



For people with intellectual
and developmental disabilities



2015 – 2017 Family Support Research & Training Center (FSRTC) State Coalitions Brief

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Submitted by The Arc of the United States

Family members provide the majority of support to people with disabilities across their lifespan. Family members often play the primary role in raising children and youth with disabilities, provide a broad range of supports to adult family members with disabilities (contributing a considerable amount of their own resources to provide care), and provide critical support to older family members, many of whom require additional support as they age.¹ The Family Support Research and Training Center (FSRTC) aims to learn more about families' needs in supporting family members with all types of disabilities across the lifespan, as well as current promising family support practices around the country.

As part of its work on the FSRTC, The Arc of the United States (The Arc), the largest and oldest advocacy organization for people with intellectual and developmental disabilities (I/DD) and their families, provided grants to seven state and local chapters of The Arc to organize coalitions aimed at improving support to all families of people with disabilities and seniors in their states. The coalitions were hosted in Arizona, California, Kentucky, Pennsylvania, Tennessee, Washington, and Wisconsin between 2015 and 2017. Two coalitions - Kentucky and Tennessee - met twice in this period due to significant coalition progress or substantial changes in the structure of family support in the state. These coalitions had the following goals:



- To discuss and better understand systemic challenges in providing family support to all families of people with disabilities in the state;
- To share promising practices in family support that currently exist in the state; and
- To develop and implement an action plan to address challenges in the state's family support systems.

In total, the coalitions engaged 334 people from 217 organizations in identifying challenges and creating action plans. These organizations served the following populations:

- 68% serve people with intellectual and developmental disabilities;
- 40% serve people with physical or sensory disabilities;
- 42% serve people with mental health disabilities;
- 34% serve caregivers; and
- 24% serve people who are aging or elderly;²
- 34% serve other stakeholders (e.g., educators, school district representatives, medical professionals, legislators).³



This brief summarizes the systemic challenges and promising practices identified by coalition members as well as challenges in developing coalitions and implementing action plans. The full report can be found [here](#).

Family Support Challenges and Promising Practices Identified

Each coalition was unique. Each state has a distinct demographic make-up and provided a different type and amount of governmental support to families of people with disabilities and seniors. Also, community organizations and agencies in each state coordinated with each other differently because of the varied service systems and other differences among the states.

Despite these differences, state coalitions identified several overarching themes and challenges. These challenges center around (1) a lack of awareness; (2) a lack of resources; and (3) systemic/coordination failures.

Lack of Awareness by Groups Involved in Supporting Families:

- Perceived lack of awareness by families, health care professionals, and service providers of all available resources and services in state.
- Perceived lack of education for agency staff on how to make recommendations or coordinate services with other agencies.
- Perceived lack of awareness of medical professionals on how to provide connections to the service system at time of diagnosis.
- Perceived lack of awareness of educators on how to support transition age youth with disabilities and their families with available family support resources.
- Perceived lack of awareness of lawmakers on importance of funding for family support services.

Lack of Resources to Serve Families Effectively:

- Perceived lack of affordable and accessible housing for families in both rural areas and urban areas.
- Perceived lack of transportation options for families, particularly in rural areas.
- Perception that there is a lack of respite services that provide quality care and meet individuals' needs.
- Perceived lack of resources and flexibility by employers to allow caregivers to provide care.

Systemic/Coordination Failures in Service System:

- Perceived lack of access for families, especially families of color, to available resources and services.

¹ These general themes come from the *Caregiving in the US 2015 - Executive Summary* report (National Alliance for Caregiving and AARP Public Policy Institute, 2015).

² Coalitions experienced difficulty recruiting aging organizations to participate. This difficulty has been attributed to budget challenges and to the reported perceptions by some aging organizations that working with disability organizations could impede their ability to effectively advocate and provide services to people who are aging or that there were not many areas of shared concern between people with disabilities and seniors. In some cases, organizations accepted invitations but did not participate in meetings. This occurred despite chapters partnering with aging organizations to host the meetings.

³ Analysis conducted by reviewing mission statements of all organizations listed in Attachment A in the full report.

- Perception that too much stress is placed on families to navigate the often overly bureaucratic family support system.



- Perception that families lack clarity on how to effectively enter or navigate the system.
- Perception that service providers must compete for resources; this competition sometimes dissuades providers from working together.
- Perceived lack of trust by families, particularly families of color, in the service system and system providers that evaluate eligibility for services.
- Perception that services provided by the system do not match the need of the family (e.g., not flexible enough for family to use, too much/little support offered, only available in crises, only available for qualifying families)
- Perception that there is a lack of quality direct care due to high turnover in the direct care workforce. Coalition members perceive this high turnover is the result of low wages for the valuable and difficult work and a lack of training.

To address these challenges, each state coalition developed an action plan. Common items included:

- Development of a one-stop or online resource database of family support programs and services for families.
- Development of literature reviews, questionnaires, and focus groups to engage with historically underserved communities and families that do not currently receive services in order to understand diverse needs and to determine how to improve existing programs and services to support these families in a culturally competent manner.
- Development of methods (e.g., email listsers, small groups meetings) to facilitate information-sharing among organizations.
- Replication of culturally competent models of outreach and support for families of color.
- Development of training and resources guides for agency staff to educate them to more effectively support families on how to access available services and resources across agencies.
- Development of training and resource guides for health care professionals and educators to enable them to provide family support resources at the time of diagnosis and during transition.
- Development of educational efforts aimed at lawmakers to illustrate the importance of funding for family support programs and services.
- Development of community awareness activities to educate the public about family support issues.
- Implementation of training for human services professionals to educate them about how to support families to create plans for the future.

Challenges Implementing the Action Plan

The Arc followed-up with host organizations quarterly after each coalition meeting to determine how the coalition was progressing. Most chapters reported holding coalition meetings or communicating with an email list of coalition members. Many chapters had made some progress on one or two strategies identified in their action plan. However, most chapters experienced challenges advancing their action plans after the initial meeting occurred.

One chapter had more success advancing their action plan. The Kentucky state coalition — which assured members of its dedication to funding the project for at least two years — reported significant progress in achieving its plans. The Kentucky state coalition created a new comprehensive resource guide for families and held resource fairs around the state to connect families with resources in their communities. Kentucky's success suggests that implementing and sustaining an action plan depends on ongoing funding as well as significant commitment by coalition members.

Challenges Engaging the Aging Community and Historically Underserved

All coalitions made significant efforts to engage the aging community, including inviting most — if not all — state government aging agencies, partnering with aging organizations, and inviting senior staff at aging organizations to provide presentations to coalition representatives. These efforts were met with mixed success in recruiting organizations to attend initial coalition meeting; only 24% of the organizations that participated in family support coalitions represented the aging community. Some aging organizations reported to the chapters of The Arc that they do not see significant overlap in issues that impact people with disabilities and seniors. Aging organizations also cited their lack of interest in issues like primary, secondary, and collegiate education and employment as reasons for not participating in these discussions.

Additionally, coalitions reported difficulty recruiting organizations that represent historically underserved communities. Coalitions had mixed success identifying and reaching out to these organizations. In Arizona, Native American groups were invited but did not attend the coalition meeting. Both Washington and Wisconsin had success in reaching out and engaging groups representing historically underserved communities in their coalitions. In Washington, groups that focus on serving diverse communities and prioritizing cultural competence participated throughout the day. In Wisconsin, representatives from diverse communities participated and presented their models and insights as part of a panel on cultural competence.

Regardless of the level of participation, all coalitions identified the need for continued and rigorous outreach to and engagement with historically underserved communities in determining challenges, promising practices, and participating in coalitions.



Conclusions

The family support coalitions held in seven states were successful in engaging the disability and caregiving communities to identify challenges that families experience within the family support system and promising practices to serve these families. More input and engagement is needed from the aging community and organizations that represent historically underserved communities since in many of the family support coalitions. Additionally, sustainability of coalition activities will benefit from continuous funding so that organizations have sufficient incentive and investment to carry out work on their action plans. The family support coalitions have provided an important venue for organizations to come together to develop a plan for action in states with the goal of improving support to all families of people with disabilities and older adults.





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