Attachment 4: Individual and Family Survey Results

Human Services Research Institute

INDIVIDUAL AND FAMILY SURVEY FINDINGS

SEPTEMBER 2, 2022

Introduction

In July 2022, the Rhode Island Division of Developmental Disabilities (DDD) established a goal to obtain information from individuals who receive services through DDD and their family members about the services received today and what services individuals would like to see DDD offer in the future.

An electronic survey (attached as Appendix A) was made available using the Qualtrics survey platform beginning on June 30, 2022. Information collected through July 26, 2022 is included in this analysis and summary. Invitations to take part in this survey were distributed through email listservs and through announcements in two concurrent DD News notices. DDD received sixty-one (61) responses to this survey. Seven (7) respondents were service recipients, and fifty-four (54) respondents were family members of service recipients.

Approach

Analysis of the survey responses was conducted using a qualitative approach. Qualitative research and analysis aim to provide an in-depth, detailed, and information rich understanding of a topic.[1] Qualitative analysis provides detailed description as well as classification or quantification of some aspects of the findings for ease of interpretation. By using a qualitative approach, we will develop a better understanding of individuals' and families' priorities for covered services.

As with any approach, the qualitive approach has limitations. Perhaps most notably is that findings from qualitative analysis lack statistical probabilistic generalizability. Instead, the qualitative approach seeks to identify themes and key elements in the context of a specific inquiry using a variety of analytic techniques to summarize findings in ways that can be informative about the larger population.[2] While specific numbers and percentages should not be generalized to the overall population, the themes presented in the findings should be considered generalizable to some unknown proportion of the population.

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[1] Snape, D. & Spencer, L. (2007). The Foundations of Qualitative Research. In J. Ritchie & J. Lewis (Eds.) *Qualitative Research Practice* (2nd ed., pp. 1 – 23). Sage Publications.
[2] Ayres, L., Kavanaugh, K., and Knafl, K.A. (2003). Within-Case and Across-Case Approaches to Qualitative Data Analysis. *Qualitative Health Research*, 13(6), 871-883.

Survey Findings

Overview

Overall, more respondents were satisfied (than not) with the amount and uses of funding and liked the opportunity to self-direct services. Half of respondents felt like they had the information and resources necessary to self-direct services, while the other half indicated they needed additional support. Most respondents provided feedback about what they liked and did not like about the current services, and many provided additional constructive comments about program administration, individualized budgets and other programmatic changes they would like to see in the future. This feedback is reflected in the findings below.

Key Finding #1

Respondents have concerns about finding, recruiting, and retaining well-trained direct support staff.

In response to every question except one (*What do you like about your services?*), respondents identified concerns about finding, recruiting, and/or retaining well-trained direct support staff. Most respondents (who identified this concern) commented that they had difficulty finding qualified direct support staff. In particular, some respondents noted difficulty finding behavior consultation providers, technology assessment providers, and employment support providers. Many respondents identified low wages as a contributing factor to their inability to recruit and retain well trained direct support staff. Several family members of individuals who self-direct their services in Tiers D and E suggested they would like to be able to use their funding to increase direct support staff compensation. Finally, several respondents indicated they would like to be allowed to use their funding to pay for training opportunities for direct support staff.

Key Finding #2

While respondents like certain aspects of their current services, they would still like to see changes to the service array in the future.

When asked – *What do you like about your current services?* – some respondents praised group home supports because they felt services in group homes were individualized and responsive to behavioral needs, and that staff in group homes were committed to individuals' well-being. Similarly, another respondent liked that residential supports are flexible and tailored to individual's needs. Still others noted that they like being able to access telephonic and virtual supports during the pandemic.

Some respondents like the current day services, employment supports and transportation services, but others suggested these services could be improved. Respondents would like to see day programs be more individualized and offer more opportunities for:

- socialization with peers;
- a wide variety of recreational activities and events;
- social activities specifically for adults over age 30; and
- social activities in community on nights and weekends.

Regarding employment supports, respondents would like to see more opportunities for job development and volunteering to gain work experience. Respondents also wanted increased access to transportation in all parts of the state.

Individuals in the self-direction program would like the ability to use their funding to:
- participate in social clubs;
- access group services;
- hire parents as caregiver;
- purchase gym memberships; and
- purchase phone, computer, and internet service.

Finally, respondents recommended that the overall service array should offer access to:
- online courses and supports after the public health emergency ends;
- broader transportation services and vehicle modifications;
- speech, communication and interpreter services;
- increased limits on respite services;
- overnight respite services;
- mental health supports; and
- person-centered planning facilitation.

Key Finding #3

Individuals felt information and resources should be more accessible using plain language and easy to navigate websites.

An individual receiving services stated that "[a]ccess to resources needs to be more consumer friendly by being written in terms that everyone can understand." Respondents highlighted a need for clearer explanations of available benefits, explanations of DDD program processes, and policies about ways individuals can use self-direction budgets.

To improve individuals' and family members' understanding of the program, respondents suggested that information be presented on easy to navigate websites. More specifically, respondents indicated a need for a centralized source for information about self-direction.

Other Notable Findings

- When asked if funding was adequate to meet individuals' needs, several respondents indicated that funding was only adequate because the individuals lived with family and/or had other substantial natural supports.

- One respondent suggested that DDD establish a "pool" of self-direction direct support staff willing to fill-in when an individual's staff is temporarily unable to provide supports (e.g., when staff is out sick or last-minute cancellations).

- Regarding individualized budgets, one respondent expressed concern about the difference in budget amounts at the same tier between individuals who self-direct their services and individuals who receive agency services.

- Respondents felt like case workers were over-extended with high caseloads, and as a result case workers are not able to provide the level of highly-involved assistance needed by some individuals.

- One respondent suggested simplifying the plan approval and plan amendment processes.

- Respondents indicated that the program could do more to support unpaid caregivers. They suggested establishing a helpline staffed by trained professionals to respond to questions from parents and other unpaid caregivers. Additionally, they suggested more training opportunities for natural supports.

- One respondent suggested providing life planning supports for individuals in the program. They suggested providing educational opportunities to learn about transitioning from school to adulthood, residential options for adults, guardianship, supplemental security income (SSI), career development, impact of employment on SSI, medication management, bereavement counseling upon death of a parent, and transitioning to retirement.

Conclusion

The survey findings discussed above reflect the feedback and comments received from recipients of DDD program services and their family members about services received today and what services individuals would like to see DDD offer in the future. At a high-level, respondents expressed concern about finding, recruiting, and retaining well-trained direct support staff, made valuable recommendations for future changes to the service array, and emphasized the importance of easy access to plain language information about the program.

Through their positive and constructive comments, respondents expressed overall support for the DDD, and the future of the program.

Appendix A

Rhode Island Service Recipients and Families Survey

PREPARED BY THE HUMAN SERVICES RESEARCH INSTITUTE

The state of Rhode Island is interested in hearing about what is working well and what could be improved about the services you receive through DDD[1]. This survey includes questions both about the services you receive today and what services you would like to see DDD offer in the future (i.e., the service array). Before answering questions about the DDD service array you may want to view to following presentation: link here.

Your participation is voluntary, and the information you provide will not be connected to your name or impact your services directly. We are collecting information to inform how to make services better for everyone receiving them.

Thank you for taking the time to answer these questions. If you have any questions or concerns about this survey, please contact: [HSRI contact].

This survey is for individuals who receive services through the Rhode Island Division of Developmental Disabilities (DDD).

1. Am I responding to this survey on behalf of:
   - Myself
   - A family member or person I am a guardian for
   - Someone else (please specify)

2. What kind of living setting do you live in/What kind of living setting does the person live in?
   - Living with relative
   - Apartment of house
   - Group home (24 hour)
   - Shared living arrangement (SLA)
   - Other (please specify): _____
   - I don't know

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[1] Rhode Island Department of Behavioral Healthcare, Developmental Disabilities, & Hospitals (DBHDDH) Division of Developmental Disabilities (DDD) is working on evaluating and developing a new rate and payment model for Medicaid Home and Community Based services for people with intellectual and developmental disabilities. DDD contracted with Burns & Associates, a division of Health Management Associates (HMA), along with their subcontractors, Human Services Research Institute (HSRI), to assist with this project.

3. What tier are you assigned to/what tier is the person assigned to?
   - Tier A
   - Tier B
   - Tier C
   - Tier D
   - Tier E
   - I don't know

4. Do you receive self-directed services or traditional services/Does the person receive self-directed services or traditional services?
   - Self-directed services (You chose a fiscal intermediary, write a plan, become an employer, recruit and hire your own employees, and decide what supports are needed and how best to spend their plan dollars.)
   - Agency services (You and your family chose a provider agency. The agency hires and trains employees, and then provides services on your needs and funding level.)
   - Both
   - Unsure

If Self-Direction/Both:

5. Are you happy with the ways you [/your individual] can use your funding? Please explain your answer. If you are not happy, tell us how you would like to use your funding.

6. Do you feel that the funding the individual receives is enough to meet your [/their] needs? Please explain your answer.

7. Do you have the information and resources you need to self-direct services, such as managing the budget, finding and hiring staff, etc. This help could come from the fiscal intermediary, a DDD social case worker, a plan writer, or others. Please explain your answer.

If Agency/Both:

8. What kinds of DDD funded services have you [/the individual] received in the past year? Select all that apply:
   - Group home/SLA
   - In-home services
   - Supported employment
   - Day program
   - Transportation
   - Technology
   - Other

9. What do you like about your current services?

10. What don't you like about your current services?

All respondents:

11. Is there anything else you would want DDD to know about the services they offer (e.g., things you would change about the available services)?