting and selecting committee members; staff time for coordination of administrative and communication needs	Phase 1: TBD/Check in with Boulder County Commissioners office regarding timeline and process for an advisory council

ONGOING MONITORING AND EVALUATION				
Investment Area	**Policy, Literature, and/or Stakeholder Context**	**Benefits**	**General Cost Information/ Resources Needed**	**Phase** Phase 1: up to 6 months Phase 2: 6-18 months Phase 3: 18-36 months.
<u>Recommendation</u> Create definitions for eligible and allowable expenses under the Mill Levy • The ballot language identifies monies "allocated for facilities and services for people with DD" • Amend the contract exhibits to specify what constitutes an allowable cost to ensure appropriate funding of the Mill Levy in the future • Amend contract reporting to focus on systemwide metrics • Consider limiting and verifying that administrative expenses do not exceed 15% and require grantees classify executive salaries as administrative expenses • Clarify that fundraising expenses are not allowable expenses. • Require any communications or outreach expenses to be for the sole purpose of IDD programs	<u>High/Immediate</u> Best practice and recommendations made to Denver County in their audit	Creating these definitions will protect County and organizations receiving funding Increases accountability and transparency to the public	<u>Low</u> Staff time to develop definitions, amend contracts and creating limitations for funding uses Staff time to develop monitoring tool and reporting indicators. Staff research data is collected and reported to Medicaid	<u>Phase 1</u> Determine process for needed definition approvals before determining phases

ONGOING MONITORING AND EVALUATION				
Investment Area	**Policy, Literature, and/or Stakeholder Context**	**Benefits**	**General Cost Information/ Resources Needed**	**Phase** Phase 1: up to 6 months Phase 2: 6-18 months Phase 3: 18-36 months.
<u>Recommendation</u> Increase evaluation reporting requirements for all funded programs in the areas of client satisfaction and perceptions regarding the responsiveness of services; program outcomes such as participant improvements in health, mental health, social/behavioral areas of life, adaptive functioning, etc. Reorient contracts, metrics and outcomes from agency-level to systems-wide and facilitate quarterly review by County commissioners <u>Recommendation</u> Require more formalized reporting for all recipients of funds • Develop a monitoring tool that would ensure adherence to explicit contract requirements and provide a transparent process for oversight and understanding how funds are spent • The reporting should include Non-Medicaid reimbursed activities, percent of use by participants and Medicaid-reimbursed activities, percent of use by Medicaid participants	Stakeholder input and best practices in evaluation	Increases accountability and transparency; prepares for potential increases in state or Federal reporting requirements Enhances program evaluation and ongoing monitoring of intended outcomes	<u>Low</u> Staff time and advisory committee input on developing reporting indicators and requirements When possible, access existing participant data available through the larger state and federal reporting systems that providers currently utilize	Determine process for needed definition approvals before determining phases

ONGOING MONITORING AND EVALUATION				
Investment Area	**Policy, Literature, and/or Stakeholder Context**	**Benefits**	**General Cost Information/ Resources Needed**	**Phase** Phase 1: up to 6 months Phase 2: 6-18 months Phase 3: 18-36 months.
Monitor available data and where gaps and opportunities may exist, invest in ongoing data collection about disability and service needs at the community level Additionally, ensure ongoing monitoring of state and national policy initiatives and changes, with analysis of implications at the county-level, collaborating with core policy advisory or implementation groups as appropriate. *Reference specific policy initiatives to monitor in Medicaid Trends Part I.	Stakeholder input and best practices in evaluation	Ensures access to larger policy context to inform decision-making	Low Staff time	Determine process for needed definition approvals before determining phases

Appendix A: Detailed Methods

Each of the core needs assessment methods are described in detail below, including any data limitations and considerations.

Community Survey

OMNI worked closely with Boulder County and multiple stakeholder groups to develop a community needs assessment survey. OMNI conducted a review of the literature as well as evaluation measures and items commonly used in community needs assessments, to assess IDD service needs and responsiveness of existing services. Questions were identified to assess the following key areas:

- Availability of information about IDD services in key areas
- Perceptions about the assessment and eligibility determination process
- Access to services in a range of areas
- Responsiveness of services including issues such as person-centeredness and staff turnover

Survey content and items were tailored for 4 key groups including: 1) individuals with IDD; 2) family members of individuals with IDD; 3) community members; and 4) providers of services. OMNI then translated the survey into Spanish and built online versions in both English and Spanish. Several community members as well as OMNI's internal survey team piloted the survey before community dissemination.

Sampling and Analysis

A convenience sampling method was used and outreach was conducted through a broad range of channels including BCDHHS social media and public announcements, Boulder County provider networks, and parent and organizational networks developed through the initial phase of the needs assessment. Surveys were open and available online for 6 weeks.

A total of 313 surveys were analyzed after data quality assessment and cleaning. Records were excluded when there was insufficient information for analysis, duplicated information, or other data inconsistencies that could not be reconciled. Mean scores and frequency distributions were calculated for all survey items and each of the four respondent groups. Full survey findings are presented by stakeholder group and coded by color in Appendix B.

Qualitative Stakeholder Engagement Efforts

Qualitative efforts served to explore in depth perspectives about needs and priorities for Boulder County community members with IDD and deepen understanding of survey findings. The assessment included a broad range of forums and opportunities for community members to provide input. Community advisors such as state and local advocacy groups and family members were engaged early in the process to discuss outreach strategies, communications and engagement. Efforts were made to ensure accessibility in communications, locations and formats

for participation. Participants were also asked to request accommodations as needed. The following qualitative information gathering efforts from stakeholders took place:

- **Evening community forums** for community members with IDD and their families, in which OMNI facilitated small and large group discussion as well as prioritization exercises. Participants were also provided dinner at each forum. Two forums were hosted in English with an additional forum offered in Spanish (this third forum was cancelled due to low participation)
- **Focus group at a day program** for people with IDD and **individual interviews with community members with IDD at their work site.**
- **4-hour drop-in interview event** at which community members with IDD could drop in at their convenience to complete an interview and engage with other community members. Refreshments and $5.00 gift cards were also provided to participants.
- **Individual phone and/or in-person interviews** with: 1) people with IDD; 2) family members; and 3) systems professionals and service providers

Sampling and Analysis

Outreach for all events was conducted through a broad range of channels including BCDHHS social media and public announcements, Boulder County provider networks and parent and organizational networks developed through the initial phase of the needs assessment.

Ultimately, the following participants took part in qualitative information gathering efforts.

- 25 individuals with IDD and/or autism spectrum disorders participated in 1:1 interviews or small group conversations
- 6 family members of people with IDD participated in interviews
- 45 community members (including people with IDD, family members, systems professionals) participated in evening community forums
- 41 systems professionals from 27 different organizations participated in phone or in-person interviews, either individually or in small groups

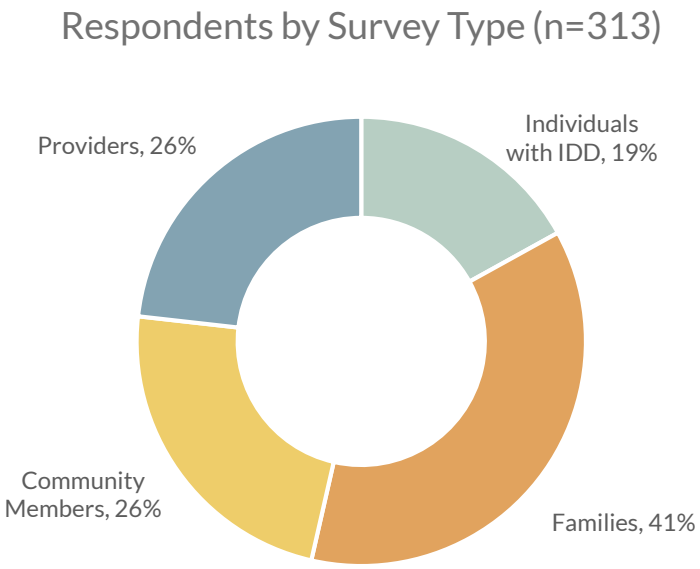
Appendix C provides a snapshot of participants from four community events at which brief demographic surveys could feasibly be collected (two evening community forums, the focus group with people with IDD and the drop-in interview event). These data provide some basic information regarding stakeholders who participated in key events but exclude service professionals and other stakeholders who participated by phone.

OMNI conducted a qualitative, thematic analysis of transcribed recordings and interview notes. The data were analyzed using NVivo, a qualitative analysis software, and analysis was guided by the development of key themes and a standard coding structure. Analyses placed particular emphasis on issues raised by individual groups more than others, across multiple groups, and themes raised with particular intensity. Unique ideas or anecdotes are also included as relevant to specific larger themes. Findings commonly refer to participants as "stakeholders" if the issues were raised by all groups and specify when issues were raised only by some groups.

Limitations

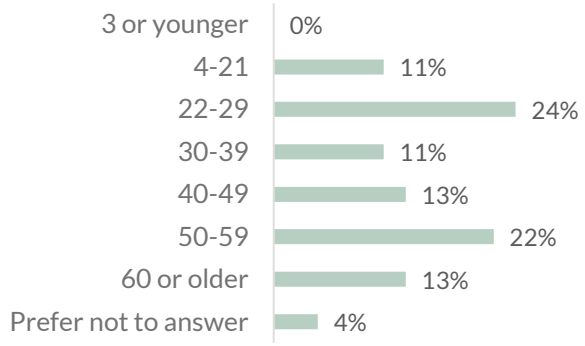
For all stakeholder engagement efforts, respondents self-selected to participate (i.e., volunteered). It is important to consider that participants who chose to take the survey or engage in interviews of forums may have had specific interests in responding and/or may differ from other community members who declined to participate. Perspectives included in the assessment therefore, may not be representative of the Boulder County population as a whole.

Appendix B: Community Survey Data

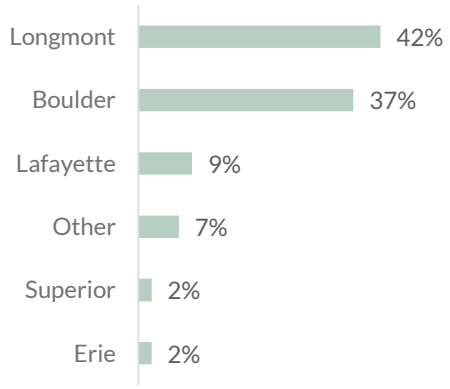


Survey Respondent Demographics: Individuals with IDD

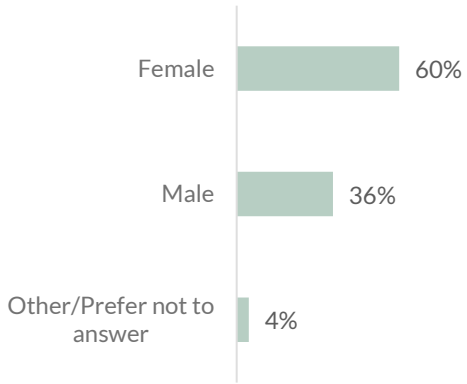
Individuals w/IDD:
Age (n=45)



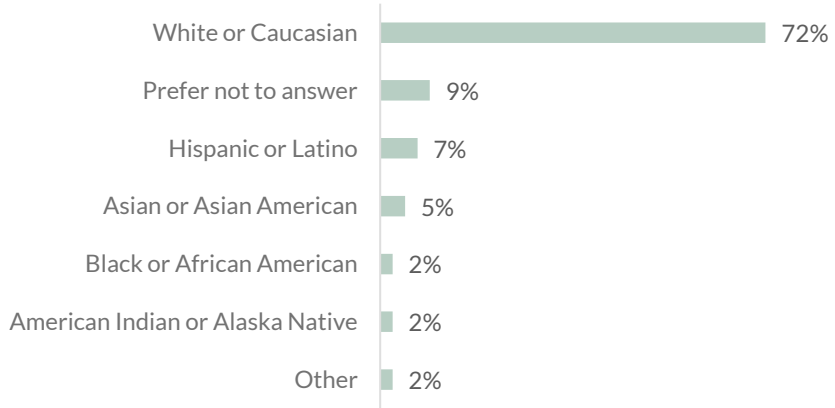
Individuals w/IDD:
Location (n=43)



Individuals w/IDD:
Gender Identity (n=45)

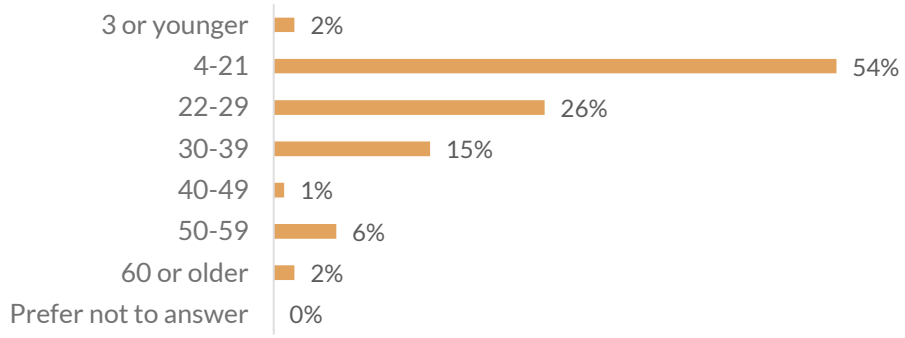


Individuals w/IDD:
Race/Ethnicity (n=43)

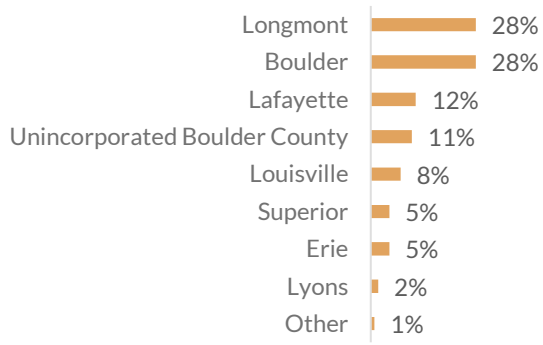


Survey Respondent Demographics: Family Members

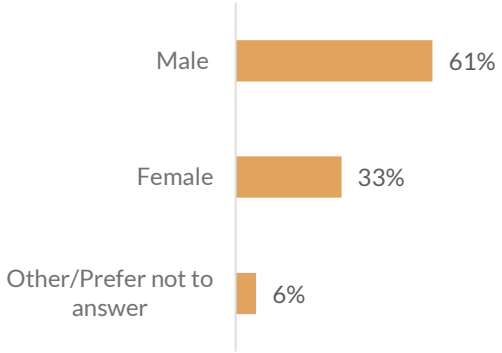
Family Members:
Age (n=106)



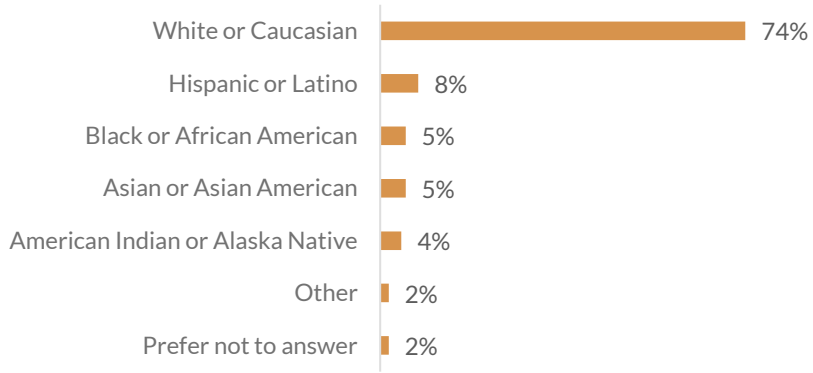
Family Members:
Location (n=106)



Family: Gender Identity (n=110)

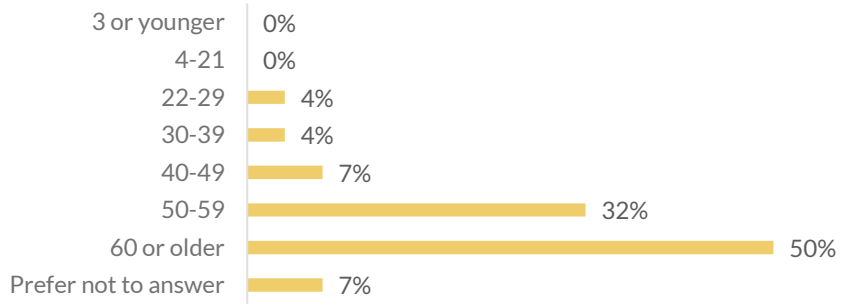


Family:
Race/Ethnicity (n=116)

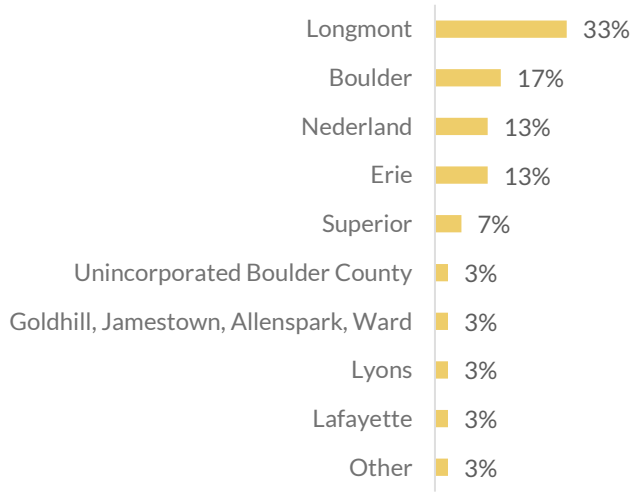


Survey Respondent Demographics: Community Members

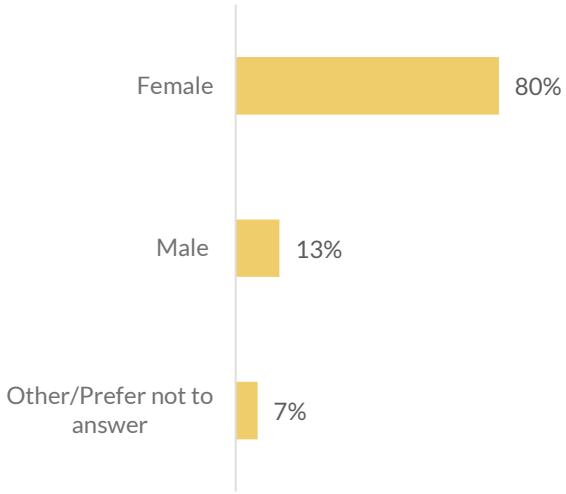
Community Members:
Age (n=29)



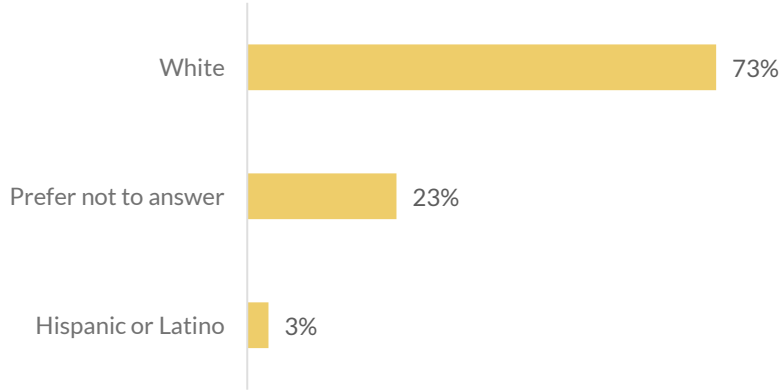
Community Members:
Location (n=30)



Community Member:
Gender Identity (n=30)

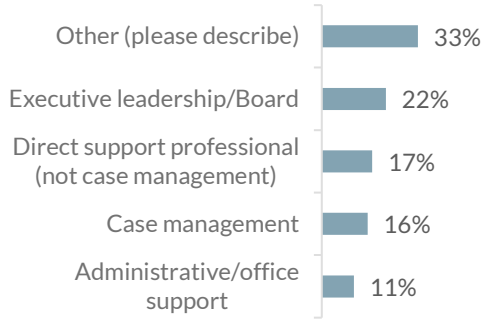


Community Member:
Race/Ethnicity (n=30)

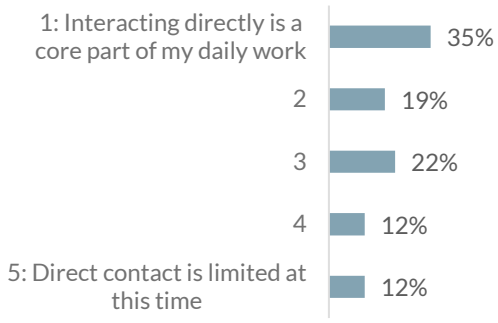


Survey Respondent Demographics: Providers

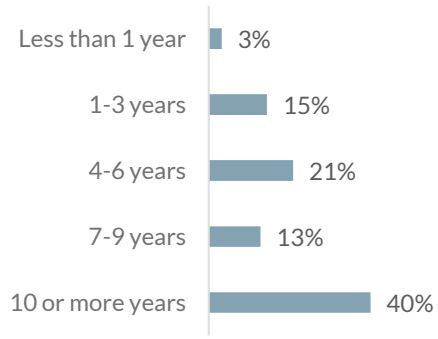
Provider:
Job Position (n=71)



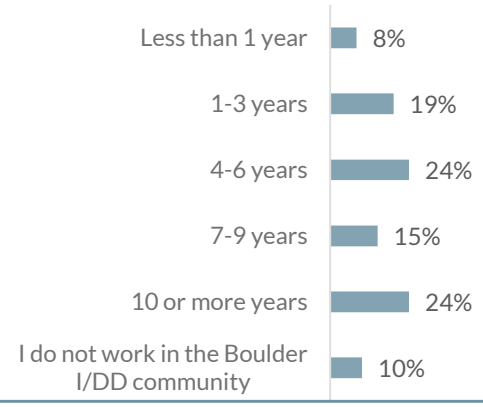
Providers:
Level of Direct Contact (n=58)



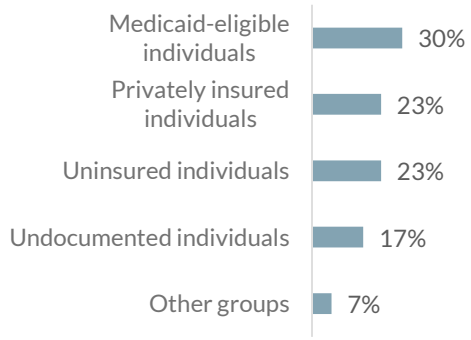
Providers:
Number of years working with the I/DD Community (n=62)



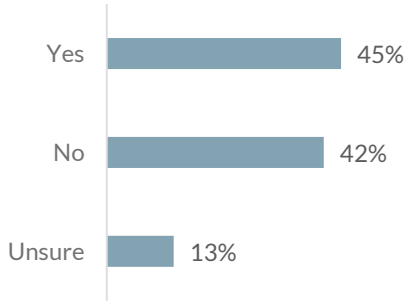
Providers:
Number of years working in Boulder I/DD Community (n=62)



Providers:
Groups Served by Organization (n=169)



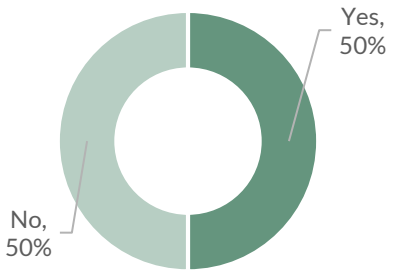
Providers:
Does your organization/agency currently have a wait-list for any of its services? (n=62)



Information and Access to Services*

Individuals w/IDD	Item N	No	Kind of	Yes
Do service providers have the information you need?	46	32%	35%	32%
Is it easy to get the services you need?	45	33%	29%	24%
Do you know what services you can get?	46	30%	35%	26%

Individuals w/IDD:
Do you receive all the services you need right now? (n=52)



*Totals may not equal 100% due to rounding

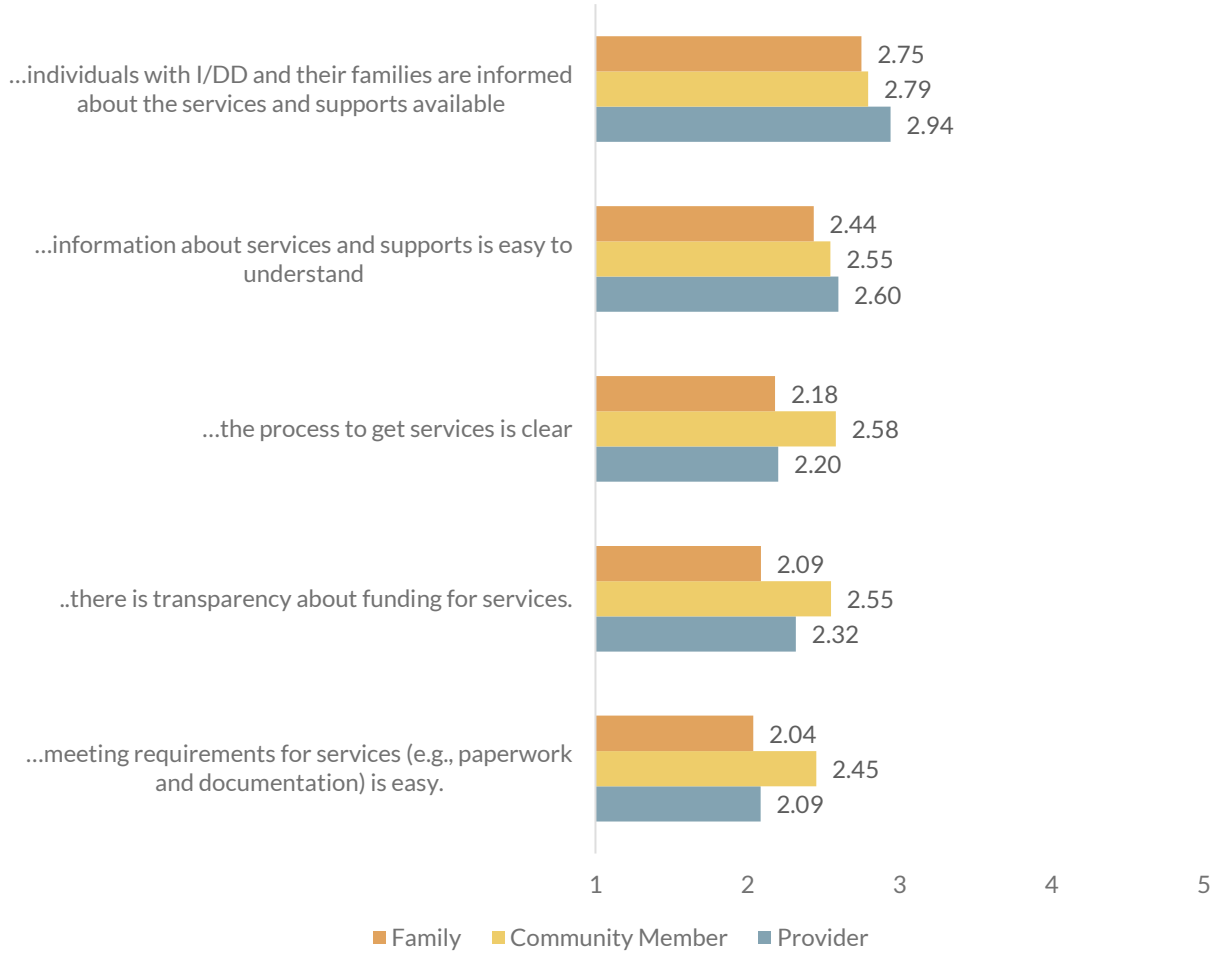
Family Members*	Item N	Mean Score	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not sure & Does not Apply
Our service providers have the information we need.	107	2.94	7%	25%	27%	27%	4%	10%
Our family member has the range of services needed right now.	116	2.84	15%	30%	16%	30%	7%	2%
Overall, my family member receives needed services in a timely manner.	115	2.93	18%	21%	16%	37%	6%	4%

Community Members*	Item N	Mean Score	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not sure & Does not Apply
In Boulder County, individuals with IDD have the range of services they need.	43	2.82	9%	26%	19%	16%	7%	23%
In Boulder County, individuals with IDD receive services in a timely manner.	44	2.53	14%	27%	18%	7%	7%	27%

Providers*	Item N	Mean Score	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not sure & Does not Apply
In Boulder County, individuals with IDD have the range of services they need.	76	2.49	12%	38%	26%	13%	1%	9%
In Boulder County, individuals with IDD receive services in a timely manner.	76	2.34	20%	29%	22%	13%	--	16%

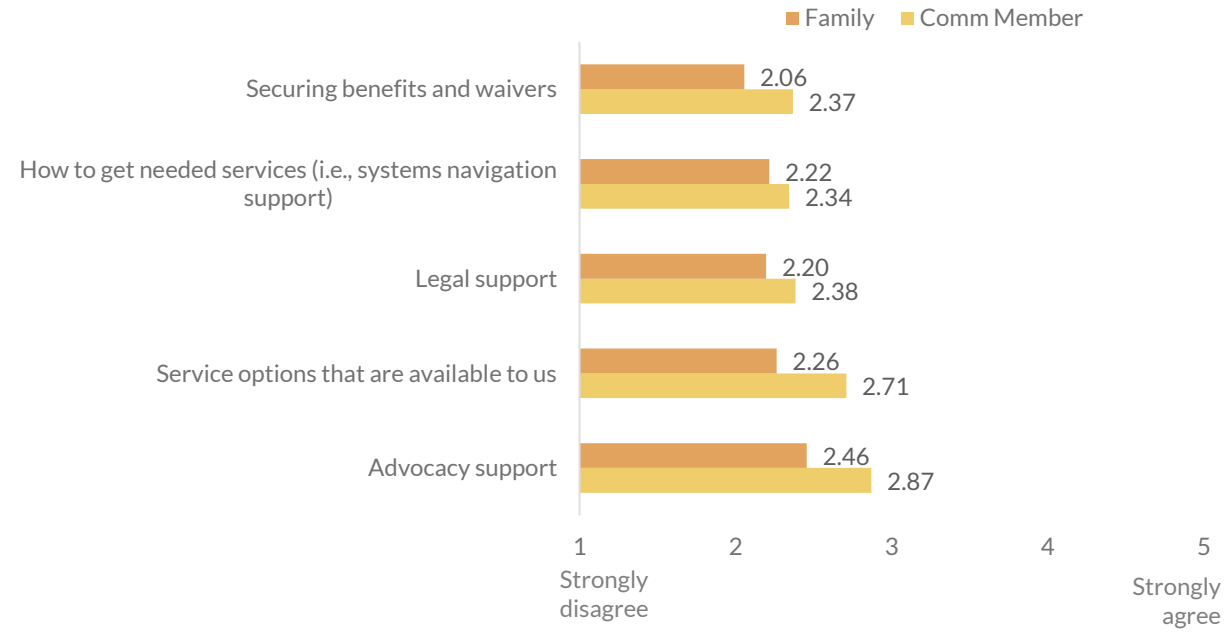
*Totals may not equal 100% due to rounding

Family Members, Community Members & Providers:
In Boulder County....



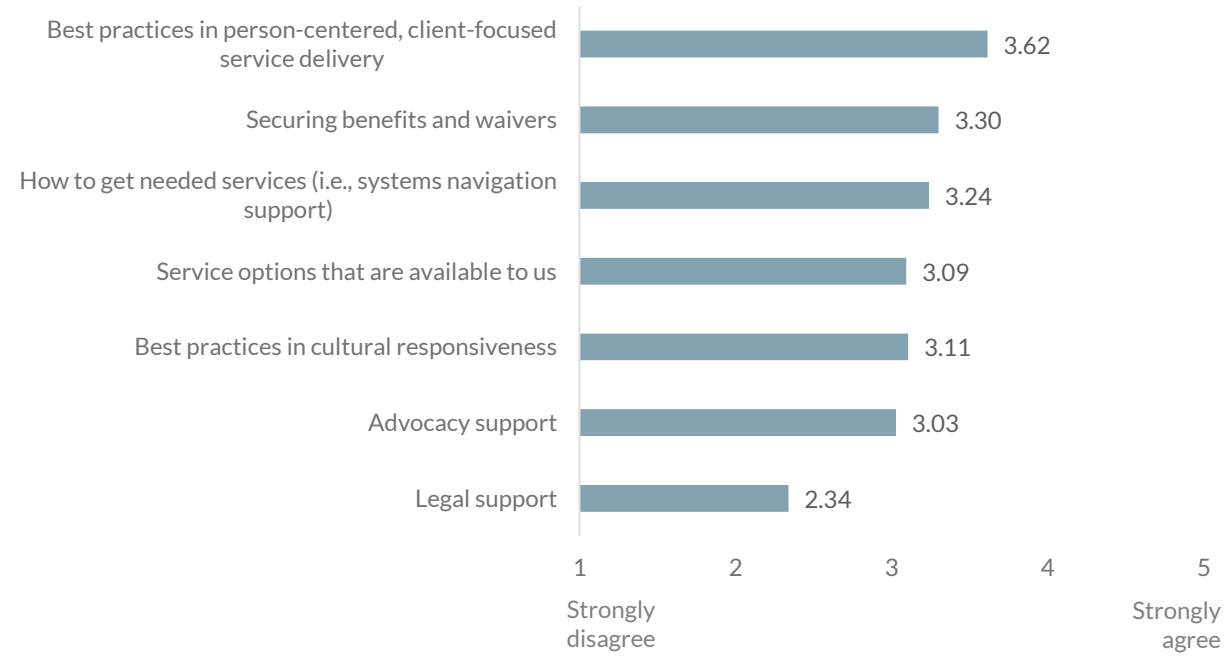
Community and Family Members:

Individuals with IDD and their families have enough clear information in the following areas:



Providers:

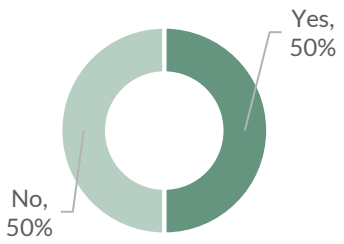
My organization would benefit from resources/additional training in the following areas:



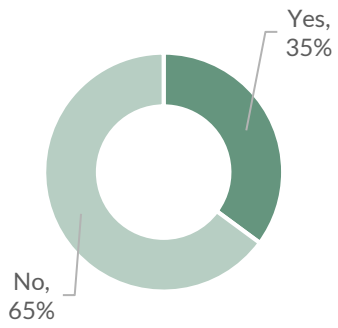
Service Needs and Satisfaction

Individuals w/IDD: **Services and Satisfaction Survey Items***	Item N	No	Kind of	Yes	Not Sure/ Does not Apply
Are you happy with your social life right now?	46	28%	35%	35%	2%
Can you get to the places you want to go easily?	46	24%	35%	37%	2%
Are you happy with your services right now?	44	22%	27%	44%	4%
Are you happy with your health care right now?	45	20%	29%	44%	7%
**For respondents reporting a current case manager:* Are you happy with your case manager right now?	34	15%	29%	44%	11%

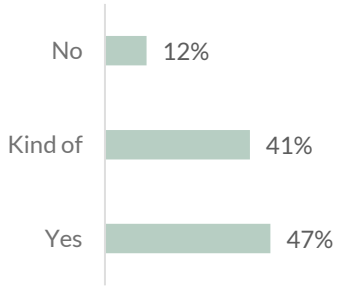
Individuals w/IDD:
Do you receive all the services you need right now? (n=52)



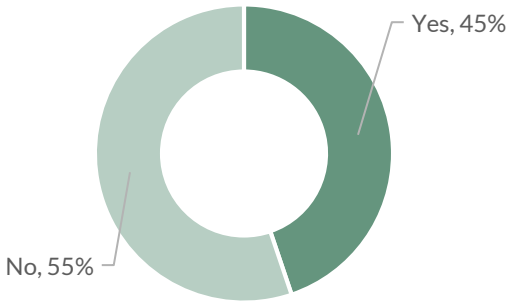
Individuals w/IDD:
Do you have a job right now? (n=57)



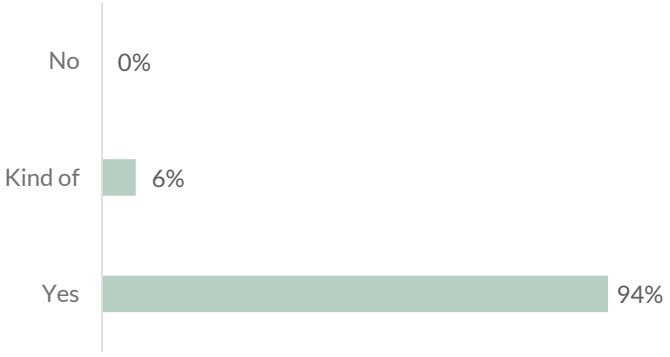
Individuals w/IDD:
Are you happy with your job right now? (n=17)



Individuals w/IDD:
Do you recieve educational services right now? (n=56)



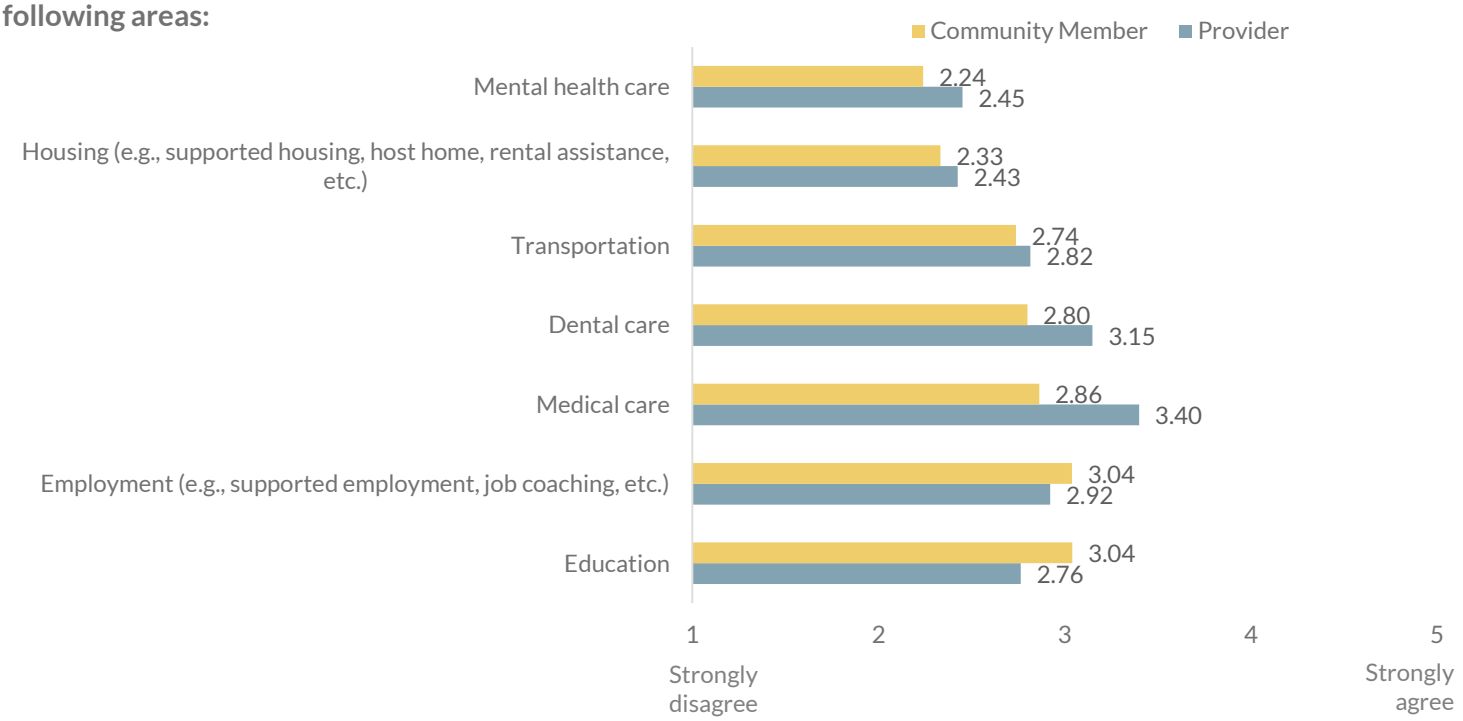
Individuals w/IDD:
Are you happy with your educational services right now? (n=17)



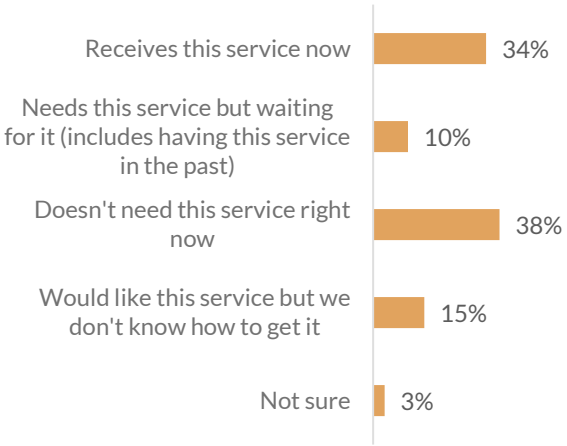
*Totals may not equal 100% due to rounding

Service Needs: Core Areas

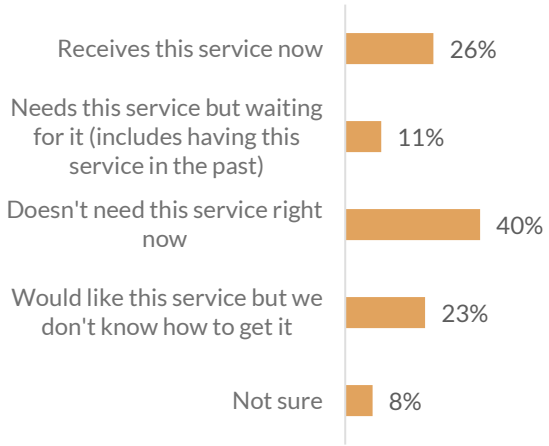
Community Members & Providers:
Service needs for individuals w/IDD in Boulder county are being adequately met in the following areas:



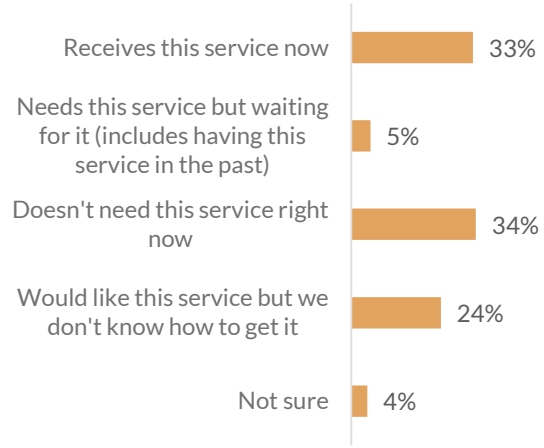
Family Members:
Mental health care (n=125)



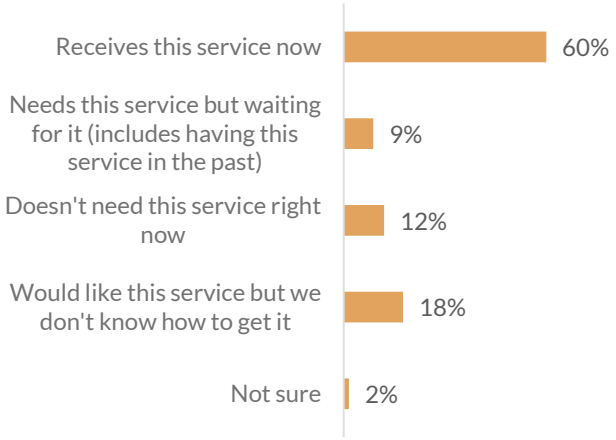
Family Members:
Housing (n=124)



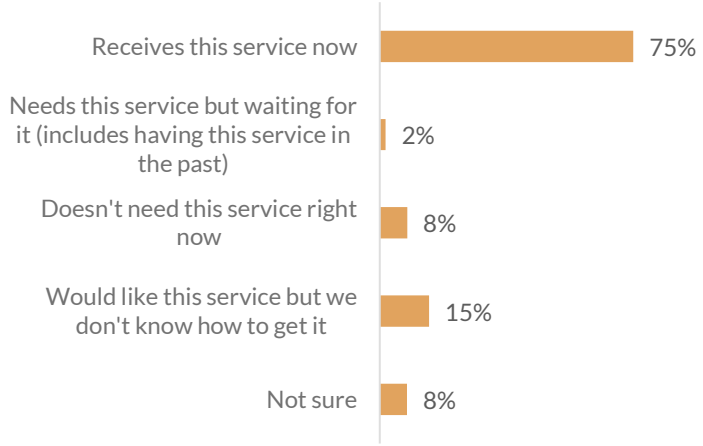
Family Members:
Transportation (n=124)



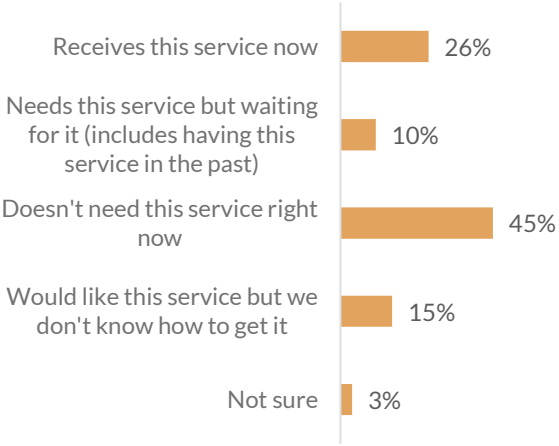
Family Members:
Dental Care (n=125)



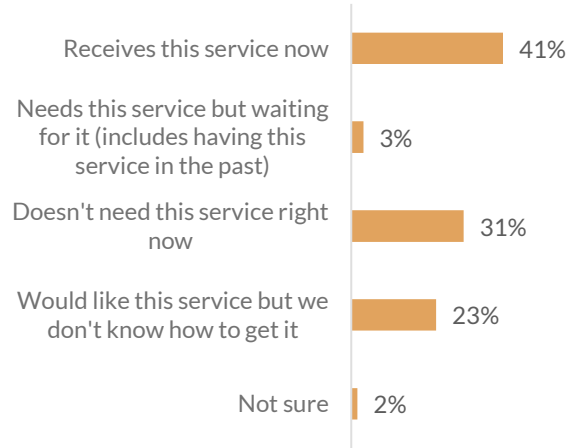
Family Members:
Medical care (n=124)



Family Members:
Employment (n=125)

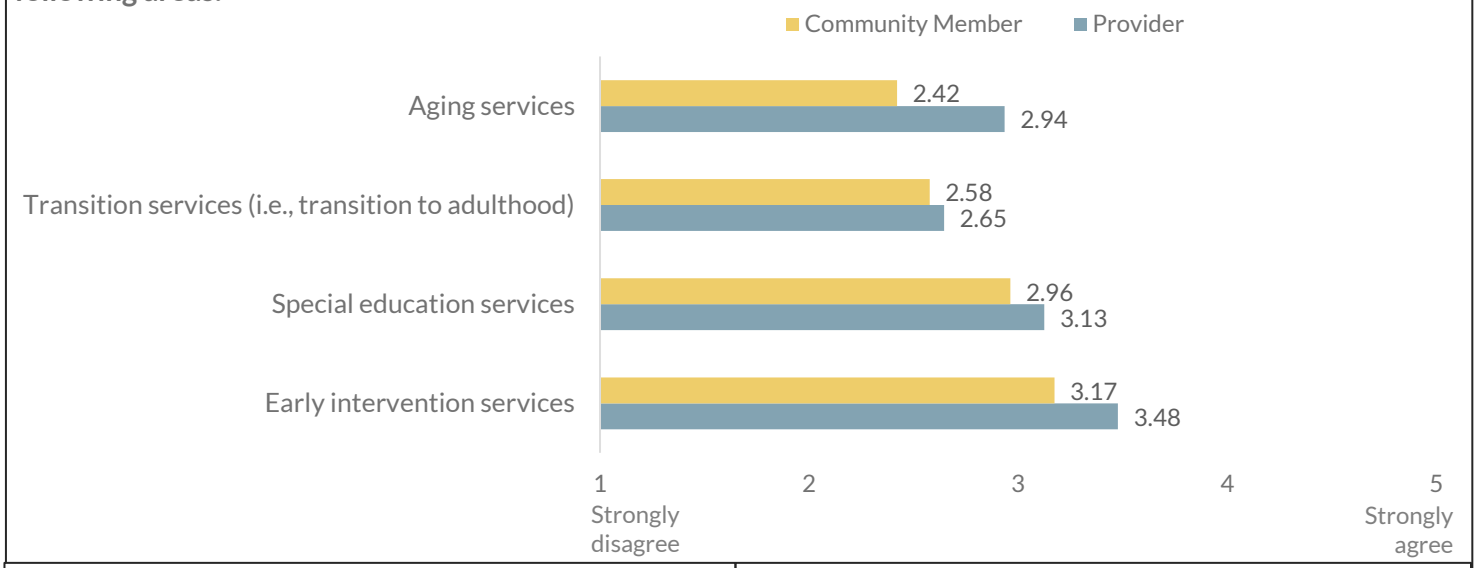


Family Members:
Education (n=121)

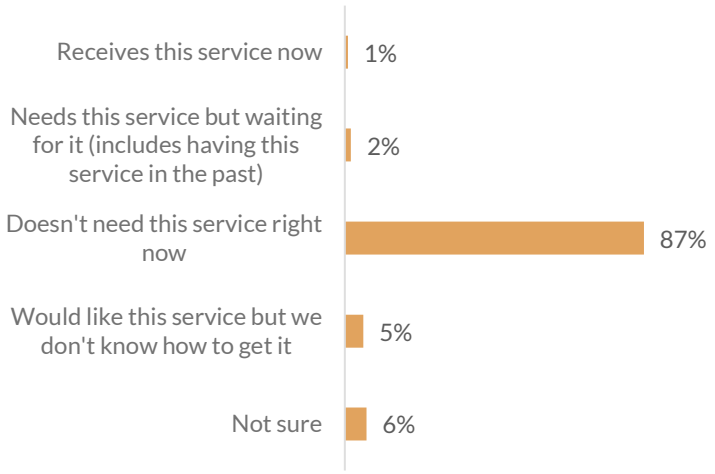


Service Needs: Age Specific Services

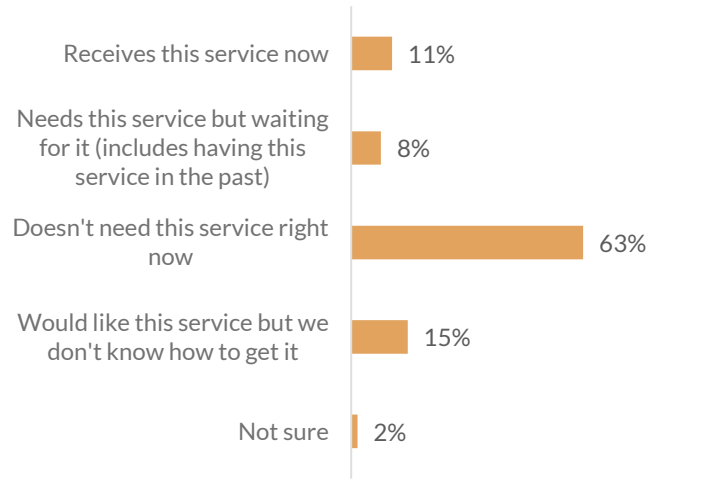
Community Members & Providers:
Service needs for individuals w/IDD in Boulder county are being adequately met in the following areas:



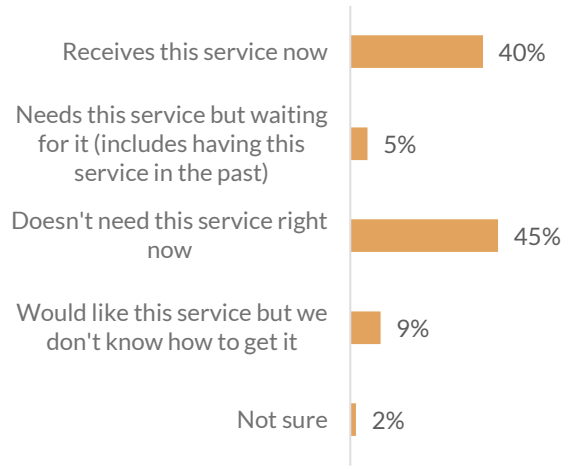
Family Members:
Aging services (n=119)



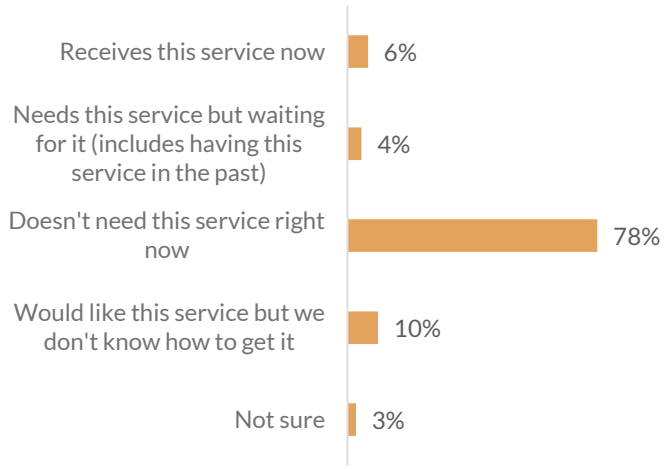
Family Members:
Transition services (n=123)



Family Members:
Special education services (n=121)

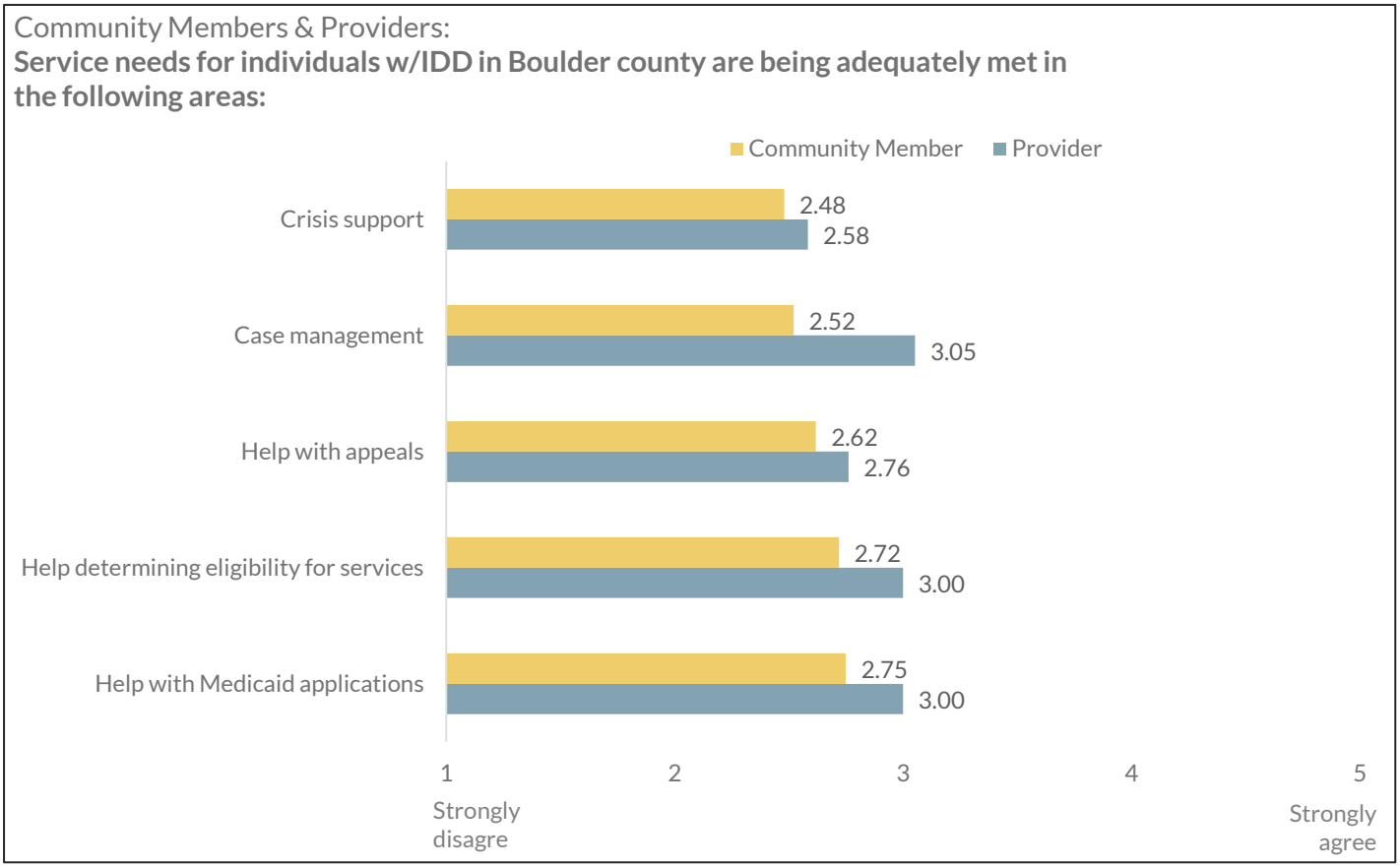


Family Members:
Early intervention services (n=116)

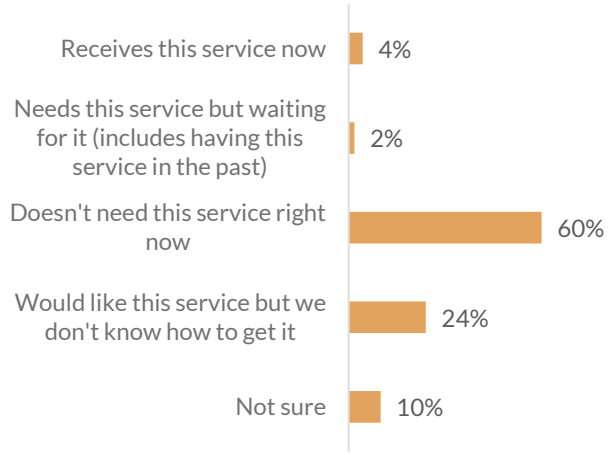


Service Needs: Systems Navigation

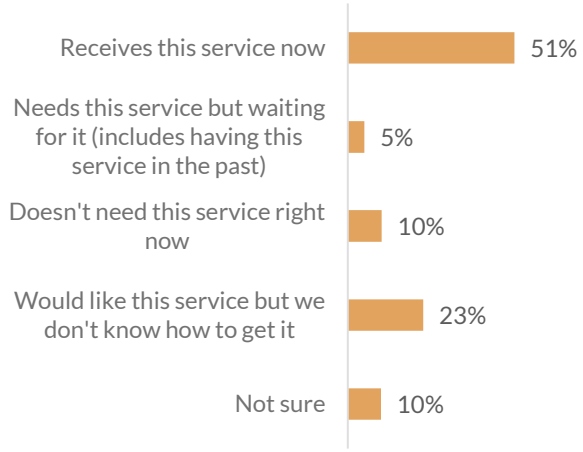
Community Members & Providers:
Service needs for individuals w/IDD in Boulder county are being adequately met in the following areas:



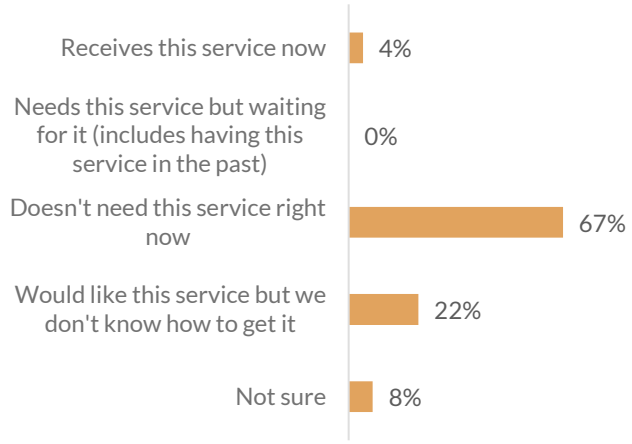
Family Members:
Crisis support (n=121)



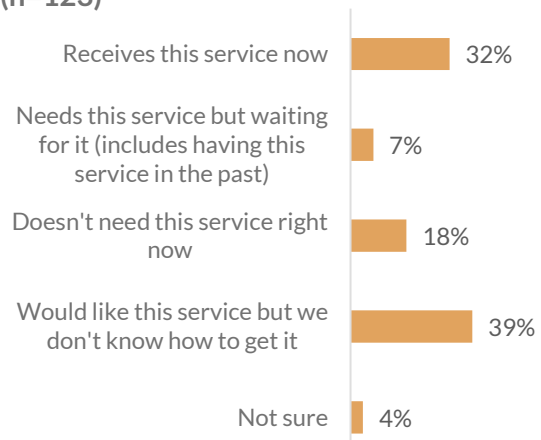
Family Members:
Case management (n=125)



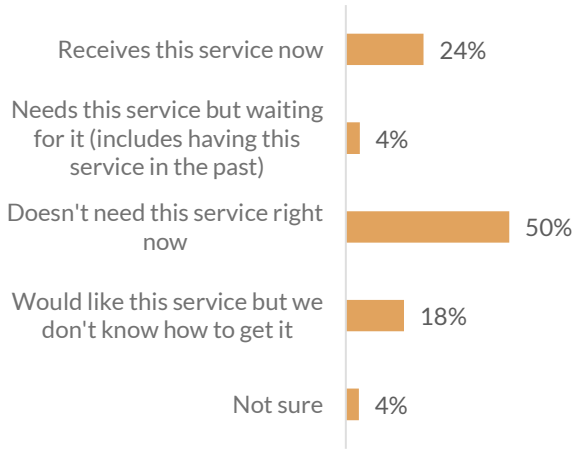
Family Members:
Help with appeals (n=120)



Family Members:
Help determining eligibility for services (n=123)

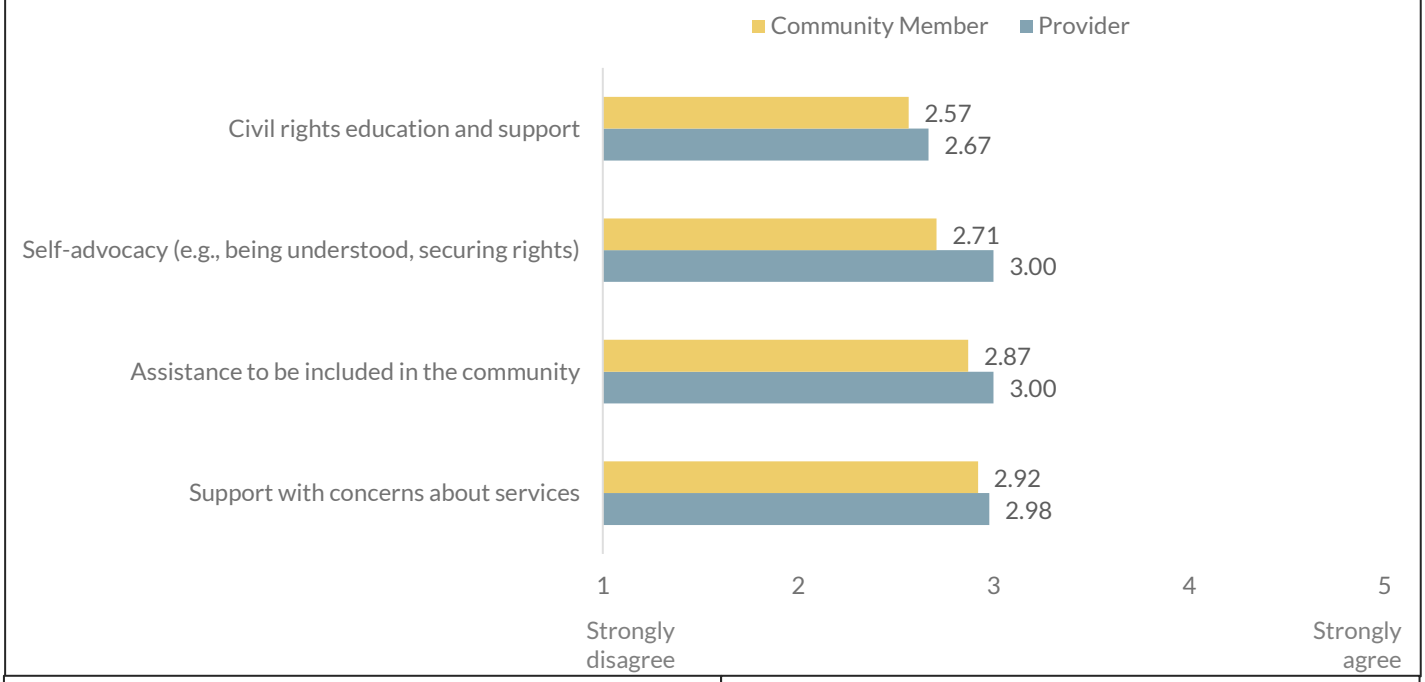


Family Members:
Help with Medicaid applications (n=123)

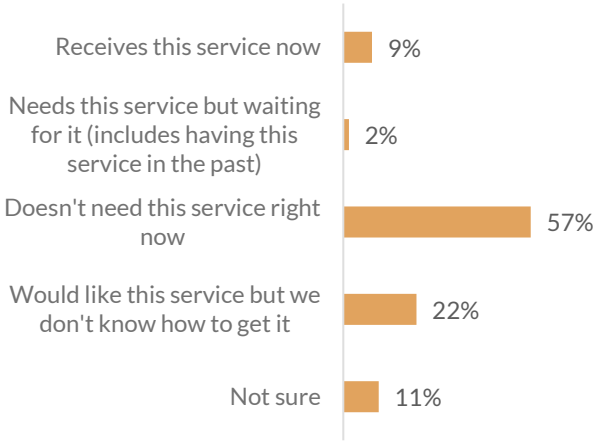


Service Needs: Advocacy

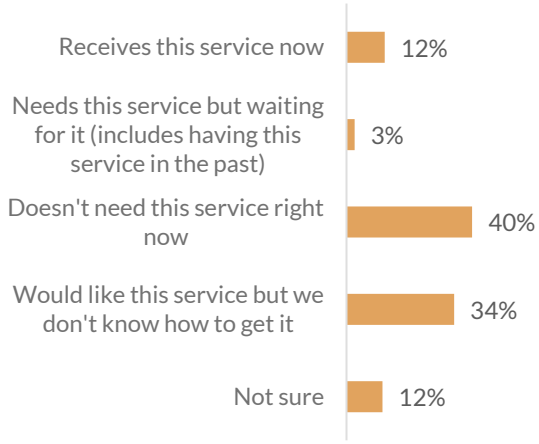
Community Members & Provider:
Service needs for individuals w/IDD in Boulder county are being adequately met in the following areas:



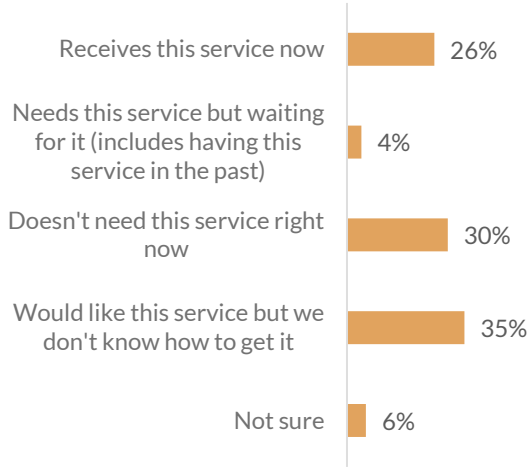
Family Members:
Civil rights education and support (n=122)



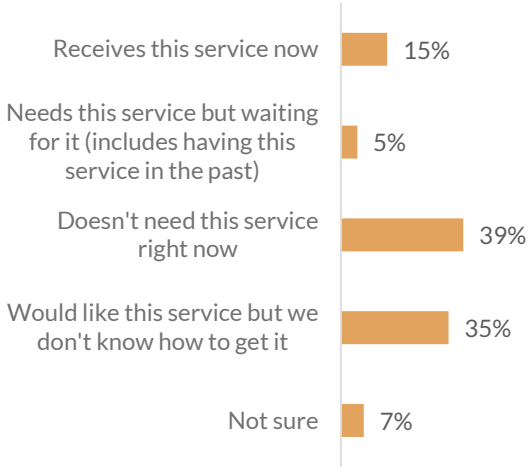
Family Members:
Self-advocacy (n=122)



Family Members:
Assistance to be included in the community (n=124)

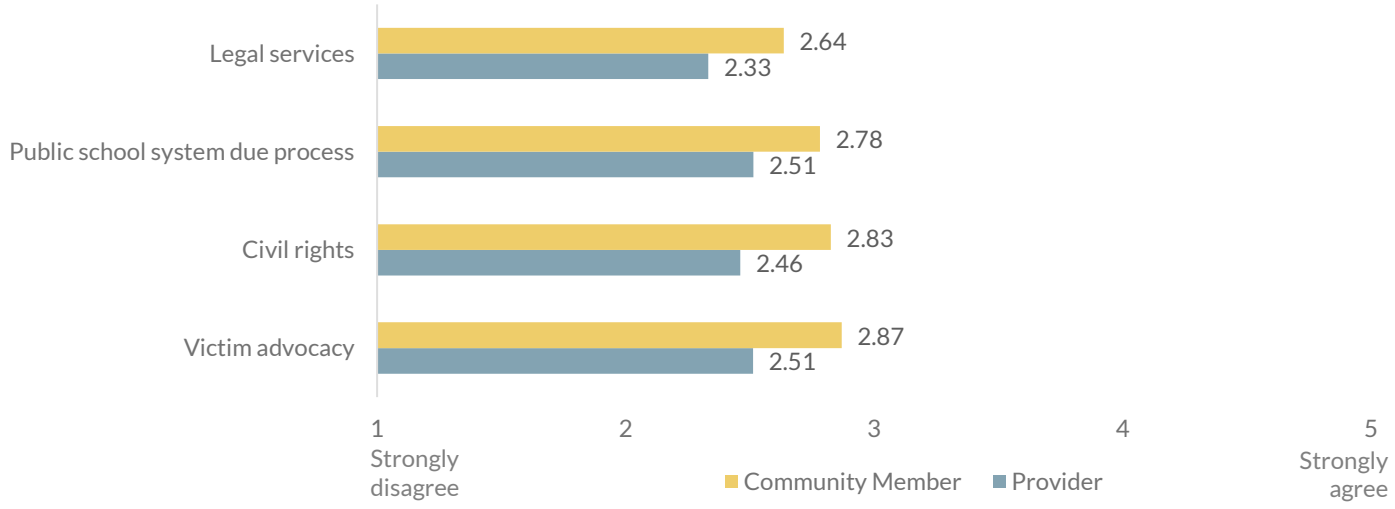


Family Members:
Support with concerns about services (n=121)

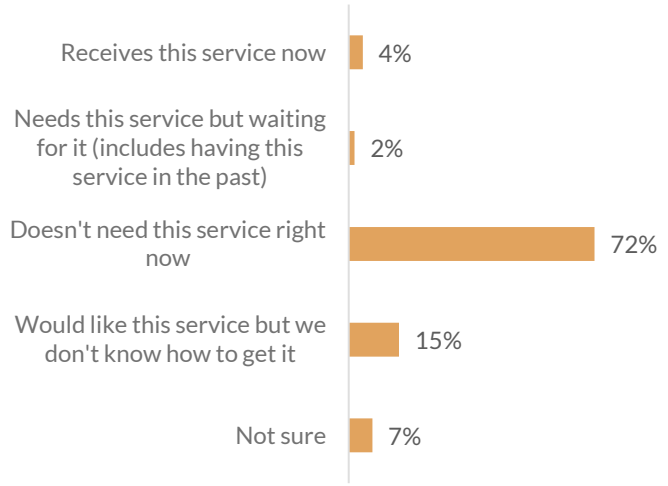


Service Needs: Justice-Legal System

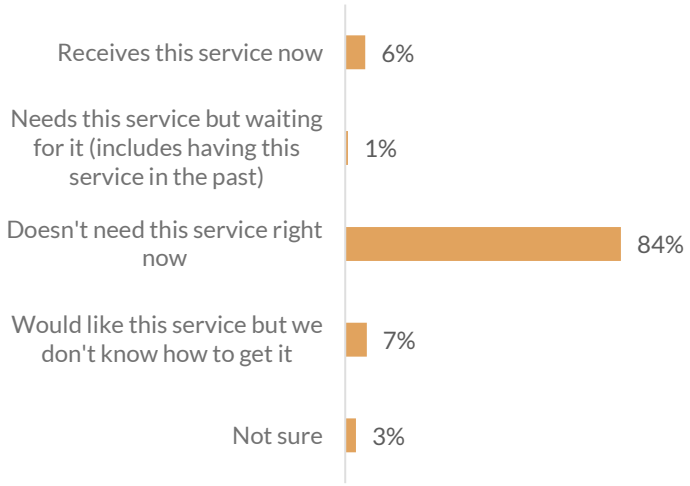
Community Members & Providers:
Service needs for individuals w/IDD in Boulder county are being adequately met in the following areas:



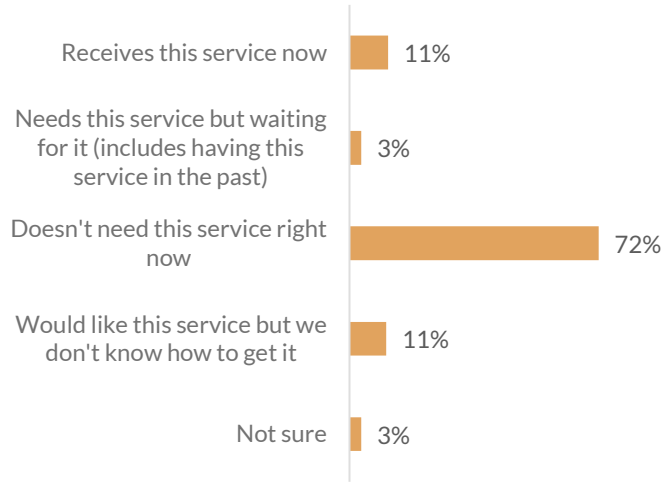
Family Members:
Legal services (n=123)



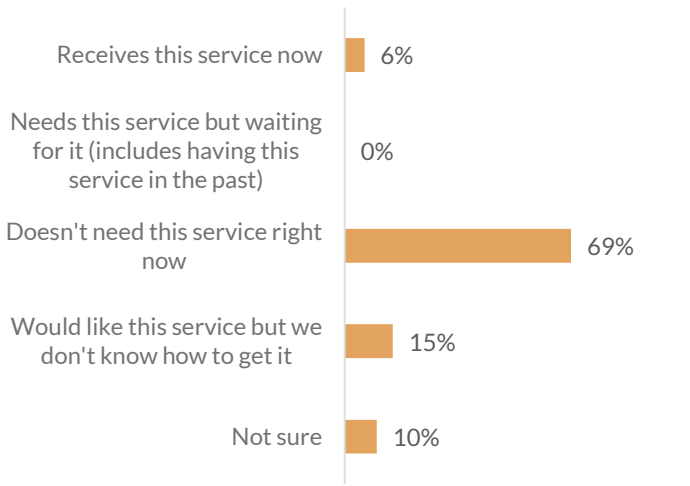
Family Members:
Victim advocacy (n=122)



Family Members:
Public school system due process (n=122)

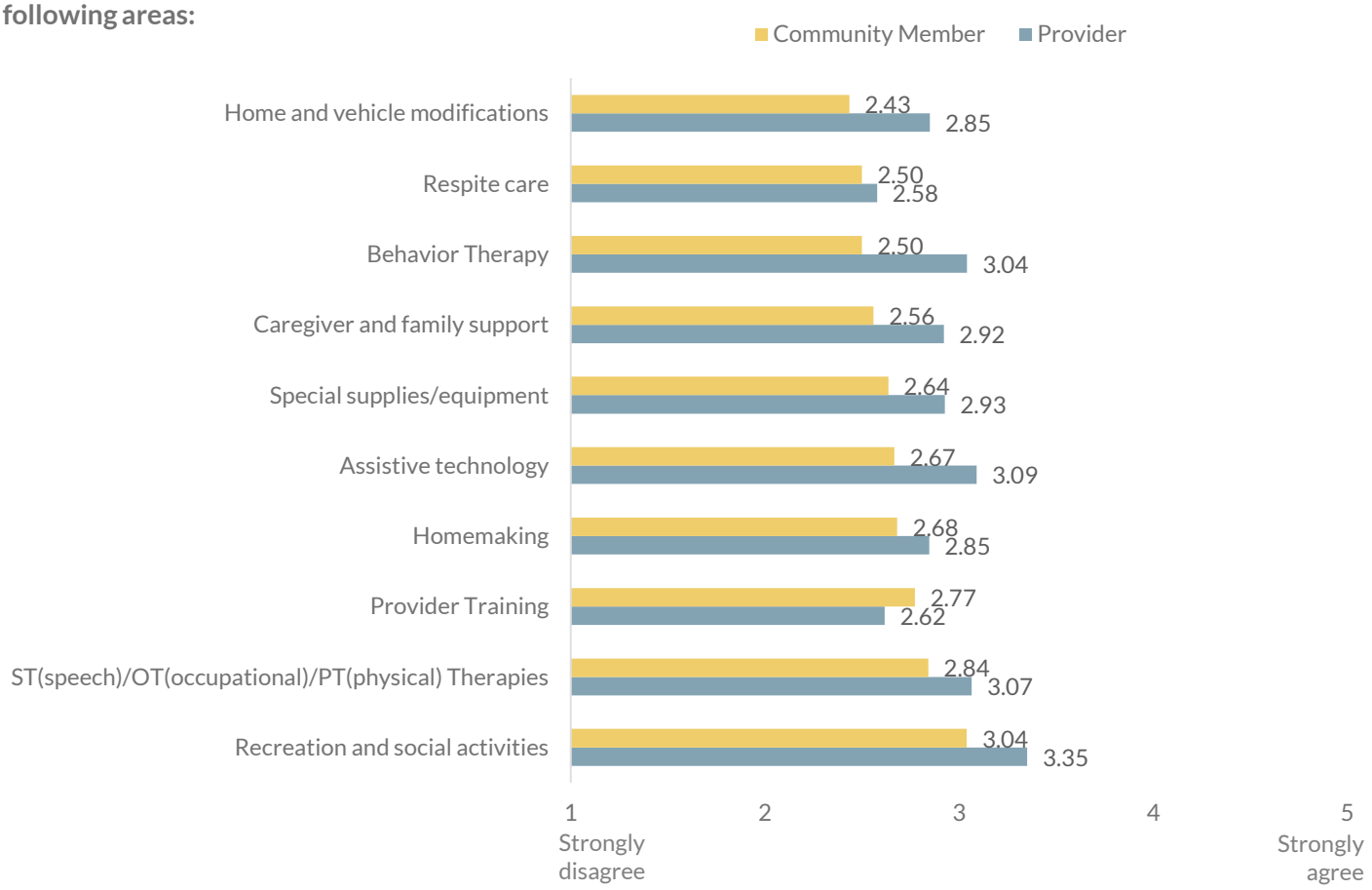


Family Members:
Civil rights (n=123)

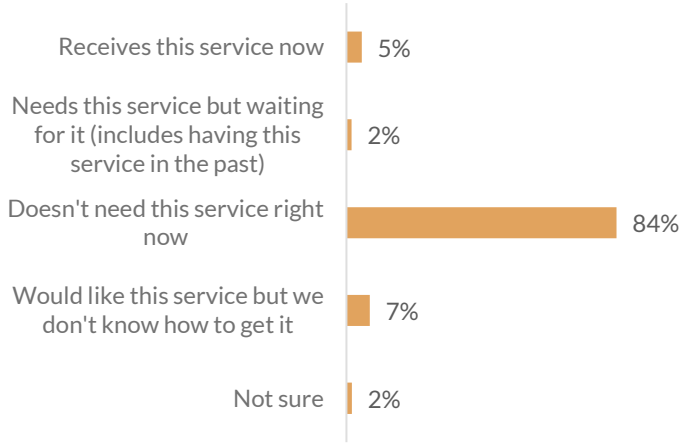


Service Needs: Other Services

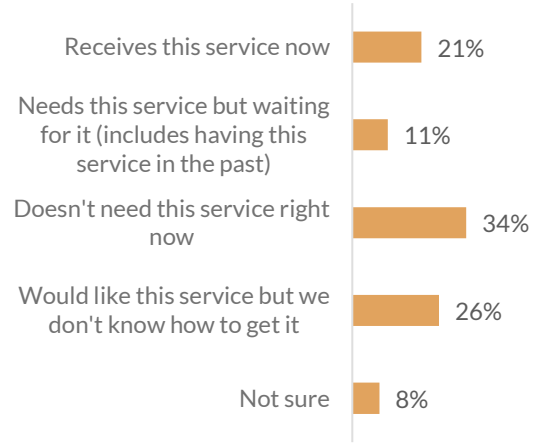
Community Members & Providers:
Service needs for individuals w/IDD in Boulder county are being adequately met in the following areas:



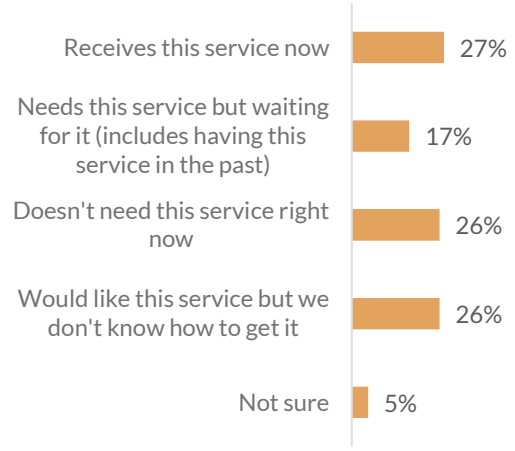
Family Members:
Home and vehicle modifications (n=124)



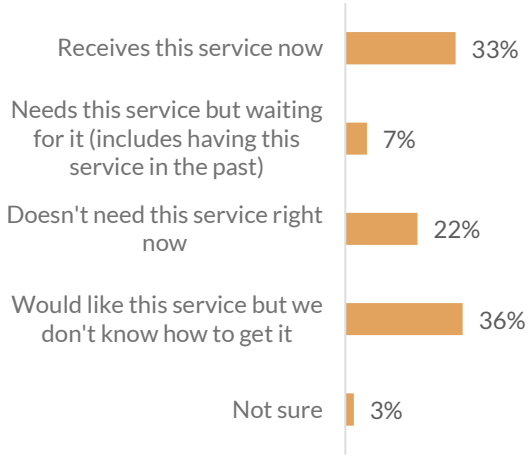
Family Members:
Respite care (n=122)



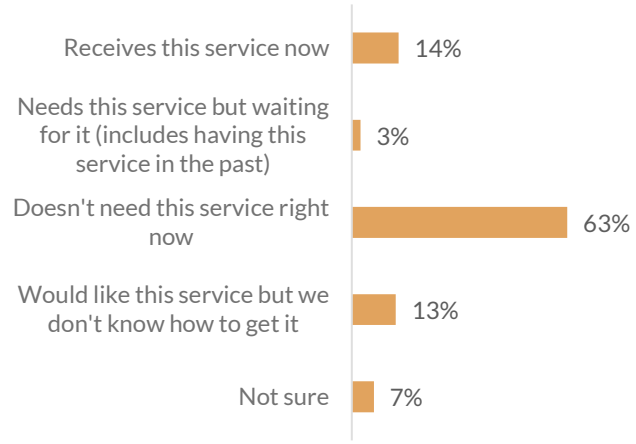
Family Members:
Behavior therapy (n=124)



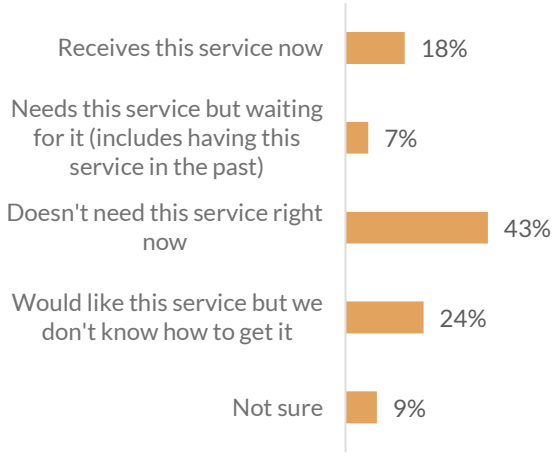
Family Members:
Caregiver and family support (n=124)



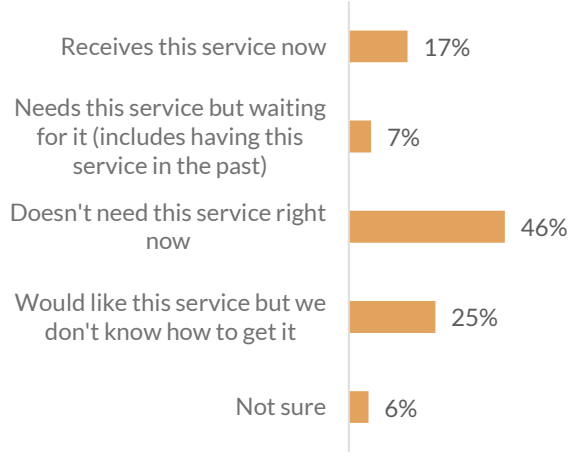
Family Members:
Special supplies/equipment (n=123)



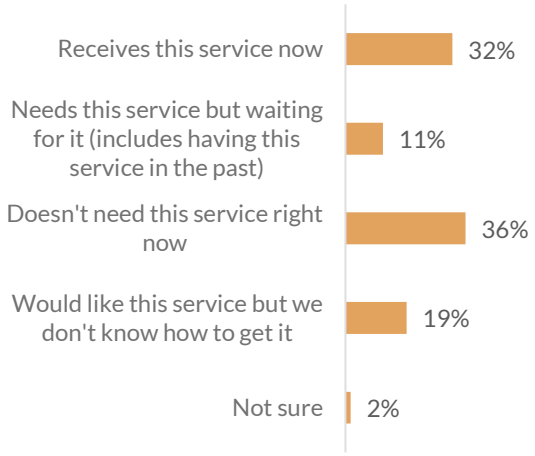
Family Members:
Homemaking (n=123)



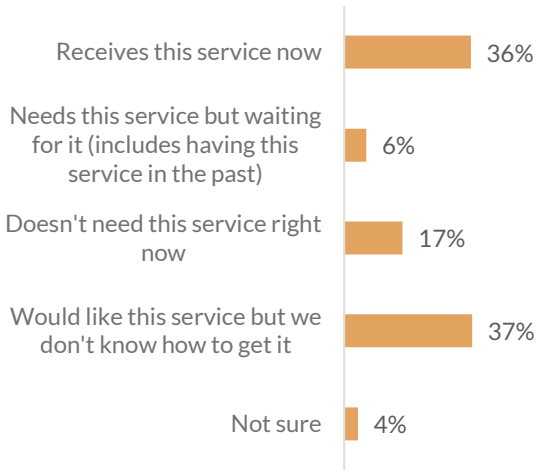
Family Members:
Assistive technology (n=123)



Family Members:
Speech/Occupational/Physical therapies (n=124)

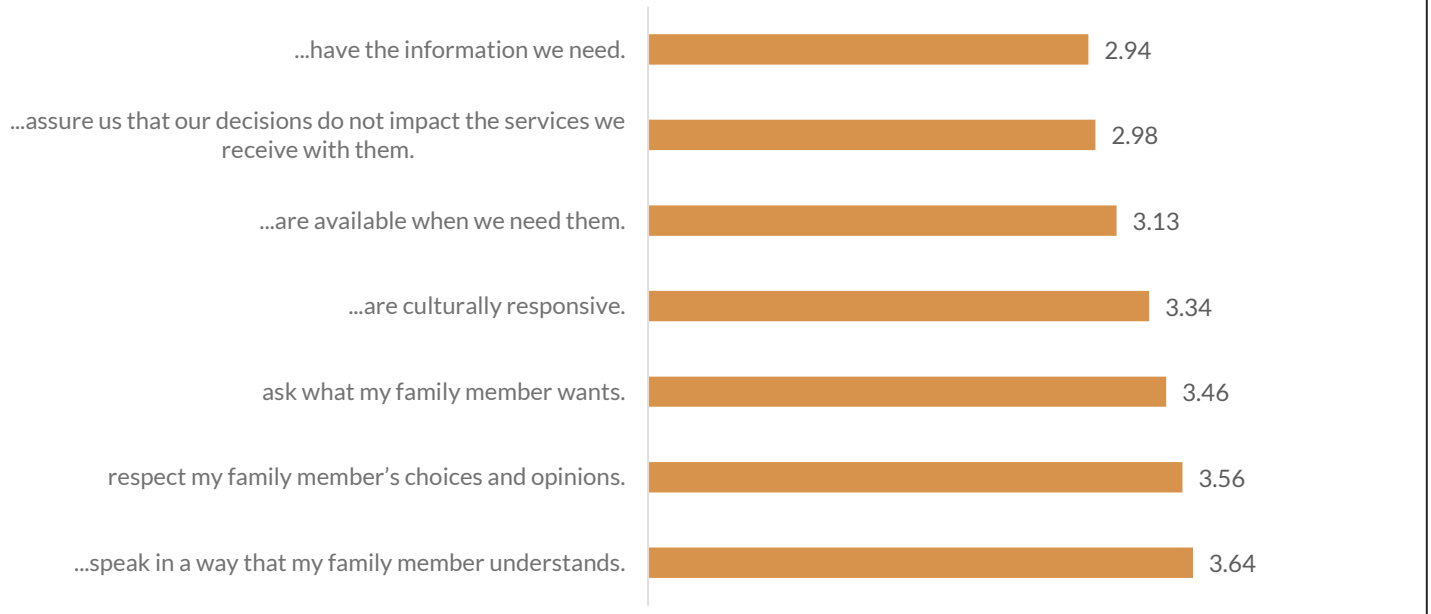


Family Members:
Recreation and social activities (n=125)



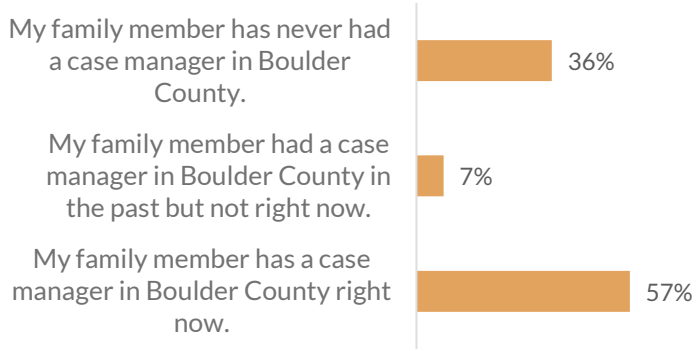
Responsiveness of Services

Family Members:
In Boulder County, service providers (n = 50-97)

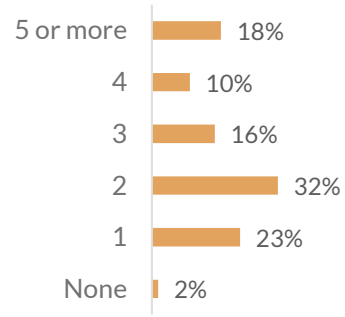


Individuals with IDD: **Responsiveness of Services Survey Items*** *Please share what you think about case managers and service providers in Boulder County.*	Item N	No	Kind of	Yes	Not Sure	Does not apply to me
Do they have the information you need?	45	22%	24%	42%	7%	4%
Do they ask you what you want?	46	15%	33%	46%	2%	4%
Are they there when you need them?	46	15%	22%	50%	4%	9%
Do they include you in your service planning?	45	16%	18%	53%	9%	4%
Are they trained to do their job well?	46	11%	26%	50%	7%	7%
Do they respect what you have to say?	46	7%	22%	63%	4%	4%
Do they talk to you in a way you understand?	46	4%	18%	67%	4%	7%

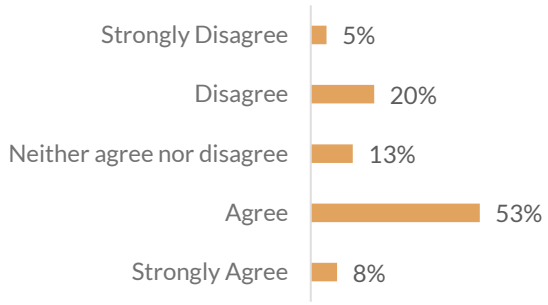
Family Members:
Describe your family member's case mangement services in Boulder County (n=111)



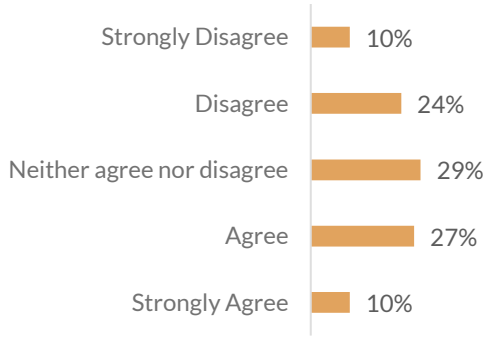
Family Members:
How many case managers has your family member had in Boulder County in the last 3 years? (n=62)

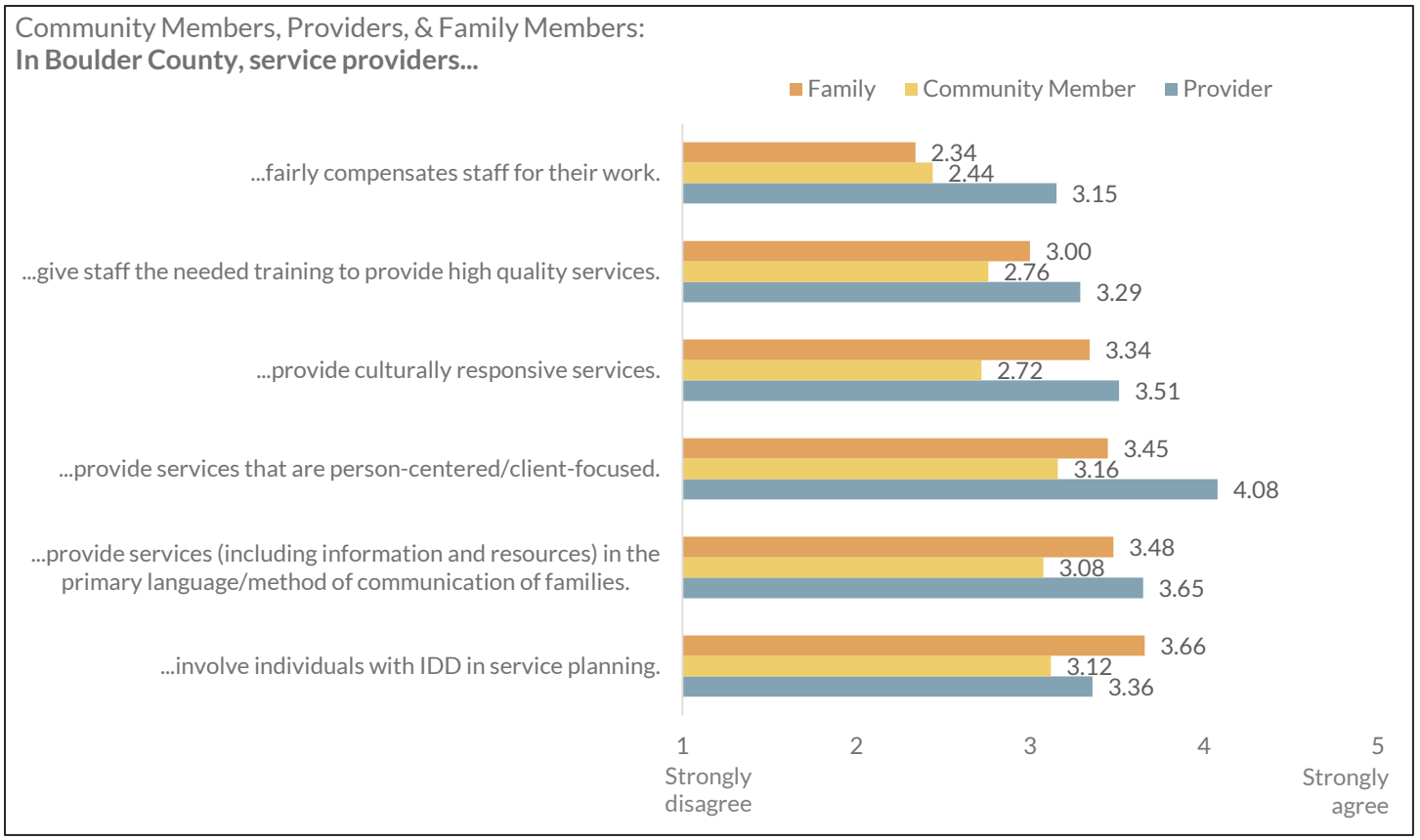


Family Members:
We are happy with the case management services my family member has received in Boulder County (n=60)



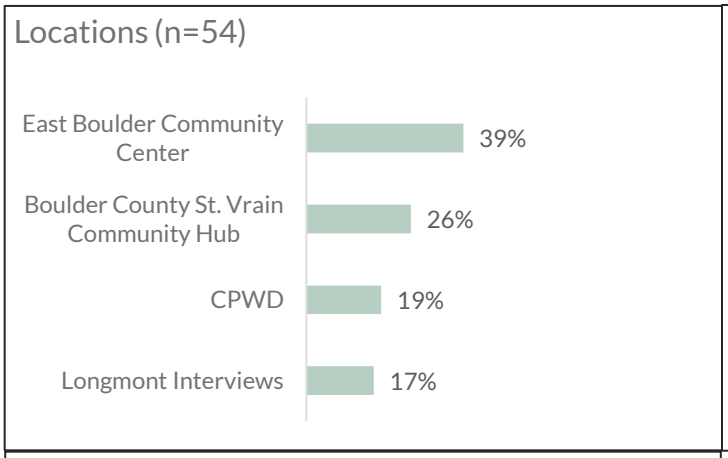
Family Members:
Over the last 3 years, the quality of my family member's case management in Boulder County has improved (n=59)

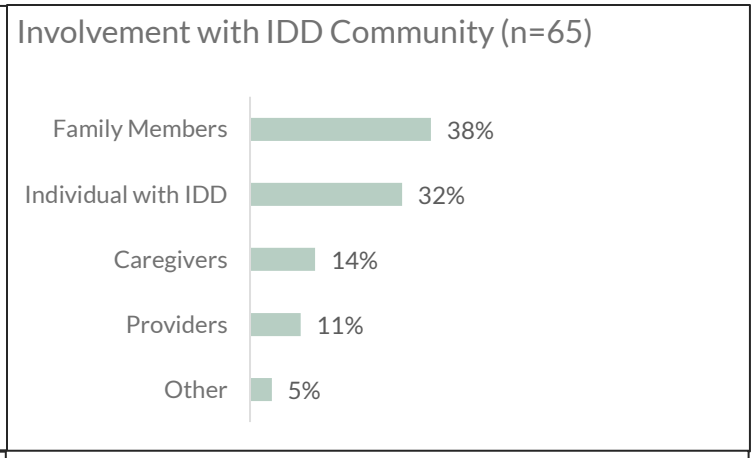


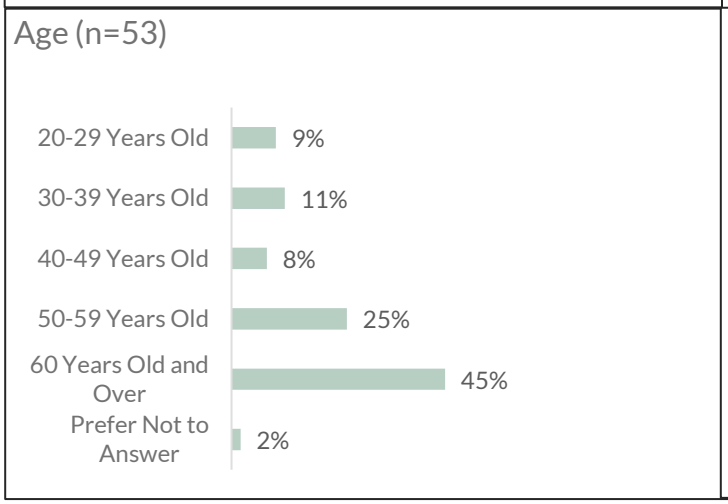

Community Members, Providers, & Family Members:
In Boulder County, service providers...
Family
Community Member
Provider
...fairly compensates staff for their work.
2.34
2.44
3.15
...give staff the needed training to provide high quality services.
3.00
2.76
3.29
...provide culturally responsive services.
3.34
2.72
3.51
...provide services that are person-centered/client-focused.
3.45
3.16
4.08
...provide services (including information and resources) in the primary language/method of communication of families.
3.48
3.08
3.65
...involve individuals with IDD in service planning.
3.66
3.12
3.36
1
Strongly disagree
2
3
4
5
Strongly agree

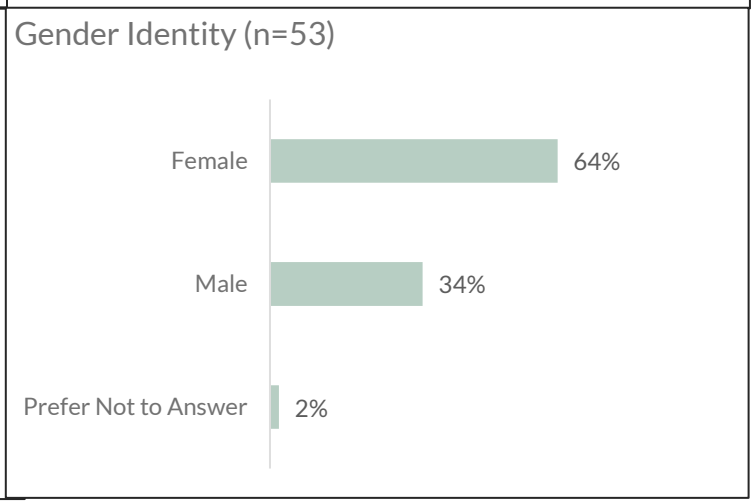
Appendix C: Participant Characteristics from Community Event Surveys

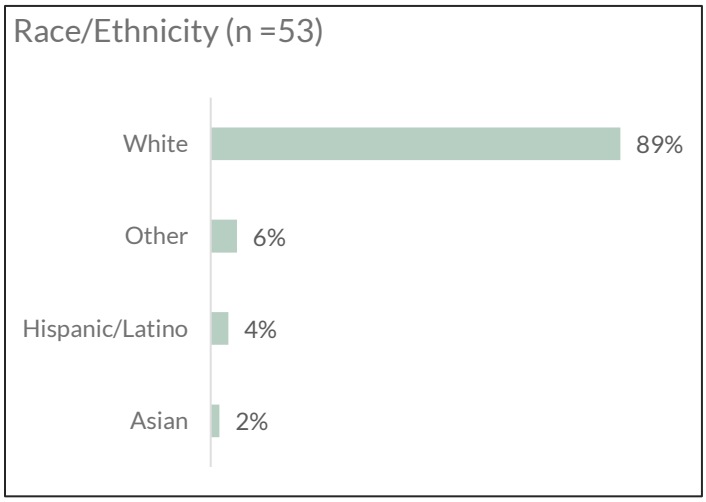
The figures below provide a snapshot of participants from four community events at which brief demographic surveys could feasibly be collected (two evening community forums, the focus group with individuals with IDD and the drop-in interview event). These data provide some basic information regarding stakeholders who participated in key events but exclude service professionals and other stakeholders who participated by phone.










Race/Ethnicity (n =53)
White
89%
Other
6%
Hispanic/Latino
4%
Asian
2%