Reaching Consensus on the Future Direction of a Resource Center within a UCEDD: A Quality Improvement Delphi Project

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Plain Language Summary

Individuals with intellectual and developmental disabilities and their families need help finding information. They also need help finding relevant services and supports. There are state systems of information and help for this population. The Waisman Center is the University Center for Excellence in Developmental Disabilities (UCEDD) in Wisconsin. It is located at the University of Wisconsin-Madison. The Wisconsin Leadership and Education in Neurodevelopmental and Related Disorders (LEND) training program is also located at the Waisman Center. An Intellectual and Developmental Disability Research Center (I/DDRC) is also located here. This represents a unique opportunity for collaboration.

The Waisman Center connects with many individuals with disabilities and their families. They are involved in research, training, and clinical service delivery. There is a need for "in-the-moment" help for these individuals and family members. The aim of this quality improvement (QI) project was to clarify the role of the Resource Center at the Waisman Center. It should align with, and not duplicate, available state resources and support.

The quality improvement project utilized a Delphi method. Stakeholders who participated in the study were mostly female (81%). They represented clinical, outreach, administrative, and research faculty and staff. They also represented self-advocates, and parents/family members of individuals with disabilities. Through this process, we identified priorities and recommendations for the Waisman Resource Center. This has applications at other UCEDDs that aim to provide support to individuals and families. In particular, this may be relevant to QI work in partnership with LENDs and I/DDRCs.

Abstract

Individuals with intellectual and developmental disabilities and their families need access to timely, quality information and assistance about relevant services and supports. Despite statewide systems of information and assistance for this population, there is a need for "in-the-moment" assistance for individuals and family members who participate in onsite research, training and/or service delivery at the Waisman Center. The aim of this quality improvement project was to clarify the role of an internal Resource Center so as to align with the staff resources available and not duplicate statewide systems of support.

The Waisman Center at the University of Wisconsin-Madison, the University Center for Excellence in Developmental Disabilities (UCEDDS). is co-located with a Leadership and Education in Neurodevelopmental and Related Disorders (LEND) training program and an Intellectual and Developmental Disability Research Center (I/DDRC), representing a unique opportunity for collaboration. The current quality improvement project utilized a Delphi methodology to clarify the role of an internal Resource Center. Stakeholders who participated in the study were mostly female (81%) and represented clinical (14%), outreach (24%), administrative (33%), research (38%), self-advocate/individuals with disabilities (5%), and parents/family members of individuals with disabilities (19%). Through the Delphi process, final priorities and future recommendations for the Waisman Resource Center were identified. This work has applications at other UCEDDs who aim to provide additional support to individuals and families, particularly in partnership with LENDs and I/DDRCs.

Introduction

The needs of individuals with intellectual and developmental disabilities (I/DD) and their families to have accurate, timely, and user-friendly information about disability services and supports is well documented in the literature (Robertson et al., 2007; Schalock & Verdugo, 2019; Zeleke et al., 2019). The service delivery system is complex and continuously changing, increasing the need for individuals with disabilities and their families to have assistance navigating and locating appropriate resources. While many states have several resource systems in place for this population, University Centers for Excellence in Developmental Disabilities (UCEDDs) may also need to respond to resource-related questions from families who participate in research, training, technical assistance, or service projects.

The UCEDD mission is to support the full inclusion and self-determination of people with developmental disabilities across the lifespan and their families through (1) development of personnel qualified to provide services in the health, education, and social service systems; (2) provision of services, technical assistance, and the dissemination of information; and (3) contribution of new knowledge about the causes and prevention of developmental disabilities, the impact of disabilities on individuals and families, and the efficacy of assessment, intervention, and support methods. Based on this mission, a Resource Center was developed within one such UCEDD to provide a mechanism for individuals with I/DD and their families to receive evidence-based, quality information as they participate in UCEDD research, training, or service activity.

Community-based Information and Referral programs aim to employ a process of engagement with an individual and/or their family to identify appropriate services and supports for the expressed needs. Information and Referral specialists require expert knowledge in the services available, the skills to discern the question being asked, and the ability to convey an open, caring, empathetic, supportive, inquisitive, and sensitive style (Hodapp et al., 2018). Evaluation data on Information and Referral programs for these families has shown effectiveness in child and young adult outcomes such as increased school attendance; academic performance and graduation rates; fewer reported unmet medical needs; and decreases in depression, suicidality, and anger. Family impacts have also been found, with significant improvements on

basic needs and parenting skills domains, as well as significant increases in family functioning, parent-child bonding, and family adaptability (Hodapp et al., 2018).

This project evaluated the Resource Center that was established at the Waisman Center at the University of Wisconsin-Madison in 2006 to offer in-the-moment resource information to individuals with I/DD and their families. At its inception, the service provided free and confidential evidence-based information and assistance related to state services and supports for individuals with I/DD and their families throughout the lifespan. Families who were physically onsite for a UCEDD clinic visit or an Intellectual and Developmental Disability Research Center (I/DDRC) research project received assistance with their questions about services. Over the last 2 decades, the scope of the Waisman Resource Center broadened, and its focus became less clear. This led to the decision to conduct a quality improvement (QI) effort. The project aims were to: gather additional information from key stakeholders about the current state and scope of the Waisman Resource Center; reach consensus about how the Waisman Resource Center should be redefined; and develop a set of recommendations for how the future Waisman Resource Center operates. This QI used a modified Delphi design, to reach consensus on (1) who the Waisman Resource Center should serve, (2) what service the Waisman Resource Center should provide, and (3) how the Waisman Resource Center should proceed/operate over the next fiscal year.

Methods

A mixed-methods modified Delphi methodology was used. The Delphi method is an attractive method for QI because it is a flexible information-gathering technique that has been successfully used to explore new concepts within and outside current knowledge. It involves an iterative process to collect and summarize the viewpoints of experts using a series of data collection and analysis techniques interspersed with feedback. This method works especially well when the goal is to improve our understanding of problems and opportunities, and to then develop solutions. Further, the Delphi method was well suited as the research methodology in the current project in which we wanted to gather feedback from stakeholders about the Waisman Resource Center, identify priorities and opportunities, and work to summarize and develop recommendations for moving forward with the Waisman Resource Center (Dalkey, 1969; Jones & Hunter, 1995).

In this project, we used established qualitative and quantitative modified Delphi techniques such as determining the priorities for stakeholder decision/feedback, priority ranking exercises, and the development of a descriptive framework of knowledge about the Waisman Resource Center and recommendations about moving forward (Akins et al., 2005; Dalkey, 1969; Jones & Hunter, 1995). In line with the Delphi methodology, the project team generated a list of possible priorities related to the clarification of who the Waisman Resource Center should serve, what service the Waisman Resource Center should provide, and how the Waisman Resource Center should operate. These priorities were presented to the stakeholder group for review in succession.

Stakeholder Selection

Project team discussions regarding the inclusion of important perspectives informed the selection of potential expert stakeholders. The project team also employed snowball sampling by asking selected stakeholders to offer additional recommendations on who else to invite to participate. Stakeholders needed to meet the inclusion criteria: experience using or referring families to the Waisman Resource Center, involvement in other UCEDD QI initiative(s), or specialist expertise in the work being done by the Waisman Resource Center (e.g., individual or family referrals to appropriate services). The final list of individuals invited to be stakeholders represented a diverse range of viewpoints and experiences with the Waisman Resource Center, including Constituent Advisory Committee members (individuals with disabilities and their family members who serve to ascertain and represent the interests of people served and affected by UCEDD programs), staff who have worked at the Waisman Resource Center (Information and Referral Specialists), and staff and faculty who access the Waisman Resource Center (primarily I/DDRC investigators or lab managers) on behalf of families. Potential stakeholders were first contacted briefly by phone to describe the quality improvement project and extend an invitation to participate. Each phone conversation was followed by individualized email invitations to take part in the project or to assign a proxy representative to complete surveys and attend meetings (e.g., a research lab manager). Stakeholders were asked to consent to participate via waiver by completing the survey. We used Qualtrics survey software (https://www.qualtrics.com) to create and administer the surveys and aimed to achieve a panel of 11–30 members. Sample sizes in this range are typical for the Delphi method and have been shown to be effective and reliable (Akins et al., 2005; Dalkey, 1969).

Data Collection

We conducted a Delphi-informed consensus-building approach (Dalkey, 1969; Jones & Hunter, 1995) between January and April 2021 through two stakeholder surveys and two face-to-face virtual meetings with stakeholders to establish consensus on the first two aims of the project: 1) who the Waisman Resource Center should serve, 2) what service the Waisman Resource Center should provide. This quality improvement project occurred during the coronavirus SARS-CoV-2 (COVID-19) pandemic, so all meetings were held face-to-face (i.e., cameras on) virtually via Zoom.

Round 1 of the modified Delphi used a structured survey comprised of the list of candidate priorities of who the Waisman Resource Center should prioritize and what service it should provide. Stakeholders were asked to rank each priority in order of importance (1 = highest priority). In addition, stakeholders were given the option to provide free-text comments to support their decision or to suggest changes. Responses to the Round 1 survey were reviewed by the research team during a 2-week period. The evaluation specialist calculated overall mean rankings and the range of rankings to present back to stakeholders for discussion.

Using an iterative process, we held meetings with stakeholders to present survey findings and collect additional stakeholder feedback. Stakeholders were given the option to attend one

of three scheduled meetings. During this first stakeholder meeting, we presented the mean rankings and the range of rankings from the first survey and asked stakeholders to give their opinion on whether to keep, remove, or modify the priorities, or to state that they had no opinion. We also asked for their opinion on the overall structure and completeness of the list of priorities. We also presented any free-text additions for discussion.

We conducted a simple thematic analysis of notes and transcripts from this meeting and created the survey for Round 2 of the Delphi. This survey was sent out to stakeholders in order to confirm consensus on (1) who the Waisman Resource Center should serve, and (2) what service the Waisman Resource Center should provide. We asked stakeholders to review the aggregated priorities determined during the first meeting. We then asked stakeholders to "agree" or "disagree" with each priority. We also provided five questions about how to move forward and integrate these priorities into the Waisman Resource Center work. Stakeholders were shown each of the candidate priorities on how the Waisman Resource Center should move forward and were asked to rank each priority in order of importance (1 = highest priority). Again, stakeholders were given the option to provide free-text comments to support their decision or to suggest changes. Responses to the second survey were reviewed by the project team during a 2-week period. We calculated overall mean rankings and the range of rankings to present back to stakeholders for discussion.

Following the compiling of Survey 2 results, we held a second series of meetings with stakeholders to present survey findings and collect additional stakeholder feedback. The objectives of these meetings were to (1) review and resolve priorities that did not reach consensus through the survey rounds, (2) draw on stakeholders' responses from Survey 2, and (3) address themes emerging from the stakeholders' open comment responses on the overall structure and completeness of the list of priorities.

After reviewing meeting notes and transcripts, the team proposed initial recommendations based on the iterative and complete quantitative and qualitative data and feedback. These recommendations were presented back to the stakeholder group for a final review (Delphi Round 3). For this meeting, we invited stakeholders who had completed at least one survey and who attended at least one meeting. The aim was to present and gain feedback on the recommendations that were drawn from the previous stages of the project.

Results

Stakeholder Demographics

The characteristics of our stakeholders were obtained as part of the first survey. Overall, 22 stakeholders participated in the project. Of these 22 stakeholders, 95% (n = 21) completed the first survey and 86% (n = 19) completed the second survey. In addition, 95% (n = 21) attended one of the first set of stakeholder meetings, 91% (n = 20) attended one of the second set of stakeholder meetings, and 64% (n = 14) attended one of the third and final set of stakeholder meetings. Stakeholder demographics are presented in Table 1.

Table 1

Stakeholder Demographics (N = 21)

Variable	*n*	%
Sex/Gender		
Female	17	81
Male	3	14
Prefer not to answer	1	5
Role at the UCEDD (could select all that apply)		
Clinical	3	14
Outreach	5	24
Administrative	7	33
Research	8	38
Self-advocate/individual with a disability	1	5
Parent or family member of an individual with a disability	4	19
Highest level of education		
Associate's degree	1	5
Bachelor's degree	5	24
Master's degree	11	52
Doctoral/medical degree	4	19
Number of years working with the UCEDD		
0-5 years	4	19
6-10 years	3	14
11-15 years	6	29
16-20 years	4	19
Over 20 years	4	19

Stakeholders also reported on their experience with the Waisman Resource Center. Overall, 77% (*n* = 17) of our stakeholder sample reported that they were moderately or extremely familiar with the Waisman Resource Center. Specifically, 18% (*n* = 4) reported that they have used it for themselves, 59% (*n* = 13) used it to gather information for others, 73% (*n* = 16) referred families, and 14% (*n* = 3) had worked at the Waisman Resource Center. Further, our stakeholders reported that they had contacted the Waisman Resource Center for themselves or on behalf of someone a median range of 6-10 times, with 10 stakeholders saying that they contacted it for this purpose more than 10 times. Similarly, the majority reported that they had referred someone more than 10 times (57%, *n* = 12).

Consensus on Who the Waisman Resource Center Should Serve

In the first survey, stakeholders were asked to rank (1 = highest priority) who the Waisman Resource Center should prioritize serving. These initial rankings are displayed in Table 2.

Table 2

Survey 1 Candidate Priority Minimum, Maximum, and Mean Rankings (N = 21)

Candidate priority	Minimum	Maximum	Mean
Who			
Individuals with I/DD and/or their families who **have participated** in UCEDD research, training and/or services	1	6	1.81
Individuals with I/DD and/or their families who **have not been involved** in UCEDD research, training, and/or services	1	7	2.38
All I/DDRC and UCEDD staff and faculty	2	6	3.90
Community partners	3	6	4.00
All UCEDD staff and faculty	1	8	5.29
Waisman Center trainees	3	8	5.48
Waisman Center leadership	2	7	5.52
What			
Disseminate information about, and refer to, local resource centers	1	6	2.38
Provide information and a warm hand-off to community-based resources	1	7	2.38
Facilitate sharing of expertise within and/or across projects in UCEDD and I/DDRC	1	6	3.67
Disseminate information about Waisman Center trainings, events, supports, and services	1	7	3.76
Disseminate information about Waisman Center research opportunities and the Clinical Translational Core Registry	2	7	4.38
Maintain a physical space to showcase Waisman Resource Center and have resources readily available	2	7	5.67
Serve as an entity which engages with key partners to apply for and receive grants	4	8	6.10

As shown in Table 2, stakeholders ranked "Individuals with I/DD and/or their families who have participated in Waisman Center research, training and/or services" (mean ranking = 1.81) and "Individuals with I/DD and/or their families who have not been involved in Waisman Center research, training, and/or services" (mean ranking = 2.38) as the highest two priorities. This point was affirmed by a write-in suggestion from a stakeholder that read "Individuals with I/DD and/or their families, regardless of participation" as their highest priority. The lowest priorities included: "Waisman Center Trainees" (mean ranking = 5.48) and "Waisman Center Leadership" (mean ranking = 5.52).

During the first stakeholder meeting discussion, we determined that #1 and #2, as well as

#3, #5, #6, and #7, should be combined. In line with the Delphi methodology, we confirmed our interpretation of the results from the first stakeholder survey and round of stakeholder meetings by including consensus questions in the second survey. Table 3 provides the list of consensus priorities. Of the stakeholders who completed the second survey, 95% (20/21) of our stakeholders agreed with the first item (see Table 3). Similarly, 90% (19/21) of our stakeholders agreed with the second item (see Table 3). Write-in comments related to this point included one comment that clarified: "Regarding #2, agree if clinic staff are not bypassing available services in a clinic that has social work or family navigation designated to it," indicating that stakeholders were suggesting that core clinic services by utilized first and that the Waisman Resource Center would serve as a safety net without duplicating other services.

Table 3

Stakeholder Consensus on Final Waisman Resource Center Priorities

Final Waisman Resource Center Priority
Who
All individuals with I/DD and their families should be a priority of the Waisman Resource Center, regardless of participation in Waisman Center research, training, and/or services.
All Waisman Center staff, faculty, and students/trainees should also remain a priority if they are seeking information or supports on behalf of families.
What
Disseminate information and provide assistance about Wisconsin services and supports related to I/DD.
Disseminate information about Waisman Center activities and research as appropriate/timely.

Consensus on What Service the Waisman Resource Center Should Provide

In the first survey, stakeholders were also asked to rank what service the Waisman Resource Center should provide (see Table 2). Stakeholders highly ranked "Disseminate information about, and refer to, local resource centers" and "Provide information and a warm hand-off to community-based resources" equally (mean ranking = 2.38). The lowest priorities were "Maintain a physical space to showcase Waisman Resource Center and have resources readily available" (mean ranking = 5.67) and "Serve as an entity which engages with key partners to apply for and receive grants" (mean ranking = 6.10).

During the first stakeholder meeting discussion, we determined the following: #1 and #2 should be combined as the Waisman Resource Center rarely just gives out phone numbers and is more likely to engage more deeply with families. Stakeholders also suggested that we remove #5 (Disseminate information about Waisman Center research opportunities and the Clinical Translational Core Registry) as most inquiries such as referrals, resources support, and research questions are forwarded to that registry. At this time, we determined that physical space is

important and should be maintained. While having physical space creates a challenge regarding HIPAA when speaking with families, stakeholders agreed that it carries weight and is beneficial for applying for grants and other funding. Regarding consensus about what service the Waisman Resource Center should provide, 95% (20/21) of our stakeholders agreed with the first item and 90% (19/21) agreed with the second item (see Table 3).

Consensus on How the Waisman Resource Center Should Provide Service

Questions regarding how the Waisman Resource Center should provide its service were based on feedback from the first stakeholder meeting and research team discussion. The first three questions in the survey focused on staff qualifications, partnerships, and service delivery methods. The final two questions in the second stakeholder survey asked about internal vs. external communication and information sharing.

Staff Qualifications

There was wide agreement that the staff working in the Waisman Resource Center should be highly skilled in their ability to (1) provide a warm hand-off; (2) communicate with a wide range of people; and (3) demonstrate empathy. In the second survey, we asked: "What are the most important qualifications for the Waisman Resource Center staff (rank order, 1 = most important)?" "Advanced training in supporting individuals with disabilities and their families" was ranked highest priority (Mean = 1.50), followed by "Shared/lived experiences with individuals with disabilities and their families" (Mean = 2.75), "Training in family navigation models" (Mean = 2.80), and finally "Members of diverse communities" (Mean = 3.25).

During the second virtual meeting, stakeholders agreed this work is important and needs to continue and that this is a service that crosses lines between different projects. For example, one stakeholder clarified that it will be important to identify and strategize around the overlap between Waisman Resource Center and other broader Waisman Center efforts and initiatives

> *That should be in our [staff's] wheelhouse you know, because we have the resources that we can provide, with updates about what's happening in different areas of research at the Waisman Center. I don't think I ever really understood how that was connected to the Waisman Resource Center.*

Partnerships

Stakeholders previously shared that partnerships are important to the successful operation of the Waisman Resource Center. Partnerships refer to who the Waisman Resource Center would work with to effectively provide the service (e.g., share staff, share resources, plan together). Therefore, in the second survey we asked: "What partnerships are most important to the successful operation of the Waisman Resource Center? (rank order, 1 = most important)" "The Regional Center for Children and Youth with Special Health Care Needs" was ranked the

highest priority (Mean = 1.72), followed by "Waisman Center Clinics" (Mean = 2.67), "Community-based partner organizations" (Mean = 3.06), "Waisman Center leadership (e.g., communication unit, director's office, and business office)" (Mean = 3.72), and finally "Waisman Center researchers" (Mean = 3.83). Frequently in the face-to-face meeting, many stakeholders agreed that it will be very important to clarify the differences between what the Waisman Resource Center and the Regional Centers offer in order to avoid duplicated services. For example, one stakeholder acknowledged that Clinic calls, State Regional Center calls, and Waisman Resource Center calls are often going to the same people/staff, which can make it difficult to determine who or what services callers may be seeking. Stakeholders also emphasized the importance of not duplicating services by strengthening partnerships with other entities providing similar services to families. One stakeholder added that they have partnerships with outside service systems to which staff refer to, and that having an open connection, as well as acknowledging that both are serving the same community, but can help in different ways, is important. Appendix A details the key partners and their roles related to the Waisman Resource Center.

Service Delivery Methods

In previous stakeholder meetings, stakeholders suggested that it is important to clarify the way the Waisman Resource Center service is delivered. Therefore, in the second survey we asked, "How should the Waisman Resource Center deliver its service? (rank order, 1 = most important)." The ranked order, starting with most important, was as follows: "Toll-free phone number with ability to leave a voicemail" (Mean = 2.55), "Email address for individualized questions" (Mean = 2.60), "Online information and frequently asked questions" (Mean = 2.95), "Appointment slots to meet with resource center staff" (Mean = 4.00), "Walk-in service for in-person questions during business hours" (Mean = 5.10), "Designated space for people to pick up hard copies of resource materials" (Mean = 5.20), and "Booth with resources and assistance to event/conference participants" (Mean = 6.30). Additional write-in comments suggested additional options for "Remote/video appointment slots to meet with Waisman Resource Center staff" or "Short videos." In the face-to-face meeting, stakeholders clarified that specific service delivery practices must be clear and agreed that the Waisman Resource Center will provide an individual (one-on-one) direct service. They agreed that the main method to reach the Waisman Resource Center will be through general points of contact (toll-free phone number, email address).

Stakeholders were enthusiastic about the idea of adding short videos to the website as people process information in different ways (what they hear vs. what they read). Stakeholders also posed questions about how to figure out when contact is complete with an individual or family and how much follow-up should be performed. In general, stakeholders expressed appreciation that families would be the focus on service delivery decisions.

Messaging/Communication/Information Sharing

The final two questions in the second stakeholder survey asked what information related

to the Waisman Resource Center service delivery should be directed to an internal (e.g., all Waisman Center staff, faculty, and students/trainees) vs. external audience (rank order, 1 = most important). Both questions resulted in "Description of service" (Mean = 1.11 and 1.11) ranked highest followed by "How to contact the Waisman Resource Center" (Mean = 2.05 and 1.95). "General email address" and "General phone number" ranked next (Mean = 3.74/4.16 and 4.37/3.68). "Location of office" (Means = 5.16 and 5.84), "Individual staff direct lines" (Means = 5.84 and 6.16), "Individual staff email" (Means = 5.95 and 6.26), and "Outlook calendar appointments" (Means = 8.00 and 7.37) were ranked lowest.

Consensus was that if an individual or family contacts the Waisman Resource Center, they will be helped, but the Waisman Resource Center will not advertise its services to the public. Conversations about communication and information sharing brought up issues of equity and a recommendation to target diverse communities. Stakeholders were enthusiastic about the development of an equity and diversity committee that could partner with the Waisman Resource Center to help address these inequities. They also discussed the potential renaming of the Waisman Resource Center and related messaging to better fit the services that would be provided to guide individual and family expectations.

Discussion

Individuals with I/DD and their families need access to high-quality information and assistance as they seek needed supports and services. While statewide systems of information and referral exist for this population, there is a need for this service "in-the-moment" as Waisman Center affiliated individuals, families, and community partners request information from staff or faculty onsite.

The current quality improvement project used an iterative modified Delphi process with 22 stakeholders to come to consensus on three primary questions related to the Waisman Resource Center's future: (1) who the Waisman Resource Center should serve, (2) what service the Waisman Resource Center should provide, and (3) how the Waisman Resource Center should proceed/operate over the next fiscal year. Overall, our stakeholders were enthusiastic about the current work to assess and reestablish the scope, aims, and recommendations for the operation of the Waisman Resource Center. They were also appreciative that this necessary work was being done.

> *I think that the [Waisman] Resource Center really is, it just provides such value so I'm glad to have heard so much more about it and have been able to think about keeping its success in the future, so thanks for how you structured this all.*

The results show that the stakeholders highly value the Waisman Resource Center service and that on behalf of the families they work with, consistently indicated that it is a service that should be maintained. The consensus was that while no one asking about resources should ever be turned away from the Waisman Resource Center, it should be primarily an internal service.

Given the statewide infrastructure for information and assistance around resources provided in Wisconsin (e.g., Children and Youth with Special Health Care Needs Regional Centers, Well Badger, Aging and Disability Resource Centers) or through an existing service (e.g., community clinics, long-term care support programs), it was agreed that the Waisman Resource Center will not replace or replicate these existing resources. The Waisman Resource Center will be focused on the immediate questions that arise from Waisman Center faculty and staff. In line with the Waisman Resource Center mission and capacity, the service will focus on gap-filling within the Waisman Center. The results indicate that a balance is needed to maintain the Waisman Center's reputation as a hub of expertise for I/DD, community partnerships and family-friendly approaches, with our need to align with our mission and not replicate statewide resources.

Stakeholders also came to consensus that the staff who work in the Waisman Resource Center need to be highly qualified in having expert knowledge and interpersonal skills so that consumers get quality services. Further, we learned that stakeholders believed that the Waisman Resource Center should disseminate information and provide assistance about Wisconsin services and supports related to I/DD, as well as Waisman Center activities and research, in collaboration/partnership with the other statewide organizations mentioned above in order to ensure that the Waisman Resource Center works in tandem with the services other organizations provide, not duplicating them.

A critical strength of this QI project was its diverse set of stakeholders: Waisman Resource Center staff, researchers who have used the Waisman Resource Center, and UCEDD Constituent Advisory Committee members (including individuals with I/DD and families who have used Waisman Center services). These stakeholders understood the needs of individuals with I/DD and their families through a mixture of perspectives. Many of the stakeholders were experts on the state system of information and referral. These attributes of the stakeholders made for meaningful discussion and engagement.

A limitation of the project is that it may not be generalizable to other centers given each state's unique system of supports and services for this population. Like all UCEDDS, Wisconsin's UCEDD has a commitment to information dissemination. Yet Wisconsin has a distinct role in its partnership with the State Title V Program, to operate a regional center (servicing 14 counties) that provides information and assistance to families with children and youth with special health care needs (birth through 21). Another limitation may be that this work was completed during the COVID-19 pandemic and immediate onsite implantation was not possible. The needs for individuals with I/DD and their families to have access to COVID-related resources became a priority, postponing the implementation of the recommendations.

Recommendations and Future Directions

The Quality Improvement Research Team has taken all of the input from stakeholders and drafted the recommendations for future steps in this process (see Appendix B). Moving forward with an action plan, the Waisman Resource Center workgroup will need to address types of supports to help staff in navigating the balance between providing service and not duplicating

other available state services. Stakeholders also brought up the importance of including members of diverse communities in staffing and the desire to keep that in mind as the Waisman Center enhances efforts to include these communities. This will also be an important consideration when selecting the work group. The breadth and depth of the Waisman Resource Center had broadened over the course of nearly 2 decades and this QI project focused on clarifying the purpose. The results led to a set of recommendations including intentionally scaling back the breadth and depth of the service provided. Additionally, there is a need for further QI to assess potential gaps in the statewide information and referral system. While the results of the current project are unique to the Waisman Center, the methodology may be useful to other UCEDDs, or other information and referral systems interested in pursuing similar QI questions.

References

Akins, R. B., Tolson, H., & Cole, B. R. (2005). Stability of response characteristics of a Delphi panel: application of bootstrap data expansion. *BMC Medical Research Methodology*, *5*(1), 1-12. https://doi.org/10.1186/1471-2288-5-37

Dalkey, N. C. (1969). *The Delphi method: An experimental study of group opinion*. RAND Corp.

Hodapp, R. M., Rosemergy, J., Garcia, B. L., Meskis, S. A., Hart, M., & McMillan, E. (2018). Information and referral services in I/DD: Toward integrated and comprehensive services? *International Review of Research in Developmental Disabilities*, *54*, 211-250. https://doi.org/10.1016/bs.irrdd.2018. 07.007

Jones, J., & Hunter, D. (1995). Consensus methods for medical and health services research. *British Medical Journal*, *311*(7001), 376-380. https://doi.org/10.1136/BMJ.311.7001.376

Robertson, J., Emerson, E., Hatton, C., Elliott, J., McIntosh, B., Swift, P., Krinjen-Kemp, E., Towers, C., Romeo, R., Knapp, M., Sanderson, H., Routledge, M., Oakes, P., & Joyce, T. (2007). Person-centered planning: Factors associated with successful outcomes for people with intellectual disabilities. *Journal of Intellectual Disability Research*, *51*(3), 232-243. https://doi.org/10.1111/j.1365-2788.2006.00864.x

Schalock, R. L., & Verdugo, M. Á. (2019). International developments influencing the field of intellectual and developmental disabilities. In K. D. Keith (Ed.), *Cross-cultural psychology: Contemporary themes and perspectives* (pp. 309-323), Wiley & Sons. https://doi.org/10.1002/9781119519348.ch14

Zeleke, W. A., Hughes, T. L., & Drozda, N. (2019). Disparities in diagnosis and service access for minority children with ASD in the United States. *Journal of Autism and Developmental Disorders*, *49*(10), 4320-4331. https://doi.org/10.1007/s10803-019-04131-9

Appendix A

Waisman Resource Center Partnerships and Infrastructure Needs

The following partnership descriptions were derived from the Waisman Resource Center Quality Improvement Project in 2021. A group of 21 stakeholders completed two surveys and attended two meetings that included discussions about partnerships.

Name of Partner	Waisman Resource Center Provides	Waisman Resource Center Receives
Southern Regional Center	Shared staff, space, and resources	Shared staff, space, and resources
Waisman Center Clinics	• Shared staff, space, and resources	• Shared staff, space, and resources
Waisman Center Communications Unit	• Information on the needs of individuals with I/DD and their families and the best available resources to post online for this population (e.g., Covid-19 resources from staff to Waisman website, hub pages)	• Appropriate referrals from Communications as they have a trustworthy place to refer impromptu questions from individuals with I/DD and their families • Waisman event flyers/URL information to be shared with individuals and families as appropriate and timely
Waisman Center Director's Office	• Information and assistance to individuals who call the director's office • An opportunity to showcase the work to donors and funders	• Appropriate referrals from the Director's office as they have a trustworthy place to refer impromptu questions from individuals with I/DD and their families
All UCEDD Projects, Staff, and the Constituent Advisory Committee	• Information on the needs of individuals with I/DD and their families and the best available resources for this population	• Support to strengthen connections with hard-to-reach populations • Infrastructure support including staffing and expertise
LEND Trainees	• Opportunity to assist an individual or family with finding services and supports and practice communicating with families in a family-friendly way • Information/training on how to find information on WI services and supports	• Help with the volume of calls that come into the center • Assistance with collection and organization of up-to-date resources related to WI services and supports for individuals with I/DD and their families
UCEDD Policy Workgroup	• Trustworthy, accurate, up-to-date information on the needs and experiences of individuals with I/DD and their families	• Information and resources (e.g., an issue brief) that Waisman Resource Center staff can share with families who come to the Waisman Resource Center with related interests (e.g., Autism Treatment Services)
Clinics Translational Core and Waisman Center Researchers	• Information and assistance to individuals and families participating in research • Warm hand-offs and referrals to the Clinics Translational Core	• Information about studies that are recruiting for individuals and families
Local, State and National Networks	• Information and expertise on the needs and experiences of individuals with I/DD and their families	• Linkages to networks that assist in staying current on an ever-changing service delivery system • Key contacts and "go-to" sources

Appendix B

Future Recommendations for the Waisman Resource Center

The following recommendations and action steps were presented by the Quality Improvement Project team. These recommendations and steps were based directly on the results of the Waisman Resource Center Quality Improvement Project.

The Waisman Resource Center will serve:

All individuals with I/DD and their families regardless of their participation in Waisman Center research, training, and/or services.

All Waisman Center staff, faculty, and students/trainees if they are seeking information or supports on behalf of individuals with I/DD and their families.

Underserved populations.

Note: No one will be turned away from the Waisman Resource Center service.

The Waisman Resource Center will provide:

Information and assistance about Wisconsin services and supports related to individuals with I/DD.

Information about Waisman Center activities and research as appropriate/timely.

Note: The Waisman Resource Center will not replace or replicate existing resource services for individuals with I/DD and their families already provided in the Waisman Center (e.g., Family Navigation, clinics) or in the state of Wisconsin (e.g., Children and Youth with Special Health Care Needs Regional Centers, Well Badger, Aging and Disability Resource Centers).

The Waisman Resource Center will be supported by the UCEDD with the ongoing infrastructure supports to small quantities of FTE to the following responsibilities and roles:

Provide an effective, quality service. A dedicated resource specialist will provide information and assistance.

Create and execute a clear internal and external communications plan. A media specialist will provide consultation on website, materials and related.

Ensure the coordination of all aspects of the service. A manager will support staffing, workplan and partnerships.

Provide ongoing data collection, analysis, and continuous monitoring to assess service impact

(e.g., who accesses the service, how individuals access the service, how it changed lives, etc.) and continually improve. An evaluation specialist will provide guidance on evaluation metrics and data analysis.

Thread equity considerations into all aspects of the service. An equity lead will assist with the development of intentional methods for reaching underserved and hard-to-reach populations.

The UCEDD Director will establish a standing Waisman Resource Center workgroup to:

Utilize this summary document to develop a workplan, which will serve as a blueprint for future work.

Consider alternative sources/mechanisms to fund this work moving forward.

Utilize fiscal year (FY) 2022 to collect data (e.g., evaluate usage), discuss funding, and FY23 staff allocations. This data will be used to make a five-year recommendation plan.

Confirm whether messaging/communications about the Waisman Resource Center will be internal, limited to the Waisman Center staff and researchers, director's office, and communications unit.

The Waisman Resource Center name will be reevaluated to:

Ensure that it accurately conveys the service, uses plain language and is easy to understand and remember.