



*For people with intellectual  
and developmental disabilities*



# 2015 – 2017 Family Support Research and Training Center (FSRTC) State Coalition Report

Submitted by The Arc of the United States  
September 2017

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- The Arc of California
- The Arc of Kentucky
- The Arc of King County (Washington)
- The Arc of Philadelphia (Pennsylvania)
- The Arc of Tennessee
- The Arc of Wisconsin

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## Introduction

Family members provide the majority of support to people with disabilities across their lifespan. Often, family members 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.<sup>1</sup>

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. To this end, the FSRTC has the following goals:

- To define the state of science in family support;
- To learn more about critical policy areas (e.g., self-direction and managed care) as well as culturally competent peer-to-peer family interventions; and
- To generate and implement a culturally-competent vision for policy and practice in family support through a national resource center.

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 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 Arc provided funding to seven different chapters over three years to develop these coalitions and report on its successes and challenges: The Arc of Philadelphia (Pennsylvania), The Arc of Tennessee, The Arc of Kentucky, The Arc of Arizona, The Arc of California, The Arc of King County (Washington), and The Arc of Wisconsin.

This report summarizes the findings from coalition meetings held in Pennsylvania, Tennessee, Kentucky, California, Arizona, Washington, and Wisconsin. The first three sections of this report provide greater detail about the background and development of state coalitions as well as the process The Arc used to capture and analyze findings from coalition meetings. This report then summarizes findings from each state coalition, compares these findings, and provides recommendations for future Family Support Research and Training Center state coalitions to use to more effectively develop and implement coalitions.

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

## About the Coalitions

The Arc's FSRTC state coalitions bring together disability and aging organizations (including organizations that represent people with physical, developmental, mental health, and aging-related disabilities, as well as organizations that advocate on behalf of underserved racial/ethnic communities) to discuss the status of family support in the state. The coalitions have 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.

The Arc of Philadelphia, The Arc of Tennessee, The Arc of Kentucky, The Arc of Arizona, The Arc of California, The Arc of King County, and The Arc of Wisconsin received grants to develop state coalitions and host an initial meeting of approximately 30 representatives from disability, aging, and caregiver organizations, as well as organizations that represent historically underserved communities. The Arc of Philadelphia, The Arc of Tennessee, and The Arc of Kentucky received funding in 2015, and The Arc of Arizona and California received funding in 2016. In 2017, The Arc of King County and The Arc of Wisconsin received funding. Both The Arc of Kentucky (2015-2016) and The Arc of Tennessee (2015, 2017) received funding in two years due to their coalition's progress or development.<sup>2</sup>

Each chapter partnered with at least one organization to reach out to disability, aging, and caregiver organizations as well as organizations that represent historically underserved communities and to invite them to join the coalitions.

- The Arc of Philadelphia partnered with Pennsylvania Link to Aging and Disability Resources, which is the state Aging and Disability Resource Center (ADRC). This agency provides connections for people with disabilities and seniors to partner agencies, assists people with applications for public benefits and services, and assists people in making a transition back to the community after an illness or accident (Commonwealth of Pennsylvania, 2015a).

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<sup>2</sup> While they did not receive funding to support another coalition meeting, The Arc of Philadelphia and The Arc of Tennessee did receive a small amount of funding in 2016 to provide follow-up information to The Arc and FSRTC regarding their state coalitions. Similarly, The Arc of Arizona and The Arc of Kentucky received a small amount of funding in 2017 to provide follow-up information.

- The Arc of Tennessee partnered with the Vanderbilt Kennedy Center, the Tennessee Council on Developmental Disabilities, and the Tennessee Commission on Aging and Disability (TCAD) for their coalition meetings.

In 2015, The Arc of Tennessee partnered with the Vanderbilt Kennedy Center (Tennessee's University Center for Excellence in Developmental Disabilities) and the Tennessee Council on Developmental Disabilities. The Vanderbilt Kennedy Center works to bring new and innovative practices to Tennessee that support people with disabilities and seniors in their communities. Examples of projects supported by the Vanderbilt Kennedy Center include the Kindred Family Stories project, TennesseeWorks, and the Statewide Forum on Dementia, Aging and Disability.<sup>3</sup>

In 2017, The Arc of Tennessee partnered with The Tennessee Commission on Aging and Disability (TCAD). TCAD provides caregiver support; information; assistance to people in nursing homes, assisted care facilities, or care homes; and nutrition services. TCAD also supports Tennessee's OPTIONS for Community Living program, which provides home and community based service choices to people who are aging and who have disabilities; provides court-appointed public guardians and conservators to people who need them; and oversees Tennessee's State Health Insurance Assistance Program (SHIP), which helps explain Medicare benefits to people who need help (Tennessee Commission on Aging and Disability, 2017).

- The Arc of Kentucky partnered with the Kentucky Department of Aging and Independent Living (DAIL). The DAIL is the federally-designated state unit on aging. It operates the state Aging and Disability Resource Center (ADRC) and coordinates the 15 local Area Agencies on Aging (AAAs).<sup>4</sup>
- The Arc of Arizona partnered with Protecting Arizona's Family Coalition (PAFCO). PAFCO is a group of organizations dedicated to giving voice to vulnerable populations by promoting essential health and human service program funding (Protecting Arizona's Family Coalition, 2016).
- The Arc of California partnered with the California Department of Aging (CDA). The CDA administers programs that serve older adults, adults with disabilities,

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<sup>3</sup> Background information provided in the letter of support from Vanderbilt Kennedy Center attached to the application to develop the coalition submitted by The Arc of Tennessee.

<sup>4</sup> Background information provided in the letter of support attached to the application to develop the coalition submitted by The Arc of Kentucky.

caregivers, and residents in long-term care facilities throughout the state. The CDA also operates California's Aging and Disability Resource Connection (ADRC), which promotes partnerships between aging and disability organizations to streamline access to information, referrals, and assistance for people seeking long-term services and supports.<sup>5</sup>

- The Arc of King County partnered with Sound Generations. Sound Generations serves seniors in King County, Washington. Sound Generations' services include information and assistance; providing meals through various programs; offering transportation to medical, dental, and essential appointments; home repair services; support to find assisted living; legal and financial assistance to plan estates, establish powers of attorney, and other needs; and support for unpaid caregivers (Sound Generations, 2017).
- The Arc of Wisconsin partnered with the Greater Wisconsin Agency on Aging Resources (GWAAR). GWAAR is a nonprofit agency committed to supporting the successful delivery of aging programs and services in 70 counties and 11 tribes in Wisconsin. GWAAR provides training, technical assistance, and advocacy to lead agencies to ensure the availability and quality of programs and services for seniors. In addition to GWAAR, The Arc of Wisconsin also partnered with Family Voices of Wisconsin, WisconSibs, The Alzheimer's Association of Southeastern Wisconsin, the Waisman Center (University Center for Excellence in Development Disabilities), and the Wisconsin Board for People with Developmental Disabilities.<sup>6</sup>

In total, the five coalitions engaged 334 people from 217 organizations. According to their mission statements, the 217 organizations serve 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 those who are aging or elderly;

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<sup>5</sup> Background information provided in the letter of support attached to the application to develop the coalition submitted by The Arc California.

<sup>6</sup> Background information provided in the letter of support attached to the application to develop the coalition submitted by The Arc of Wisconsin.



34% serve other stakeholders (e.g., educators, school district representatives, medical professionals, legislators).<sup>7</sup>

A complete list of organizations which participated in these coalitions is set forth in Attachment A.

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<sup>7</sup> Analysis conducted by reviewing mission statements of all organizations listed in Attachment A.

## Developing the Coalitions

To support chapters to organize the state coalition meetings, The Arc provided a framework agenda (see Attachment B). This framework outlined the goals and objectives for the FSRTC family support coalition meetings and provided an agenda template to assist in the organization of the initial meeting. This framework also explicitly prompted coalition members to discuss and develop strategies and steps to take to improve family support services and coordination in the state.

The Arc also provided ongoing technical assistance to the chapters as they conducted outreach, developed agendas, and worked with local facilitators to conduct the coalition meeting.

Each chapter provided coalition participants with background information on the status of family support issues in the state. Participants were asked to read the [Executive Summary of the American Association of Retired People’s “Caregiving in the US” Report](#) in advance of the coalition meetings (National Alliance for Caregiving and AARP Public Policy Institute, 2015). This report provides an overview of the status of family caregivers around the country and highlights some key issues affecting family caregivers. At all coalition meetings, participants began their discussion by learning more about the FSRTC project.

## Evaluating the Coalition Meetings

Each chapter collected data to support The Arc's evaluation of this project. The Arc employed a grounded theory approach to the evaluation of these coalition meetings.<sup>8</sup> In this approach, The Arc reviewed data collected by chapters during these coalition meetings to identify which ideas, concepts, and elements became apparent. Data was gathered from a variety of sources during these coalitions meetings, including:

- Applications that chapters of The Arc submitted to The Arc to develop state coalitions in response to a request for proposal;
- Transcripts of state coalition meeting discussions; and
- Notes written by coalition participants as well as by observing staff from The Arc.

To support data collection, The Arc provided guiding documents and resources to the chapters. These included:

- An evaluation plan summarizing The Arc and chapter responsibilities during the meeting and after (Attachment C);
- A form for note-takers to use to summarize information around coalition objectives (Attachment D);
- Recommended reading to provide facilitators with techniques on leading discussions (Attachment E);
- A template of an action plan to use on the day of the meeting to identify steps to take and strategies to adopt to improve family support in the state (Attachment F); and
- A copy of follow-up questions to be asked a year after the meeting related to the impact of the coalition (Attachment G).

The Arc contracted with a transcription service to provide captioning and a resulting rough transcript of the discussion at each meeting.

The Arc also conducted member checks with coalition members before submitting this report to determine whether data was captured and reported accurately.<sup>9</sup>

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<sup>8</sup> A grounded theory approach is a method of theory development in which a hypothesis is developed through systematic data collection rather than conforming to a predetermined hypothesis (Patton, 2002; Mertens, 2005).

<sup>9</sup> Member checking is defined as the testing data, analytic categories, interpretations and conclusions with members of the group from whom the information was obtained (Robert Wood Johnson Foundation, 2008).

## Findings

Each state coalition identified distinct challenges and strengths, promising practices and resources, strategies to advance family support efforts, any follow-up activities the coalition undertook after its initial meeting, and challenges the coalition experienced in its development or in achieving the strategies identified in its initial meeting.

For each coalition below, we identify major themes and issues that coalition members discussed during the initial meeting or reported to The Arc during follow-up meetings. These key themes were developed by reviewing and identifying distinct concepts and categories in the data.

Key themes and concepts include:

- Inadequate availability of family support services in the state;
- Systemic and community awareness challenges;
- Need for extensive education and training for families, service providers, lawmakers, and the public; and
- Obstacles to collaboration between aging and disability organizations because of limited funding for coalition or skepticism regarding the extent of overlap in the interests of people with disability and people who are aging.

These key themes and concept will be illustrated in detail in the findings for state coalitions below as well as in the “Summary of Themes from Coalitions” section in the report’s conclusion.

## 2015 Pennsylvania State Family Support Coalition

*Initial Meeting: September 30, 2015, in Harrisburg, Pennsylvania*

An estimated 1,671,000 people in the state of Pennsylvania have a disability. Pennsylvania also has a large aging population (approximately 2,041,000 people), which is expected to increase from 15% of the state population in 2010 to 23% in 2030 (US Census Bureau, 2015a; Commonwealth of Pennsylvania, 2015b).

Pennsylvania has seen consistent funding decreases in family support for families of people with I/DD and seniors over the last 15 years.<sup>10</sup> However, Pennsylvania offers the following resources to families of people with disabilities and seniors:

- The Pennsylvania Link to Aging and Disability Resources serves as the state Aging and Disability Resource Center (ADRC). This organization provides connections between people with disabilities, the elderly, and partner agencies, assists people with applications to public benefits and services, and supports people in making a transition back to the community after an illness or accident (Commonwealth of Pennsylvania, 2015a);
- 52 local Area Agencies on Aging (AAAs) provide information to older people and their caregivers (Commonwealth of Pennsylvania, 2015c); and
- Pennsylvania offers 10 Medicaid waiver programs to support the health care, prevocational, and daily living needs of women, people with AIDS, people with disabilities, and the aging population (Centers for Medicaid & Medicare Services, 2015a).

### Identified Challenges

Several times before the initial meeting, the Pennsylvania coalition brought together members by conference call to identify specific topics related to family support that members wanted to discuss at the meeting. Members identified the following issues to discuss at their initial meeting:

- Employment
- Housing
- Transportation
- Future planning
- Education and transition

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<sup>10</sup> This information comes from insights provided by The Arc of Philadelphia in their application to The Arc to develop the state coalition.

- Managing services in and out of home
- Recreation
- Relationships
- Family health care
- Respite

During the initial meeting, most discussion focused on the challenges that families and caregivers face in navigating family support issues. Specific challenges identified included:

- Many families are not connected to or do not know about available resources or services in the state;
- Caregivers often need to take time off or leave a job to care for person with a disability or an aging family member;
- Families often have difficulties navigating housing programs and tend to feel like the state rather than the family has control over their housing situation;
- Many families feel that agencies only respond to families' concerns after they have persistently asked agencies for assistance;
- Families often do not have access to transportation to take care of family members, and people with disabilities do not have accessible transportation options. Even when transportation exists, assisting the person to use the accessible transportation may require that the caregiver take a day off from work. Additionally, family members may not always be treated respectfully by organizations providing transportation services;
- Having relationships can cause dissidence in the family. Parents and siblings may be uncomfortable with the person with a disability having a romantic and/or sexual relationship;
- Families may not be able to pay for or coordinate medical care; and
- Families that do not speak English are often redirected to public clinics, which may not be the better health care option.

Other identified challenges pointed to issues that support providers have or societal issues:

- Educators often focus on teaching the academic curriculum but do not give students the opportunity to learn important living skills that will be necessary for students to have after they leave school. Coalition members thought that educators may need to know more about the adult service system and how to

navigate it effectively so they can prepare students and families for this change;

- Coalition members thought that direct service providers were often underpaid and lacked training and accountability to ensure they are providing quality support to people with disabilities and seniors. Coalition members also felt that support coordinators who are often charged with overseeing direct service providers too often are more concerned with fulfilling bureaucratic processes and checklists about care than providing intentional and individualized support to people;
- Coalition members felt that parents, staff, and educators do not consider supporting people with disabilities to participate in recreational activities and build social relationships to be high priorities;
- Members perceived that many doctors in Pennsylvania do not accept Medicaid/Medicare or refuse to treat patients with disabilities; and
- Coalition members felt that tokenism – symbolic rather than meaningful participation – is prevalent regarding people with disabilities and seniors in Pennsylvania.

## Strengths, Promising Practices, and Resources

To address the specific challenges identified, the Pennsylvania coalition identified promising practices and resources that the coalition considered in developing strategies for their coalition. Practices identified included the following:

- Development of an online database for people to find resources and link to other organizations or services in their communities;
- Engagement with faith organizations, community centers, parent/sibling support groups, and medical professionals to provide resources and support to families;
- Education of the following groups about various issues:
  - Human resource staff to dispel myths about hiring people with disabilities;
  - Teachers about the importance of relationship-building and the importance of developing independent living skills;
  - People with disabilities on how to drive cars;
  - Support staff on how to help families make future plans as well as how to develop person-centered supports and how to coordinate services and supports.
- Investigating the replicability of the following programs:

- A Philadelphia program that offers vouchers for people transitioning out of facilities;<sup>11</sup>
- Pennsylvania Link to Aging and Disability Resources in Delaware County sponsors a Landlord Breakfast each year to educate landlords and connect them with regional housing coordinators;
- Partnership with a cab company or Uber to provide transportation or use community supports;
- Finding and using “Promotores de Salud” – community health workers or peer leaders that can help provide culturally and linguistically appropriate health education to community members (US Department of Health and Human Services, 2015);
- Providing cultural exchanges between employers and people who use and provide vocational rehabilitation; and
- Children’s Hospital of Philadelphia’s Transition to Adulthood program to support transition-age youth to be more independent (Children’s Hospital of Philadelphia, 2015).

## Strategies

Significant resources would be required to investigate the viability, conduct outreach, and learn about and develop a sustainable database for many of the promising practices that the coalition identified. As a result, the coalition’s strategies for the future focus on outreach efforts, training and information dissemination strategies, and gathering additional resources.

**Strategy 1:** Identify family supports available in different areas of Pennsylvania, perceived challenges, access to resources, and available resources.

**Strategy 2:** Create regional workgroups across the commonwealth using the PA Link lead coordinators regions and partner with online forum for information exchange and dissemination.

**Strategy 3:** Engage and encourage participation of families and organizations that serve families of English language learners, culturally diverse communities, and individuals with disabilities related to communication (blind, visually impaired, hearing impaired, executive function disorders, traumatic brain injury, etc.).

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<sup>11</sup> Coalition members could not recollect the program name but resolved to identify it at a later meeting.



**Strategy 4:** Disseminate invitations to participate in “Community of Practice: Supporting Families Throughout the Lifespan” sessions across the Commonwealth and increase emphasis on family involvement at the local level within coalition participant organizations.

**Strategy 5:** Develop and expand working relationships with local and state government entities as well as with service-based nonprofit organizations.

**Strategy 6:** Discuss strategies to disseminate information to families about the importance of future planning on upcoming regional conference calls and workshops.

## Coalition Development Challenges

The state budget created unique challenges for The Arc of Philadelphia in forming a coalition. The Arc of Philadelphia partnered with the state ADRC, PA Link to create the coalition. Just weeks before the scheduled meeting, PA Link discovered that they would not be able to attend and facilitate the meeting as planned because the state budget had not been enacted. Thus, PA Link did not have any available funds to support their travel and participation. As a result, The Arc of Philadelphia and other coalition members needed to re-work their agenda and carry out the facilitation of the day’s events themselves, rather than using professional facilitators that PA Link would have provided. This necessarily caused shifts in the agenda for the meeting.

Additionally, during the meeting, the transcription failed due to inadequate internet service in the room in which the coalition meeting was held. Additional information, however, was available from the following: (1) the application that The Arc of Philadelphia submitted to develop state coalitions, (2) notes taken by coalition participants, and (3) notes taken and observations made by The Arc’s staff.

## Follow-up from Coalition Meeting

In 2016, The Arc of Philadelphia reported that the Pennsylvania coalition continued to be active.

- The coalition met quarterly by teleconference to connect with each other and be more aware of family support issues and practices around the state.
- The coalition had grown since its initial meeting, engaging caregiver agencies, parents and advocates, and people who are aging or who have disabilities in coalition meetings. This growth occurred due to the coalition perceiving a

need to more authentically represent the interests of families, people with disabilities, and the aging population.

Even with this progress, the coalition continued to experience challenges due to the political climate in Pennsylvania. There were many discussions about cutting funding for family support benefits and services – including waivers for long-term services and supports. However, the coalition remained committed to educating the state administration and the public on the importance of supporting families and advancing the strategies it has identified.

Since the 2016 discussion, no additional progress has been reported.

## 2015, 2017 Tennessee State Family Support Coalition

*Initial Meeting: October 15, 2015, in Nashville, Tennessee*

*Second Meeting: July 18, 2017, in Nashville, Tennessee*

There are over 918,000 seniors and over 968,349 people with disabilities in Tennessee (US Census Bureau, 2015a). Tennesseans with disabilities and seniors receive significant family support resources from the government. In addition to resources provided on the Kid Central Tennessee, the Department of Intellectual and Developmental Disabilities and TennCare websites, the following are available:

For people with intellectual and/or developmental disabilities and their families:

- The Department of Intellectual and Developmental Disabilities (DIDD) operates a \$7.2 million state funded Family Support program to provide an average of \$1,200 to approximately 450 families each year to provide respite care, day care services, home modifications, equipment, supplies, personal assistance, transportation, homemaker services, housing costs, health-related needs, nursing and counseling. There is a waiting list for this program (The Arc of Tennessee, 2015).
- DIDD case managers are charged with connecting families with other resources that may be available in the community.
- The DIDD also administers three HCBS waivers for people with I/DD to help people pay for services. However, these three waivers closed to new participants on June 30, 2016.
- TennCare began operating a new HCBS program on July 1, 2017 for people with I/DD called Employment and Community First (ECF) CHOICES. This program helps people and their families find and use employment supports and receive job training; build independent living skills; become involved in the community; find transportation; receive personal assistance; use assistive technology; make a home modification; receive respite; build self-advocacy and self-direction skills; receive peer support and education; navigate health care insurance options; and receive basic dental care for adults 21 and older. The program is managed through Amerigroup, BlueCare, and United Health Care. All people who were on the waiting list for the HCBS waivers mentioned above have now been transferred to the referral list for this program, which will serve up to 2,800 people in 2018 (TennCare, 2017).
- Recent legislation was passed to make sure that people with I/DD who have a primary caregiver over the age of 75 receive services; this includes people who receive existing HCBS waivers as well as some of the people receiving services

through the ECF CHOICES program. There are efforts in the next year to pass new legislation to expand the law to include all people eligible for ECF CHOICES.<sup>[1]</sup>

For families supporting seniors and people with physical disabilities:

- Tennessee offers three programs to people to receive support in the community, home, or nursing home (Centers for Medicare & Medicaid Services, 2015b).
- Tennessee also runs a state-funded program to provide home and community based choices for seniors and people with physical disabilities through its OPTIONS program (Tennessee Commission on Aging and Disability, 2015a).
- Finally, the Area Agencies on Aging and Disabilities (AAADs) provide the primary source of information about services for families and seniors themselves (Tennessee Commission on Aging and Disability, 2015b).

## Identified Challenges

Despite the resources identified above, Tennessee has challenges in coordinating family support. The coalition recognized that lack of funding was one of the greatest challenges. However, the coalition decided that lack of funding would be removed from the discussion for the day. All problems and all solutions – regardless of existing funding – were to be discussed to encourage participants to explore possibilities without feeling restricted by the current funding situation.

Thus, the following challenges were identified:

- The need to connect families to one another and to resources;
- The existence of a “silo mentality”. Participants shared the perspective that service provider and government agencies are so wrapped up in their own expertise, terms, and bureaucratic processes that they do not make it easy for families to navigate their systems nor do they often make referrals to other agencies;
- The perception of service provider and government agency staff that they do not have enough training on resources in the community and often do not know where or when to make a referral to a family;

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<sup>[1]</sup> Information gathered via email communication with The Arc of Tennessee on 12 September 2017.

- The need for families to relay their stories repeatedly to agencies and groups to find help, which eventually leads some families to stop asking for assistance. Coalition members perceive that this need and eventual drop-off of assistance requests tends to occur frequently after a student with a disability reaches his or her 22<sup>nd</sup> birthday and ages out of the school system; and
- The perception of coalition participants that physicians do not receive education or do not have the resources to provide to families regarding connecting with family support services when the family receives a disability diagnosis. This creates a missed opportunity to connect families with available services.

## Strengths, Promising Practices, and Resources

The participants in the Tennessee coalition discussed the state's many strengths, promising practices, and untapped resources that can be utilized to enhance family support efforts. These include:

- Accessible community and legal resources;
- An existing state-funded family support system;
- A multitude of intake and referral systems in the state, which are operated by disability and aging organizations;
- Strong regional centers for people with disabilities and seniors; and
- A robust self-advocacy movement and awareness about the need for services that are both person-centered and person-directed.

Participants recognized that while some connections have been made in the community, more can be done. Participants suggested reaching out to caregiver support groups, sibling groups, regional resource centers, civic groups, rural development agencies, and universities. Most saliently, participants wanted to reach out to caregivers themselves. A significant part of the discussion was related to how to support the 85% of people with disabilities and seniors who receive informal supports at home and do not access the formal support system. Participants spent significant time discussing the experiences and needs of these caregivers and families.

## Strategies

In light of the challenges and promising practices discussed, the Tennessee family support coalition developed seven strategies to improve supports to all families of people with disabilities and seniors in the state.

**Strategy 1:** Gather information directly from families, individuals with disabilities, and seniors on the challenges they face and the resources they use. This will occur by conducting focus group/town hall discussions on the topic and through the development, implementation, and analysis of surveys completed by the 85% of individuals with disabilities, seniors, family members supporting people who have disabilities or seniors who do not have formal, paid supports.

**Strategy 2:** Create a “Supporting Families Central” as part of [www.tn.gov](http://www.tn.gov) (similar to Kid Central Tennessee) to be a one-stop website for families and professionals to connect to formal and informal resources that support families with members who have I/DD or who are aging.

**Strategy 3:** Improve information sharing across state agencies and community organizations through the creation and maintenance of a multi-agency/member listserv that shares critical information.

**Strategy 4:** Compile information on relevant aging and disability specific resources, develop a plan to update materials, and research possibilities for integrating existing state information and referral systems.

**Strategy 5:** In partnership with the Department of Education, create an “alert” system that identifies students with IEPs or 504 plans at age 14 and shares that information with relevant government departments and/or community organizations.

**Strategy 6:** Provide training to all relevant state government departments on the “supporting families” model and provide them with the tools to provide families accurate information and referral services.

**Strategy 7:** Encourage information and referral organizations to include the link to The Arc’s Center for Future Planning on their website and other resources to raise awareness of the importance of future planning.

## 2016 Coalition Work

In 2016, the Tennessee state family support coalition made the following progress towards the above strategies:

- The coalition developed questions and identified cities that will host focus group/town hall discussions from **Strategy 1**.
- The coalition maintained contact with the University of Tennessee's extension offices around **Strategy 2** to explore the best ways to take advantage of the presence of extension offices to educate families.
- The coalition worked towards **Strategy 4** by investigating the cost and feasibility of developing an information and referral line that could provide assistance in multiple languages and that could be used by multiple Tennessee non-profits on a fee-for-service basis in order to better serve underserved communities.
- The coalition continued discussions with the Tennessee Department of Education regarding **Strategy 5**; however, this had not yet resulted in concrete action steps.
- Through support from the Retirement Research Foundation, The Arc of Tennessee received funding to host a one-day future planning session for human service professionals with The Arc of the United States. Human service professionals who received the training are now prepared to support families to initiate the future planning process. While this activity was completed through another grant, it advanced **Strategy 7**. This training activity also helped The Arc of Tennessee and the family support coalition to better engage with aging organizations in the state.
- The coalition also provided future planning informational meetings to two family groups in Nashville and Chattanooga and shared information about future planning with the family listservs, which reach over 100 families.
- The coalition educated families and people with I/DD about the new Employment and Community First CHOICES program that began in July 2016.

## 2017 Coalition Meeting

In July 2017, the Tennessee family support coalition met in Nashville, Tennessee, in person to discuss changes to the state's family support structure, identify new challenges in family support, and amend the coalition's strategies in order to move forward with an updated plan to better support Tennessee families.

## Changes in Family Support in Tennessee

During the day, members gave presentations to educate the coalition on their organizations and recent family support-related efforts being carried out in the state. Key updates include the following:

- Shifting focus of the Tennessee Commission on Aging and Disability and Area Agencies on Aging and Disability on developing initiatives to address shortages in transportation and to provide more legal assistance to people who are victims of crime, particularly people who are financially exploited. The shift towards a focus on victims of crime occurs at the same time as the passage of laws that (1) protect elders and vulnerable adults from contact with people who have been found guilty of exploiting people previously and (2) give businesses permission to refuse service when there is reason to believe financial exploitation or theft has occurred and report this to the Department of Human Services.
- CHOICES program has shifted to focus on supporting people with service utilization, including employment support, housing, and transportation.
- Tennessee participated in the Supporting Families Community of Practice grant (COP) through the Council on Developmental Disabilities from 2013 to 2017. They have been educating families and professionals about the LifeCourse Framework, a framework to help people with disabilities develop a vision for a good life and a plan on how to live the life they want (Curators of the University of Missouri, 2017), identify how to find or develop supports, and discover what it takes to live the lives they want to live. The COP is also collecting stories about how families use formal and informal supports in their lives.
- There is a coalition of organizations working together to start deciding how to develop laws and definitions related to supported-decision making in Tennessee. The coalition is still adding partners to work on this definition and to help better support people to make their own decisions.

## New Challenges Identified

The Tennessee coalition identified many challenges that impact the state family support system. These include a lack of education, systemic issues, and a breakdown of trust and empowerment of families. More detailed descriptions of challenges follow.



### *Lack of Education*

- One of the most common challenges discussed was a lack of education on available resources. Coalition members perceive that groups who have resources or expertise with family support issues do not know how or are unable to effectively tell their stories or share resources with communities.
- Another common challenge cited was that families have misperceptions or are not well educated about services. Coalition members feel that families receive poor-quality information about available resources, which causes them to choose not to access services or to not understand how to enter the system.
- Coalition members felt there is a need for more training for the direct care workforce to improve the quality of care provided.
- Members perceived a need to educate medical professionals on how and when to provide connections to the service system and to provide compassionate and effective care to seniors and people with disabilities in order to improve their overall health.
- Coalition members felt there is a need to educate law enforcement officers on how to interact with people with disabilities and seniors in crisis.
- Members perceived a need to educate families and professionals on all aspects of planning for the future, especially on supported decision-making and alternatives to guardianship.

### *Systemic Issues*

- Coalition members perceived that there are major challenges with the direct care workforce. There is a constant need for more and higher quality caregivers; however, there is high turnover in this industry, making it difficult to ensure that care workers are sufficiently trained or understand and consistently meet standards with their work. Additionally, because of the low wage offered for this position, there is significant competition with other industries that may offer less challenging jobs.
- One of the most commonly cited challenges was the perception that services are often not affordable or that families who need help are often not determined to be eligible for services. Many people with disabilities or seniors are found not to be “bad off” enough to be able to receive services; thus, the providers are not able to provide resources or the level of resources needed to help these families. Coalition members also feel that providers sometimes will (inappropriately) dissuade families from applying for or accessing certain services because they assume that the families will not qualify for services.

- Coalition members felt that access to affordable, quality transportation and housing remain two of the most significant challenges in the state. Particularly in rural areas, transportation may not be available to help people with disabilities and seniors get to or from places they need to go. In all areas, appropriate, accessible, affordable housing may not be available to people with disabilities and seniors. Coalition members also perceived there is some concern about people with disabilities and seniors becoming victims of housing scams.
- Members perceived that there are often few or no resources available after business hours. A significant challenge to the family support system is its lack of flexibility to accommodate caregiver schedules or location, particularly in rural areas where services may be far away or difficult to travel to/from.
- Coalition members perceived that families often struggle to navigate the system and feel it is overwhelming to find and manage services. This is further complicated because many agencies operate in silos and do not know how to make appropriate referrals to other agencies. Thus, families may not always receive direction to the next appropriate service. Coalition members also observe that there are many linguistic and cultural barriers preventing families from diverse backgrounds from accessing services and navigating the system.
- Coalition members perceived that many challenges in receiving support stem from a failure to receive a timely diagnosis of disability or of a serious health care condition.
- Coalition members observed that the system needs more resources and services to support aging caregivers, to support people with I/DD as they age (particularly people with Down Syndrome who are more likely to experience Alzheimer's or other dementia-related conditions), and to encourage the development of caregiver support and other support groups.
- Coalition members perceived that the long waiting lists and slow access to long term services and supports can cause stress to families that must wait years and years to be able to access services once determined eligible.
- Coalition members perceived that the prohibition against paying a family caregiver who resides with the care recipient fails to support many Tennessee families who need additional resources to supplement lost income due to care needs. Thus, this provision bars families from accessing key benefits that could keep them stable.

### *Trust and Empowerment*

- Coalition members perceived that there is a lack of trust and communication between families and the providers who serve them. This may arise due to

several factors, including: families' fear of the future, inter-family conflict about what services should look like, the perception of families that they are stuck in the system and don't have the resources they need, the inability of families to express needs and wants, family perception that no one can care for the care recipient as well as families, family distrust or unfamiliarity with workers providing care, provider perception that they know what families need or should want, and low provider expectations of people with disabilities and seniors related to the services they provide.

### **Revised Strategies to Improve Family Support**

The coalition reviewed the strategies and action steps previously identified. Updated strategies and steps follow.

**Strategy 1:** Continue to identify challenges and resources in the state by conducting at least two Community Conversations on the topic of supporting families caring for member who are elderly or who have disabilities in west, middle, and east Tennessee. These conversations will include families in rural and urban areas. The coalition will also develop, disseminate, and analyze the results of a survey of families caring for members who are elderly or who have disabilities (1,000 survey completed goal).

**Strategy 2:** Encourage connections among organizations and agencies that support families by researching options for improving linkages; compiling information on currently available resources; and developing plans to link resources across sites and include information in outreach to families, particularly those from diverse populations. The coalition will also improve information sharing across state agencies and community-based organizations by creating a group tasked with compiling and facilitating information-sharing across groups.

**Strategy 3:** Address the needs of historically underserved communities by partnering with University of Tennessee extension offices to reach counties not already served by coalition members; to follow-up on a language line that non-profits can use to engage families who do not speak English; to engage faith communities in outreach efforts to families; and to create and distribute public services announcements for radio in rural communities.

**Strategy 4:** Improve coordination and information-sharing to promote family support by streamlining processes for sharing confidential information across agencies that coordinate services; to research and develop methods to increase the awareness of

family needs in the medical community; and to improve coordination of electronic medical and LTSS records across relevant organizations.

**Strategy 5:** Encourage the development of a No Wrong Door system by convening stakeholders to review the information and referral systems across disability and aging fields; making recommendations to improve coordination; and hosting a webinar series on the Supporting Families Framework to educate community-based organizations about best practices in supporting all families.

**Strategy 6:** Encourage organizations and agencies to educate families about future planning and to provide resources to support families to plan by encouraging information and referral organizations to include The Arc's Center for Future Planning on their websites and resources and educating agencies and departments about the need for future planning through online training opportunities.

The coalition identified timelines for action steps to achieve these strategies and responsible parties to spearhead efforts. These strategies should be implemented by June 2018.

## Coalition Development Challenges

In 2015, The Arc of Tennessee experienced difficulties in recruiting members of the aging community to attend and participate in the initial state family support coalition. The Arc of Tennessee issued invitations to every local Area Agency on Aging, but none of them accepted. However, The Deputy Secretary for the Tennessee Commission on Aging and Disability did attend the coalition meeting and promised at the meeting to work with the Tennessee coalition to ensure the participation of aging groups going forward.

In 2017, The Arc of Tennessee experienced similar difficulties, even though they were working in close contact with the Tennessee Commission on Aging and Disability. Thus, The Arc of Tennessee issued direct invitations to providers of aging services to participate in the 2017 coalition meeting. This improved representation from aging organizations during this second meeting.

## 2015 - 2016 Kentucky State Family Support Coalition

*Initial Meeting: September 16, 2015, in Louisville, Kentucky*

*Second Meeting: August 25, 2016, in Louisville Kentucky*

There are at least 728,000 Kentuckians who have a disability, and there are over 614,000 Kentuckians over the age of 65 (US Census Bureau, 2015a). Kentucky has several very diverse regions but also has many rural and economically depressed regions. Overall, approximately 18.8% of the state's population lives in poverty (US Census Bureau, 2015b). Eastern Kentucky, an area that has lost much of its industry and jobs with the decline of the coal industry, has a high percentage of people who live in poverty (Lowrey, 2015).

Kentucky offers several state-funded Medicaid waiver programs to support its citizens with disabilities and seniors. These waiver programs include:

- Acquired Brain Injury Waiver
- Acquired Brain Injury - Long-term Care Waiver
- Home and Community Based Waiver Program
- Michelle P. Waiver Program: provides support to people with I/DD to stay in their own home and direct their own services
- Model II Waiver (MIW) Services: waiver for those on a ventilator 12 or more hours a day
- Supports for Community Living<sup>2</sup> waiver, which includes an opportunity for non-paid family members to take advantage of training dollars to gain further insight to a participant's routines, interests, coping mechanisms, and other traits (Commonwealth of Kentucky, 2015a).

In addition, Kentucky also runs several state-funded programs to support seniors and people with disabilities. These programs provide services (e.g., adult day care, homecare services, respite, caregiver support, chronic disease self-management programs, consumer directed and supported living programs, assisted living certification, personal care attendant programs, guardianship services, health promotion programs, employment programs, legal services), as well as information and resources (Commonwealth of Kentucky, 2015b).

While these services and benefits exist, many families in the state are unaware of all the services potentially available to them through these waivers and programs. This occurs because of a lack of collaboration between state and regional agencies, as well

as the fact that many families live in rural areas without access to the internet or other sources of information about available services.<sup>12</sup>

There is a peer/resource network developing among agencies around the state that serve people with disabilities and the aging community; however, much of this collaboration occurs at annual conferences, through the dissemination of resource guides, and informally.<sup>13</sup>

## Identified Challenges

Coalition members identified systemic, accessibility, educational, and environmental challenges that create challenges to providing family support to all families in Kentucky.

Identified systemic issues included:

- Lack of or unsustainable resources or services;
- Disparities in family support systems across categories of people supported (e.g., students, aging, disability community);
- The perception that agency staff have a “silo” mentality (staff do not know of other resources or tend not to refer people to other resources outside of their agency or expertise) that contributes to a lack of coordination between the agencies;
- Competition between different service provider organizations results in agencies not referring consumers to other organizations;
- A perception of coalition members that the system is too bureaucratic and thus too stressful for families to navigate;
- Inappropriate scope of public resources. For example, coalition members perceived that there are many people who only need a small amount of assistance, but public resources often only are available to assist people who need significant resources;
- Unclear entry points to the service system;
- A disconnect between the medical field where families receive a disability diagnosis and public service systems which provide support; and
- A disconnect between the school system and adult services for people with disabilities.

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<sup>12</sup> This information comes from insights provided by The Arc of Kentucky in their application to The Arc to develop the state coalition.

<sup>13</sup> This information comes from insights provided by The Arc of Kentucky in their application to The Arc to develop the state coalition.

Identified access-related issues included:

- Lack of access to resources and services in rural areas;
- Lack of transportation options in many areas;
- Lack of internet access in many parts of Kentucky;
- Failure of the agencies that offer Medicaid waiver or other state-funded programs in Kentucky to engage underserved groups; and
- Lack of knowledge of government and service provider organizations regarding family support services needed by underserved populations.

Identified training and information dissemination issues included:

- Families and the public often do not receive information about the importance of inclusion or about the family support system; and
- Perception of coalition members that those operating family support services do not proactively disseminate information about available services to the public but wait for people to go to the system.

Identified community integration issues included:

- Lack of inclusion of the family or person with disability in the community;
- Biases against people with disabilities and/or those who use public services; and
- Tendency for people with disabilities, seniors, and families to live in poverty, be unemployed, and/or have poor health.

## Strengths, Promising Practices, and Resources

While Kentucky's coalition identified many challenges, participants also identified some resources and promising practices for the coalition to investigate further. Several practices and resources were discussed; many of these issues focused on addressing challenges related to access and coordination issues.

In terms of improving access, participants discussed the following:

- Developing an online database of resources available in Kentucky that borrows on successes found through Kentucky's Kynect health care website ([kynect.ky.gov/](http://kynect.ky.gov/));

- Working with the Bowling Green Migrant Center to identify models to employ to connect with underserved communities, particularly those in small, rural communities;
- Working with schools and medical professionals to connect families to family resource centers and services;
- Developing a resource manual to be shared or available at public places in the community like hospitals, schools, public libraries, welfare offices, and housing assistance centers;
- Supporting the Kentucky Wired broadband initiative, which is attempting to ensure that everyone in Kentucky has broadband internet access;
- Supporting initiatives to make the 2-1-1 information system a statewide system; and
- Investigating the “No Wrong Door” systems in existence and exploring the creation of an office that would act as a point of entry for families into the service system

Training and information dissemination interventions discussed included:

- Educating the public on the importance of expanding resources and services for people with disabilities and the aging community. This education should include radio broadcasts, social media posts, and presentations at family resource fairs and conferences; and
- Disseminating information about available resources and promising practices in interagency coordination at conferences for organizations in the state.

## Strategies

In light of the challenges and promising practices discussed, the Kentucky family support coalition developed six strategies to improve supports to all families of people with disabilities and seniors in Kentucky.

**Strategy 1:** Identify existing print and online resources in Kentucky that address family support and update resources to support the early childhood and aging populations.

**Strategy 2:** Family support coalition members will meet regularly and reach out to add additional members - including caregivers - to the group to ensure that the coalition is addressing needs of families.



**Strategy 3:** Ally with historically underserved communities (e.g., non-English-speakers, grandparents raising grandchildren, offenders re-entering the community, military families, low-incidence populations like the deaf, hard of hearing, and deaf-blind communities, and homeless populations) to evaluate resources for cultural and linguistic accessibility and competence.

**Strategy 4:** Identify venues where family support information can be provided in an accessible, respectful way to families; engage the media, medical community, and schools to provide resources to families and the public about family support resources.

**Strategy 5:** Investigate using health navigators as a resource for families and find out what support can be provided to families on wait lists for services and educate and inform state officials on importance of family support, state-funded waiver and other programs, and the 2-1-1 System Initiative.

**Strategy 6:** Create master list of future planning resources and support the development of person-centered future planning for families and train providers so they know how to begin conversations about future planning sensitively.

## 2016 Coalition Meeting

In August 2016, The Kentucky family support coalition met in Louisville, Kentucky, in person to review progress made towards the strategies outlined above and to identify further action steps to take to improve family support for all Kentucky families.

Progress reported by the coalition at the meeting includes the following:

- During June and July 2016, the coalition sponsored six resource fairs that provided information to approximately 575 families across Kentucky. Each event included 15 roundtables where experts assisted families with important issues related to family support. The fairs also included exhibits by agencies advertising local programs and resources available to people with disabilities and seniors in their community (around 20 per event). See Attachment H for news articles and promotional materials about these events, as well as for a map identifying where the events were held. **(Strategy 1)**
- Coalition members have identified available family support directories and resource lists and made sure their own lists are up to date. One example of this is The Arc of Kentucky’s “The Keepsake.” It is available online at [arcofky.org](http://arcofky.org). **(Strategy 1)**

- Coalition member HDI developed an online directory that provide families important resources by topic area and is guided by many of the resource listings that the group found. This resource directory is now available online at [resources.hdiuk.org](http://resources.hdiuk.org). **(Strategy 1)**
- The Kentucky coalition has grown from 42 people representing 37 organizations in its first year to 93 people representing 63 organizations. **(Strategy 2)**
- The Kentucky coalition will seek greater representation from underserved populations, including the homeless population. **(Strategy 3)**
- The coalition has developed a shared Google calendar to share information about trainings and resources that are available to families. The calendar is accessible at [tinyurl.com/KentuckyFamilySupportCoalition/](http://tinyurl.com/KentuckyFamilySupportCoalition/). **(Strategy 4)**
- The coalition has worked to educate and inform state officials in Kentucky’s new administration about family support issues. **(Strategy 5)**
- Members of the coalition are exploring how to provide updated information on community resources to people on waiting lists for Medicaid services. The representative from the Department for Medicaid Services said that the Department would work with other coalition members to disseminate the information. **(Strategy 5)**
- The coalition created a master list of available future planning resources. **(Strategy 6)**
- The Arc of Kentucky provided statewide trainings on future planning and can provide materials to other members to host informational future planning events in their area. **(Strategy 6)**

The coalition also identified next steps that they will take to improve connections within the coalition, engagement with other stakeholder agencies, and with Kentucky families. These steps follow.

#### **Improving Inter-Coalition Connections**

- Create a Facebook page and consider creating a Twitter account for the coalition;
- Post events and meetings in the shared Google calendar; and
- Create a newsletter to share information that can be disseminated across each member’s network.

#### **Improving Engagement with Other Stakeholder Agencies**

- Continue to reach out to faith-based communities, health departments, the medical community, and Family Resource and Youth Service Centers;

- Continue to explore with United Way and 211 how to collaborate and expand services throughout Kentucky; and
- Develop a one-page document listing all the coalition partners with brief information on each to share at various statewide events to connect with other agencies and families.

### **Improving Outreach to Families**

- Outreach to students transitioning from high school to provide information to families when it is needed (which the coalition often feels is during high school). The coalition will ask an expert in transition planning from HDI to attend the next coalition meeting to explore this further;
- Update resource lists and directories with information for the homeless;
- Send resource lists and directories that the coalition has identified and developed to key contacts at the Department for Medicaid Services to distribute to people on the waiting list for Medicaid waiver services; and
- Consider hosting additional Regional Resource Fairs in other areas during the year. These fairs would be held during the school year and at different times of the day to maximize participation by family caregivers.

## **Coalition Development Challenges**

Kentucky's family support state coalition has had many successes; however, the coalition has also experienced challenges connecting with and educating families who are on waiting lists to receive Medicaid waiver services. As the coalition continues to develop, members will focus on conducting additional outreach to connect families in Kentucky with available family support resources and information.

## **Follow-up from 2016 Coalition Meeting**

As of August 2017, the host of the Kentucky state coalition, The Arc of Kentucky, will no longer lead the coalition due to the chapter's re-organization.

Prior to this change, the Kentucky state family support coalition had made the following progress towards the above strategies:

- Created a master list of resources for families in Kentucky. The Kentucky Council on Developmental Disabilities is working on developing an information hub, and the coalition was partnering with them to facilitate this.

- Developed a listserv and collaborative meetings between organizations and agencies that support families.
- Improved coordination and information sharing through the creation of a Google calendar.
- Combined the Family Support Coalition with the Supporting Families. Community of Practice group to make the group stronger.
- Held three trainings on the LifeCourse framework to families to help them with future planning.

The group experienced several challenges in further advancing these strategies.

Challenges included:

- Difficulty keeping resources and calendars up-to-date;
- Scheduling conflicts causing meetings to be cancelled;
- Difficulty receiving accurate information about people who are on the waiting list;
- Discontinued funding for the Supporting Families Community of Practice and lack of continual funding for the KY Family Support Coalition funding meant that there was no staff time to dedicate to these efforts;
- Similar efforts by other organizations made it difficult for people to designate time and effort to this coalition's objectives.

## 2016 Arizona State Family Support Coalition

*Initial Meeting: May 25, 2016, in Phoenix, Arizona*


There are an estimated 1,120,054 Arizonans over the age of 65, and there are an estimated 767,091 people with disabilities in Arizona (U.S. Census Bureau, 2016a; U.S. Census Bureau, 2016b). In the next 35 years, the growth rate of the aging portion of the population is projected to significantly outpace the growth in total Arizona population, meaning that more and more Arizonans will be over the age of 65 (Arizona Department of Health Services, 2014). As the rates of disability increase with age - and people age into disability - it is likely that the number of Arizonans who identify as having a disability will also increase (Stoddard 2014, 3).

Although most of Arizona is rural, most people who live in Arizona live in the Phoenix and Tucson metropolitan areas (Mel and Enid Zuckerman College of Public Health, 2008). Arizona is diverse in the racial and ethnic heritage of its inhabitants. Thirty percent of Arizonans identify as Hispanic and/or Latino, 4% of Arizonans identify as African-American, and another 4% identify as American Indian or Alaskan Native (U.S. Census Bureau, 2016c).

As they age, Arizonans receive support through the Area Agencies on Aging. The Agencies on Aging connect aging Arizonans with services in the community and provide respite support to caregivers (Arizona Association of Area Agencies on Aging, 2013). While Arizonans with disabilities may also access the Agencies on Aging for some services and resources, most support is provided to Arizonans with disabilities and their families through nonprofit organizations. Arizonans who are aging or who have disabilities may access health services via the Arizona Long Term Care System. However, each person must meet the eligibility requirements to participate in the system (Arizona Long Term Care System, 2016).

### Identified Challenges

At its initial meeting, the Arizona family support coalition spent the first portion of the meeting identifying the most challenging issues in family support as well as those issues they felt were most susceptible to change or “changeable”. Each coalition member was asked to identify and then indicate the three issues that they felt were most challenging and the three issues they felt were most changeable. The table below summarizes these results. Issues that were perceived by the most people to be more challenging or more changeable are at the top of the table and issues that were perceived to be least challenging or changeable are at the bottom of the table.

|  | Challenging Issues                       | Changeable Issues                        |
|--|--|--|
| Most<br><br>Least | Housing                                  | Family<br>Relationships/Sexuality/Health |
|  | Transportation                           | Education                                |
|  | Care Coordination                        | Recreation                               |
|  | Transition Services                      | Transition Services                      |
|  | Finances/Benefits/Costs                  | Employment                               |
|  | Respite                                  | Care Coordination                        |
|  | Education                                | Respite                                  |
|  | Employment                               | Finances/Benefits/Costs                  |
|  | Family<br>Relationships/Sexuality/Health | Transportation                           |
|  | Access to Services                       | Access to Services                       |
|  | Maneuvering the System                   | Marriage                                 |
|  |  | Assistive Technology                     |

This activity helped set the agenda of the most salient issues to address during the meeting. Issues specifically discussed included some of the most challenging issues: housing, transportation, and respite. Specific challenges include the following:

### Housing

- Coalition members perceived a lack of affordable, accessible, and safe housing options in the community for people with disabilities and seniors.
- Coalition members perceived a need to aid families to identify and review housing options available in the community and to assist the family in deciding when to transition to a new home in the community.
- Coalition members perceived that families often struggle to find the right staff to support a person in his or her home.

### Transportation

- Coalition members perceived that the lack of transportation services provided through the Arizona Long Term Care System inhibits families from getting health care services they need. Not only can this result in poorer health outcomes for seniors and people with disabilities, but missed appointments result in the family incurring “no show” fees.
- Coalition members perceived that many families – particularly families in rural areas – lack access to transportation to go about life (e.g., go grocery shopping, go to senior center). Lack of access to transportation often also results in social isolation.

- Coalition members perceived that people with disabilities and seniors may benefit from training on how to use public transportation in regions where adequate and reliable systems operate.

### **Respite**

- Coalition members perceived that families often lose respite hours to which they are entitled due to the inability to locate programs that will provide respite services for their sons or daughters. Often, this is due to the providers' not having space or not being able to care for people with serious medical, emotional, or behavioral issues.
- Coalition members perceived that respite services are also often unavailable to families who use private insurance or Medicare only. Coalition members discussed the need for more funding for voucher programs so that more families can access respite services.
- The coalition members also perceived that parents and caregivers often must pay for more hours than needed (*e.g.*, pay for 2-3 hours when only need 1 hour)
- Coalition members also perceived that there is not a large pool of workers who will provide respite services. Lack of availability of respite workers, according to coalition members, is due to low pay, lack of structure for their work and employment, and the many requirements that they must adhere to in order to provide respite services.

In addition to these topical issues, the Arizona state coalition identified several systemic issues that impact how family support is provided in the state. In addition to a lack of funding generally, systemic challenges include cultural competence, coordination, workforce, and public awareness issues. Specific concerns included:

### **Cultural Competence Issues**

- Coalition members perceived that Arizona experiences barriers to providing culturally competent assistance to Hispanic, Latino, and Native American families due to language barriers, lack of understanding of the needs of diverse communities, and lack of current connections in these communities.

### **Coordination Issues**

- Coalition members perceived that the quality of family support services in Arizona often appears inconsistent or inefficient to its users.
- Coalition members perceived that provider agencies often compete with one another, which reduces the potential to coordinate services across agencies.

- Coalition members perceived that families often do not understand how different facets of the complex family support system interact with one another and often feel lost due to jargon.

### **Workforce Challenges**

- Coalition members perceived that the family support system in Arizona does not incentivize people to work as direct care workers (DCWs). Working in the field is very stressful, and wages are generally low. As a result, there is often high turnover in DCWs. Current estimates for DCW turnover statewide are between 50 and 70 percent annually.<sup>14</sup> For providers, training and onboarding for these positions is often costly and inefficient.

### **Public Awareness Issues**

- Coalition members perceived that many families who support someone who is aging do not know that they can receive respite due to difficulty getting information to families, especially families who come from historically underserved communities.

## **Strengths, Promising Practices and Resources**

To address the challenges identified, the Arizona coalition identified the following promising practices and resources:

- Creating a guidebook or one-stop website for families;
- Encouraging state government to mandate that each family needs or receives a support coordinator or systems navigator to help understand the system of support in place;
- Encouraging insurance plans to become invested in good health of people with disabilities and seniors by focusing on providing outcome-based care in the medical home community;
- Encouraging provider, service, and advocacy organizations to identify a range of possibilities for services and focus on discussing transition planning earlier and more frequently with families to support families and help them avoid health and other crises;
- Implementing public awareness campaigns in communities statewide to educate the public on the importance of integrating and involving people with

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<sup>14</sup> This data comes from Dr. Laura Love, Assistant Director and CEO, Arizona Dept. of Economic Security-Division of Developmental Disabilities. She made this statement in a meeting with Jon Meyers, Executive Director of The Arc of Arizona on 20 September 2016.



disabilities and seniors in the community, on issues important to caregivers, and about available family support services;

- Providing training to service providers on ways to better address key challenges, like providing housing and transportation solutions for families or navigating support systems;
- Encouraging lawmakers to invest money in the system to create incentives for state and local agencies and aging and disability organizations to talk to one another; and
- Educating physicians on how to speak more positively about disability and on the importance of providing effective resources at the time of diagnosis to help parents and other caregivers understand the diagnosis and better support their family member(s).

The coalition also identified several programs that may be replicable across the state, including the following:

- The Arc of Chandler-Gilbert has a van sharing program and agreement with several other local nonprofits. The organizations join together to provide transportation services to their communities.
- The Phoenix Dial-a-Ride program provides door-to-door shared-ride transportation to people with disabilities, seniors, and the public living in Maricopa County.
- The Ability-360 independent living center provides home modifications for people with disabilities and seniors in the greater Phoenix area.
- Tucson paratransit agency Sun Van provides transportation services to people with disabilities.
- The Arizona Health Care Cost Containment System provides housing allotments available for people with a Serious Mental Illness (SMI).

## Strategies

In light of the challenges and promising practices discussed, the Arizona family support coalition developed nine strategies to improve supports to all families of people with disabilities and seniors in the state.

**Strategy 1:** Expand the base of available information related to family support needs, resources, and challenges through outreach to institutions and individuals. This will occur by conducting a statewide survey to identify the family support system's strengths and weaknesses. The coalition will also host listening sessions targeted to families in Phoenix, Tucson, and Flagstaff to

better understand families' challenges and identify potential geographic or cultural trends related to these challenges.

**Strategy 2:** Document the range and availability of family supports in Arizona and identify any disparities based on geography, socio-economic status, and ethnic/racial background.

**Strategy 3:** Further explore the intersection of aging and developmental disability-related challenges in Arizona to understand how, where, and to what degree agencies from the two disciplines can collaborate. The coalition will establish a steering committee of leaders in aging and I/DD service and advocacy organizations that will focus on specific issues identified as highest priorities (e.g., respite, transportation, care coordination). The coalition will also develop a mechanism to disseminate information about family support through both service systems.

**Strategy 4:** Work with governmental agencies, cross-disability, and aging groups to develop an online information clearinghouse for programs serving target populations.

**Strategy 5:** Engage stakeholders representing Native American and Hispanic/Latino residents throughout state. The coalition will survey residents from these communities to identify the challenges that they experience and will convene community representatives to discuss potential solutions, improvements, and innovations.

**Strategy 6:** Reduce or eliminate information access barriers that prevent agencies from adequately serving target populations. The coalition will create and implement a Universal Release of Information form that would be valid across all government agencies and state-contracted provider agencies.

**Strategy 7:** Convene a group of stakeholders to review the current information and referral systems across aging and disability fields. This group will develop and implement a survey of state government departments, private/non-profit agencies, and other community organizations to learn about their current information and referral services and to identify how the systems can work better together.

**Strategy 8:** Host a one-day summit on Supporting Families Framework (Life Course Tools) for behavioral health, adult protective services, early education, and exceptional student services government departments to learn a new and common framework on providing family support.

**Strategy 9:** Disseminate future planning information and resources to state and private agencies and outreach about future planning to constituents and other consumers at conferences around the state.

## Coalition Development Challenges

The Arizona coalition faced two challenges in developing its coalition.

First, The Arc of Arizona issued invitations to Native American tribes, behavioral health experts, and local Area Agencies on Aging to join the coalition. However, these efforts were not initially successful.

- Despite repeated attempts, The Arc of Arizona was unable to secure participation from any tribes in the Phoenix metropolitan area. However, The Arc of Arizona is aware that the effort to involve these communities will take time and is prepared to approach participation with a more long-term perspective.
- There was only minimal participation from behavioral health experts. The National Association on Mental Illness Arizona was invited but did not to attend the meeting. Only one mental health provider attended the initial coalition meeting.
- Four Area Agency on Aging directors were invited and accepted invitations for the initial coalition meeting. However, three of the four unexpectedly cancelled. This greatly reduced the pool of knowledge about aging issues in rural areas from which the group could draw.

Second, coalition members who attended the initial meeting also experienced difficulty in agreeing on the extent to which the needs of the aging and disability populations overlap and how they can be collaboratively addressed. Coalition members spent two hours of the meeting day determining how the group should collectively approach the day's discussions, with aging organizations expressing concern that including issues like employment and education in a family support discussion would not be relevant to their constituents' interests. As a result of this debate, the time to fully address solutions to critical issues identified during the meeting was limited.

## Follow-up from 2016 Coalition Meeting

As of August 2017, the Arizona Family Support Coalition has yet to achieve the action steps outlined in the plan in a measurable way. While the coalition members had achieved general agreement on each of the strategies and that they merited ongoing

attention, the groups experienced many challenges that made substantive progress difficult. The challenges included:

- Lack of financial or human resources by the host agency to execute plan fully
- Lack of will/assistance from coalition partners to advance the plan
- Existence of other immediate policy and programmatic events that took precedence over the work of the coalition, including legislative matters and events surrounding the uncertain Medicaid landscape
- Lack of commitment to collective action due to a degree of resistance in tackling all problems together due to historic rivalries, political and philosophic differences, and distrust between public and private sector agencies

The Arizona coalition did note one positive aspect that they are seeing in Arizona: increased general awareness for improved family supports and future planning. The coalition noted that many groups who were engaged in the coalition, including financial planners and attorneys, the Sonoran University Center for Excellence in Developmental Disabilities (UCEDD), state agencies working with seniors and people with disabilities, and multiple nonprofit organizations are working to promote learning opportunities and educate policymakers about the need to improve family support. The coalition meeting allowed these groups to get to know each other better and more frequently work with each other to promote awareness about family support.

## 2016 California State Family Support Coalition

*Initial Meeting: June 28, 2016, in Sacramento, California*

According to the US Census Bureau, there are an estimated 5,189,558 Californians over the age of 65 and 3,851,442 Californians with a disability (U.S. Census Bureau, 2016a; U.S. Census Bureau, 2016b). California is projected to be one of the fastest growing states in the nation in total population. Even so, its elderly population is expected to grow more than twice as quickly as the total population (California Department of Aging, 2015a).

California is also a diverse state. According to US Census Bureau data, 38.2% of Californians are Hispanic or Latino, 13.5% are Asian, and 5.9% are Black or African American (U.S. Census Bureau, 2016c).

California has several different programs that offer family support resources to people with disabilities and their families. Multiple programs and services are available through the California Department of Developmental Services (DDS) and the Department of Rehabilitation (DOR), including self-directed and independent living services, housing assistance programs, rehabilitation programs and services, and employment services.<sup>15</sup>

For seniors and their families, the California Department of Aging (CDA) contracts with 33 Area Agencies on Aging (AAAs) to coordinate local community-services. Each AAA is responsible for determining the array of services, including caregiver information, assistance in gaining access to services, counseling and training support, temporary respite, and limited supplemental services to complement the support provided by family caregivers. Services are available to unpaid caregivers supporting older individuals, as well as grandparents and older relatives caring for children.<sup>16</sup> The CDA also implements the Aging and Disability Resource Center (ADRC) initiative, which aims to streamline access to long-term services and supports for people with disabilities and seniors (California Department of Aging, 2015b).

Additionally, Medi-Cal – California’s Medicaid Agency – offers several waiver programs that can be accessed by people who are aging or who have physical, mental and/or behavioral, and/or intellectual or developmental disabilities. These waivers provide home and community-based or managed care services, mental health, or

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<sup>15</sup> Background information provided in the application to develop the coalition submitted by The Arc California.

<sup>16</sup> Background information provided in the application to develop the coalition submitted by The Arc California.

palliative care services to eligible participants (California Department of Health Care Services, 2016).<sup>17</sup>

## Identified Challenges

While a significant infrastructure exists to support families in California, the coalition identified a variety of systemic, education, and community awareness challenges that impact efforts to support California families.

### Systemic Challenges

- Coalition members identified challenges surrounding the amount and quality of services provided to families.
  - Members perceived that there is a shortage of high-quality medical care resources, direct care workers, respite services, mental health services, transportation services, and behavior-based projects that serve people who are aging or who have disabilities and their families.
  - Coalition members perceived that services are often provided in response to crises rather than by a person's and family's current needs and desires. As a result, there is often inadequate planning for resources and prescribed services do not always match the real care need.
  - Members perceived that high staff turnover at agencies that provide support services negatively impacts the quality and quantity of services that can be provided to California families.
- The coalition identified many challenges related to funding.
  - Some coalition members perceived that Proposition 98 – a state law which mandates that a certain percentage of the state budget be spent on education – means that other services, including family support for people who are aging and who have disabilities, must compete with other services for the remaining dollars. This endangers these needed services.<sup>18</sup>
  - The coalition perceived that this competition for funding and services often makes it difficult for agencies and groups (e.g., aging and disability groups) to come together and advocate in a unified manner for services that all families need.
- Coalition members perceived that the system itself often provides disparate services to families.

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<sup>17</sup> In 2016, family planning services were also included in Medi-Cal programs. However, as of our 2017 update, these services have been removed.

<sup>18</sup> More background information provided in the reference material (Legislative Analyst's Office, 2005).

- Members perceived that there are often multiple points of entry to the service system, depending on the group needing assistance. This can cause confusion or frustration for families trying to find needed services and may dissuade families from seeking assistance from the service system.
- Members perceived that there is often very uneven access to services and supports for families from diverse ethnic or cultural groups. There appears to be a dearth of accessible resources tailored to these families' needs and many families in these communities lack access to the technology needed to facilitate access to information and resources.
- Coalition members also perceived that the family support system is often challenged by the state's geography and changing demographics.
  - Coalition members perceived that California's many urban and rural areas make providing and coordinating support for all families difficult.
  - Members perceived that caregiving is increasingly occurring across generations and in diverse and often inter-generational families as opposed to the traditional two-parent nuclear family.
  - Coalition members perceived that the support system has failed to provide adequate supports for the increasing number of Californians who are diagnosed with autism.

#### **Lack of Awareness or Education**

- Coalition members perceived that caregivers and staff providing services often need education about what resources are available in the community, as well as about how to identify and access all available benefits and services.
- The coalition perceived that regional centers and AAAs often have a knowledge gap about the resources available to families.
- Members perceived that there is a lack of well-trained staff to provide services to families. Reasons coalition members reported for this lack of staff include lack of training to provide effective services and high staff turnover.
- The coalition perceived that families often get information from other families; however, this information is often inaccurate or anecdotal.

#### **Community Awareness**

- Coalition members perceived that community members often have a negative perception of people who are aging or who have a disability.
- The coalition perceived that there is a tendency within American and Californian culture to shame people who access public benefits or services, often blaming their need for support on laziness or a sense of entitlement.

Members reported that this tendency may impact the generosity of public support offered to people who are aging or who have disabilities.

## Strengths, Promising Practices, and Resources

The California family support coalition identified the existence of significant infrastructure to provide family support as the state's greatest strength. California has several programs that provide family support services to families of people with disabilities and seniors. These include several resource centers, policy institutes, public benefit systems like Medi-Cal, supported employment and day programs, language support programs, healthcare providers and centers, independent living centers, respite programs, a 2-1-1 information system, regional centers for people with developmental disabilities, and school systems that can help provide assistance to families in the state. California also has legislation in place that guarantees services and support. For example, the Lanterman Act gives people with developmental disabilities the right to services and supports to live independent lives in the community (California Department of Developmental Services, 2001). However, while the infrastructure exists, there aren't enough resources available within the system to provide the support needed – and families often do not have the money to access the supports on their own.

In addition to identifying strengths, coalition members also identified promising practices and resources to investigate or consider further. These include:

- Engaging local park and recreational centers, faith communities, and community centers in order to encourage families to participate in existing support programs;
- Investigating existing telehealth models that provide remote access for health care appointments as well as technology applications that provide care coordination or training to live more independently; and
- Connecting with PACE, a state health care and service coordination program for seniors so that they may live in their homes rather than receive care in a nursing home (CalPACE, 2016).

The coalition also identified some opportunities centered around federal or state-level system changes.

- Currently, there is discussion about expanding eligibility for services through the PACE program and through community-based adult services to a broader group of people with disabilities. This may result in additional opportunities for collaboration between the aging and disability communities.



- The California state legislature has developed a California Task Force on Family Caregiving, which currently does not include representatives from the I/DD community. Joining this community may enrich policy conversations about how to support all California caregivers.

## Strategies

In light of the challenges and promising practices discussed, the California family support coalition developed six strategies to improve supports to all families of people with disabilities and seniors in the state.

**Strategy 1:** Advocate for coalition members to participate in public policy forums and collaborations that discuss the implications of the challenges family caregivers face. During the initial meeting, the coalition learned about the new California Task Force on Family Caregiving sponsored by the California state legislature. This task force had not yet appointed anyone from the I/DD community. Coalition members want to advocate for a position for the I/DD community on this task force.

**Strategy 2:** Encourage greater connection among organizations that support families by maintaining effective collaborations in a variety of policy areas important to all California caregivers. These include presenting family support coalition updates at the California Collaboration for Long Term Supports and Services and the Aging and Disability Resource Connections Stakeholder.

**Strategy 3:** Participate in forums and community groups representing underserved populations. The Arc of California will develop a list of diverse advocates to participate in the California Task Force on Family Caregiving. The Arc of California will work closely with the state appointment agency to advocate for one of these candidates to be appointed to the task force. The coalition will also establish regular contact with Fiesta Educativa, a Hispanic and Latino advocacy organization, as well as the Chinese Parent Association for the Disabled.

**Strategy 4:** Improve coordination and information-sharing to promote family support by convening the coalition to discuss policy developments impacting family caregivers and suggest additional strategies that advocates can work to accomplish.

**Strategy 5:** Work collaboratively with the senior groups and independent living centers to establish and later implement a model “no wrong door” referral system in the state’s Aging and Disability Resource Centers.

**Strategy 6:** Encourage organizations and agencies to educate families about future planning and to provide resources to support families to plan for the future. The coalition will do this by reinstating Partners in Policymaking advocacy project to include parents of mature adults and presenting The Arc’s Center for Future Planning tool at the California Department of Aging and during The Arc of California’s and United Cerebral Palsy’s Public Policy Conference.

## Coalition Development Challenges

The California state coalition encountered two challenges: attendance of organizational representatives at the event and prioritizing and developing a concrete action plan.

The Arc of California invited 43 organizations to the state family support coalition’s initial meeting. While 20 organizations accepted the invitation, only 15 organizations attended the initial meeting. The Arc of California identified the following challenges that made it difficult to attract attendees during their August meeting.

- It is often difficult to get stakeholders in the room during the summer.
- Five coalition members were unable to participate in the meeting because they had to attend to an urgent need of an aging parent.
- Many representatives from the disability community related that they do not see the value in partnering with aging services and feel protective of the “silos” services they receive.

When coalition members began to develop an action plan that included concrete strategies, they struggled to identify steps that could be taken. While coalition members felt overwhelmingly positive about the discussion at the meeting, this was the first time that many of these organizations had been brought together. As a result, the organizations were not yet willing or trusting enough to suspend the needs of their constituents to work together. However, the coalition has great interest and desire to keep moving forward together to build trust and take steps to benefit all families.

## Follow-up from Coalition Meeting

In winter 2016, The Arc of California’s executive director resigned. The new executive director has postponed the development of California’s state coalition as he acclimates to a new role and new organization. However, family support is a priority for The Arc of California, and the director will look for future efforts to advance the work of the coalition.

## 2017 Wisconsin State Family Support Coalition

*Initial Meeting: August 3, 2017, in Racine, Wisconsin*

According to the US Census Bureau, there are an estimated 900,763 Wisconsinites over the age of 65 and 660,830 Wisconsinites with a disability (U.S. Census Bureau, 2017a; U.S. Census Bureau, 2017b). By 2040, the population ages 65 and older will grow by 72%; the population is rapidly aging in the northern half of the state. This may be particularly challenging, as northern counties have moderate to high rates of poverty based on U.S. Department of Agriculture data and a higher level of health concerns per County Health Rankings (Wisconsin Department of Health Services, 2017b).

Wisconsin has an increasingly diverse population. Currently, Hispanic and Latino and African Americans make up the state's largest minority groups at 6.3% of the population each. These population groups have been growing steadily but remain concentrated in the southeast region of the state. For example, in Racine county, both the Hispanic and Latino and African American populations are nearly double the state average at 12.3% and 11.1% (U.S. Census Bureau, 2017c).

There are many resources available in Wisconsin to support people who are aging and who have disabilities. These include:

- **Home and Community Based Waivers:** Seventy-five thousand Wisconsinites with disabilities or seniors receive services that can include assistance with activities of daily living, supportive home care, employment supports, transportation, and care.
- **Aging and Disability Resource Centers (ADRCs):** Forty-one ADRCs around the state provide information, advice, and help with locating services or applying for benefits. Main functions of an ADRC include providing long-term care options counseling, prevention of nursing home admissions, assistance with nursing home relocations to the community, personal follow-up to options and other resource counseling, short-term service coordination, benefit coordination, and help with transition age youth.
- **National Family Caregiver Support Program:** Every county and Wisconsin tribe has a program to help caregivers of older adults and people with dementia find solutions to challenges. Services offered include assistance navigating and scheduling care and helping families understand options for care.

- **Wisconsin Alzheimer’s Family and Caregiver Support Program (AFSCP):** The AFSCP serves people with Alzheimer’s or other dementia-related conditions by providing respite care, household services, caregiver support, and education. The AFSCP is available in 16 counties and 3 tribes.
- **Medicaid waivers for children with disabilities:** Children who qualify may receive long-term supports through Medicaid waivers. Services include service coordination, respite care, and community supports.
- **Children with Special Health Care Needs Regional Centers:** Five regional centers serve families with children and youth with special health care needs to help them find services, receive information, and connect to community resources.<sup>19</sup>

## Identified Challenges

The coalition identified a variety of services and supports that Wisconsin families need and challenges Wisconsin families face. These challenges were collected through a pre-meeting survey of attendees.

### Wisconsin Families’ Needs

- *Access to Quality Supports and Services:*
  - Support to keep life and family balanced (e.g., respite, long-term support, day services, employment services), including more flexible benefits and services
  - Background checks for caregivers to ensure quality care
  - More flexible benefits and services, including specialized resources when needed
- *Resources, Information, and Guidance to Navigate Issues:*
  - Information on available resources and how to access them and a “Go-To” person with whom families can have a conversation about services
  - Support for aging caregivers of adults with disabilities to plan for the future and plan for care after parents can no longer provide care
  - Education on caregiving, dementia, and other relevant topics
  - Support to coordinate services and navigate services, especially when navigating multiple systems

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<sup>19</sup> This information comes from insights provided by The Arc of Wisconsin in their application to The Arc to develop the state coalition.

- Information about guardianships and decision-making supports
- Support and training regarding the individualized education plan (IEP) process and working with schools
- *Emotional Support*
  - Emotional support from professionals, friends, and peers
  - Support to connect with other families to learn from each other
  - Support to form community connections and be engaged in the community
- *Existence of More Resources or Better Resources for Families*
  - More financial support for families
  - Affordable and accessible transportation
  - Education for employers and workforce policies that encourage employers to better support and provide flexibility to employees who are caregivers
  - Housing Assistance

## Challenges Families Face

- Coalition members felt that concerns about the sustainability of the support system is one of the most important issues for families. Members feel that families are worried about how the state will deal with challenges to the Medicaid and Medicaid Long-Term Care (LTC) services currently offered. There have been discussions around possible cuts in services, including discontinuing pay for family caregivers. Thus, families are worried they will lose critical supports for their family members who need them.
- Members felt that many families lack effective access to and the ability to navigate the current family support systems. Families, especially families of color, do not always have access to clear, comprehensible information about available services. Many families of all backgrounds find it difficult to access and coordinate care and navigate the system. Families often need – but do not receive – help to problem-solve issues when services are not sufficient, not available, or do not meet family needs.
- Coalition members reported that families often feel isolated. Many families are dealing with feelings of being stigmatized. Many family members may have difficulty communicating their needs, sometimes out of fear.
- Members perceived that services in the current system are inadequate. They cite a shortage of in-home care workers; lack of housing options and community living arrangements that meet family needs; lack of transportation; lack of quality health care; and lack of community support for people with dementia. Members perceived that there a lack of services in certain

geographic areas, which means that family members sometimes receive services in counties where they do not live.

- Coalition members perceived that aging parents struggle to plan for the future of adult sons and daughters with disabilities and often do not receive the help they need to make future plans.
- Members observed that families often find it difficult to find trustworthy supports and services, including natural supports, that can allow them to live and age safely in their own homes.
- Coalition members perceived that many families do not have enough money to pay for services and health care and to keep family members at home.
- Members perceived that families often lack resources/awareness to support self-determination when adults with disabilities live with their families and to support children with disabilities to become independent adults.
- Coalition members also perceived that multilingual families and families from diverse cultures sometimes fall through the cracks. This is sometimes due to lack of trust between the family and the service system; the system not providing information in a culturally-sensitive manner; or families being afraid to access services due to concerns about immigration status or fear that it will undermine other services and supports received by the family.

## Strengths, Promising Practices, and Resources

The Wisconsin family support coalition identified several strengths, promising practices, and resources available across the state. Coalition members identified 16 state programs, four national programs, and five promising ideas that could be used to enhance supports and services for Wisconsin families in the meeting pre-survey. Many of these programs were also discussed or highlighted during the meeting.

During the meeting, attendees were asked to identify the four most promising programs. Programs identified included (from most commonly identified to least):

- *Journey Forward (WisconSibs)*: This is a program specifically for siblings. This program focuses on supporting siblings to help their family make future plans, using their unique strengths and role in the family.
- *Living our Visions, Inc. (LOV-Dane)*: This is a family-led program where families work together to address common interests. Families select themselves to be part of a group, develop shared values and interests and work together to address issues. Families are given a limited amount of money, training, and support to make person-centered plans, and facilitation support to address

issues. Recent work has surrounded employment, building social networks, moving into a next home, and future planning.

- *Building Dementia-friendly Communities*: This is a toolkit developed by the Wisconsin Department of Health Services, the Alzheimer’s Association of Southeastern Wisconsin, AARP Wisconsin, and local communities to implement projects to create dementia-friendly areas throughout the state (Wisconsin Department of Health Services, 2017a).
- *Caregiver Coach program (La Crosse county)*: This program employs a staff person to visit a home, assess needs, and determine services a family needs to access (e.g., adaptive equipment, respite). The staff person develops a care management and case plan. This plan emphasizes support for the caregiver. This program aims at providing intensive involvement for a short period, not sustained support.
- *Specialized Supportive Services*: A staff person is dedicated to supporting African American and Latino families to navigate the support system. This staff person does a home visit, aids the family to identify and navigate services, refers the family to resources, and provides crisis planning. This person receives referrals through Aging and Disability Resource Centers. The program also provides training for other organizations in Milwaukee county.
- *The Center for Future Planning (The Arc)*: In 2014, The Arc founded the Center for Future Planning, which focuses on providing resources and information to support families to plan for the future. The website includes a tool that helps people walk through steps of making a future plan. The Center is developing a series of videos in which self-advocates discuss how they made future plans. The Center also hosts a full-day training for professionals to train them on how to provide assistance to families about future planning. A training will be held in Wisconsin in fall 2017.
- *Parent University (Milwaukee)*: This is a grassroots community organizing model that helps African American families access needed services and address family support needs. A trusted advocate (a peer with a “degree of life” in supporting families) develops a relationship with the family. The advocate makes the family feel comfortable and creates trust, which enables the advocate to provide education, resources, and counseling after the relationship has developed. Parents who receive education and information then pass along this support to other families. There is also a central office space where

families can go if they need support to solve problems and do not want people to visit their home.

- *Sib 2 Sib program*: This program connects adult siblings to one another.
- *Home Chore program*: Several counties implement this program, which connects caregivers with basic, monthly housekeeping services at low or no cost.

Other promising practices identified included:

- *Memory Care Connections programs (ADRCs)*: Six-week, evidence-based program that teaches caregivers how to communicate with people with dementia, take care of themselves, and address behavior issues. Many caregivers come in with reservations and do not want to discuss difficult issues. Through the program, caregivers are referred to services they need.
- *The Future is Now (University of Illinois Chicago)*: The Future is Now is a multi-session training that brings the whole family together to make a plan for the future. The person with the disability decides who should be involved. During the training, there is time and space for peers to talk to each other and then time for the family to come together and learn from each other. The program includes homework for the family to make a future plan roadmap.
- *Community Conversations model*: Brings a diverse group of people from a community together to develop a shared sense of what the community needs related to an issue. Most recently, this discussion centered around employment. As a result, some people who were previously unemployed were able to find jobs.
- Use of evidence-based programs for falls prevention, self-management of chronic illness, and tools for caregivers at the Wisconsin Institute for Healthy Aging.
- *Community Engagement models (e.g., Bridges over Poverty)*: Wisconsin tribes are using these models to create change within their communities and to better implement tribal programs.
- *AT Home with Dementia (Brown county)*: A program to provide adaptive equipment to people with dementia.



- Use of dementia care specialists to assess family needs and connect them with services.
- Use of evidence-based best practices in providing parent-to-parent support for families raising children with disabilities by Parent to Parent of Wisconsin.
- *Supported Decision-Making Community of Practice*: Program increases access and connections for families in various communities statewide.
- *Learning for Independence (Fond du Lac High Schools, Moraine Park Technical College)*: a cooperative transition program for students with disabilities.

In addition to overall best practice programs, the coalition specifically focused on promising practices in serving families who are traditionally underserved because the coalition perceived this was an area that needed increased attention.

The coalition convened a panel with expertise in supporting families that are African American, Hispanic, Native American, and Hmong to offer advice and guidance. Key individual and organizational promising practices included:

- Individual Practices:
  - It is critical to build trust and reduce parents' and families' fears.
  - You need to be patient; you cannot set a timeline to build trust.
  - Establishing common ground is critical, and it is important to have someone the family trusts vouch for you.
  - Do not assume that people have technology skills or that writing a form is a solution.
  - Recognize that people are afraid or hesitant to access services, and there are reasons for this fear.
  - It is critical to understand culture, cultural barriers, and how people in a specific culture communicate so you know how to frame information in a way that is consistent with the culture and so you do not threaten or scare people.
  - Recognize that missing a meeting or a lack of progress does not mean someone does not care. The family may be facing many challenges.
  - Hear from the family what their immediate needs are and give them the information they need, not the information you want to give them.

- Organizational Practices:
  - Consider offering role-playing or simulations to teach staff how to serve or interact with families.
  - Balance expectations for the staff person to provide the flexibility and time to develop relationships of trust.
  - Do not deny cultural beliefs or traditions. Identify ways to allow people to access the system and still practice their traditions.
  - Ensure staff reflects the diversity of the community in which you work.
  - Work with organizational leadership to show commitment to this issue.

## Strategies

In light of the challenges and promising practices discussed, the Wisconsin family support coalition developed six strategies to improve supports to all families of people with disabilities and seniors in the state. Many of these strategies incorporate major challenges identified or promising practices discussed in detail. The coalition also sought to combine this work with efforts already being initiated by the Department of Health Services to support caregivers.

The coalition identified responsible parties for each strategy with an anticipated timeline to complete all action steps by May 2018. The strategies follow below.

**Strategy 1:** Continue to identify challenges and available resources in Wisconsin by re-convening the family support coalition. The coalition will advance work in this plan and in the draft Caregiver Strategy advanced by Wisconsin's Department of Health Services. This coalition will particularly seek to advance work related to expanding respite options, improving supports to families of color, engaging with employers, improving access to information, improving quality of and coordination of supports, and expanding availability of future planning.

**Strategy 2:** Encourage greater connection among organizations and agencies that support families by creating a workgroup that will explore respite, which is a key area of need in Wisconsin. The workgroup will seek to create respite hubs at the local, regional, and state level. These hubs will make it easier for people to find and coordinate respite services. The workgroup will also develop an awareness campaign to rebrand respite as an opportunity to enhance the life of the person with a disability or a senior rather than just giving families a break. The coalition will request that the Department of Health Services adopt this messaging as well.

**Strategy 3:** Address the needs of historically underserved communities by analyzing and recommending updates to government agencies to amend current caregiver background check policies and ensure families can hire the care providers they want. The coalition will also improve peer supports and culturally competent programming for families of color by reviewing existing programs to identify ways to fund programs and expand access to peer support resources.

**Strategy 4:** Improve coordination and information-sharing to promote family support by encouraging business association and employers to be partners in supporting family caregivers and by analyzing existing employer resources and making recommendations on communications strategies for employers. The coalition will also recruit community leaders to promote and participate in statewide community forums hosted by the Department of Health Services and the Wisconsin Women’s Council as part of their Family Caregiver Strategy.

**Strategy 5:** Encourage the development of a No Wrong Door system by developing a job description for “Navigators” and “Community Connectors” in the disability and aging systems. These positions will be focused on being a one-stop-shop to support families to connect with meaningful resources. The coalition will also explore expansion of family led initiatives that encourage engagement of and connection between like-minded families in a community to share resources, information, ideas, and support. The coalition will seek to write proposals to build and sustain these programs.

**Strategy 6:** Encourage organizations to educate families about future planning and to provide resources to support families to plan for the future by recruiting case managers and service providers to participate in train-the trainer activities to enable them to better understand and promote future planning and to present on future planning at annual conferences in Wisconsin.

## Coalition Development Challenges

The Wisconsin coalition did not experience any trouble hosting the initial meeting, but it flagged some state-specific challenges that the coalition will need to address in the next few months. These include the following:

- Pressure on the Medicaid budget in Wisconsin has made finding new funds for pilots or other projects to benefit Medicaid-eligible individuals difficult.

Solutions to family support issues in Wisconsin may need to be found at least initially without an expectation of new funds.

- There is a significant divide in Wisconsin between the needs of rural and urban communities. Collaboration can be difficult given the great distance between key areas of the state; northern Wisconsin communities and their needs are too often left out.

## 2017 Washington State Family Support Coalition

*Initial Meeting: August 7, 2017, in Seattle, Washington*

According to the US Census Bureau, there are an estimated 1,036,626 Washingtonians over the age of 65 and 869,865 Washingtonians with a disability (U.S. Census Bureau, 2017a; U.S. Census Bureau, 2017b). In 2014, 12 percent of Washingtonians were age 65 or older; this percentage will grow to 20 percent by 2030 (AARP, 2014).

Washington is not only a diverse state in terms of its population but also in terms of its geography. Twelve percent of Washingtonians are Hispanic or Latino; 7.7 percent are Asian; 3.6 percent are Black or African American; and 1.3 percent are American Indian or Alaska Native. Approximately 5.2 percent of Washingtonians identify as being of two or more races, most commonly White and Asian (U.S. Census Bureau, 2017c). Western Washington is urban and densely populated, with an estimated 52% of Washington's total population of 7.28 million people living in the Seattle metropolitan area (U.S. Census Bureau, 2017d). Outside of the metropolitan area, Washington is rural, with 30 or 39 counties in the state having a population density of less than 100 people per square mile or are smaller than 225 square miles (Washington Office of Financial Management, 2017).

Washington has several different programs that offer family support resources to people who are aging or have disabilities who qualify for or have a waiver to receive services and their families. Services offered include residential care services, caregiver training, information and assistance, and limited respite and crisis support. The state also funds resource centers in each county to help people with disabilities, seniors, and family members connect with available services.<sup>20</sup>

In June 2017, Washington's Department of Social and Health Services' [Aging and Long-Term Support Administration](#) was recognized by AARP as the most successful state in the country in supporting seniors and adults with disabilities. AARP evaluated all state departments of health on five criteria: affordability and access, choice of setting and provider, quality of life and quality of care, support for family caregivers and effective transitions for clients (Washington State Department of Social and Health Services, 2017).

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<sup>20</sup> This information comes from insights provided by The Arc of King County in their application to The Arc to develop the state coalition.

## Identified Challenges

The coalition identified a variety of services and supports that Washington families need and challenges that Washington families face. These challenges were collected through a pre-meeting survey of attendees as well as discussion during the coalition meeting. Common themes included a need for more services and flexibility in services; a need for more assistance accessing and navigating the system; a greater emphasis on serving underserved families; more effectively addressing lack of information and misinformation; closing system gaps; and providing greater incentives to providers to give quality care.

### Need for More Services and Flexibility in Services Offered

- Coalition members perceived a lack of providers for specific services including respite, behavioral support, medical care, system navigation, crisis support, mental health services, housing assistance and specialized homes, legal support, support in the criminal justice system, hoarding, direct care services, daycare options, employment opportunities (including flexible leave policies for working caregivers), and educational opportunities.
- Members observed that people who live in rural areas experience significant barriers due to a lack of providers, services, and transportation to get to and from services.
- Coalition members perceived that there are inadequate resources for people who need behavioral supports and people who have dual diagnoses of I/DD and mental health issues.
- Members perceived that the system does not provide sufficient specialized support services for people with complex needs.
- Coalition members perceived that the lack of housing support and assistance leads to more homelessness and instability in the lives of seniors, adults with I/DD, and their families.
- Members observed that trends of people moving further out from cities due to economic/housing displacement is causing people to become less able to access services.

### Need for More Assistance Accessing and Navigating System

- Coalition members felt that families often experience stress and a sense of being overwhelmed due to the huge learning curve that they experience when navigating the family support system.

- Members perceived that points where families need to access the system (e.g., agencies, providers, medical providers) are sometimes “broken” and families are unable to access or be referred to other services.
- Coalition members perceived that there are many procedural hurdles that families must overcome to navigate the systems of care (behavioral, disability, educational, vocational, and aging) and these systems do not think across the lifespan or needs of a person.
- Members observed that changing names and acronyms and use of different terms and languages cause challenges for families in navigating available services.
- Coalition members perceived that individuals and agencies struggle to determine which services and choices are best for the individuals being served due to a lack of knowledge of how systems cross over. Sometimes, professionals will “misguide” people based upon the professional assuming that services are not available.
- Members perceived that there needs to be a more efficient structure for reviewing and navigating services and better coordination between nonprofits to disseminate information.
- Coalition members observed there is a need to identify and then provide outreach, education, and support to assist families that are in denial about needing services. There is a need to help these families navigate conflict over what support is needed and to assist the family to develop a shared expectation about accessing care so that the family can access needed services.

### **Greater Emphasis on Serving Underserved Families**

- Coalition members perceived that providers often need additional training to provide services to families in a culturally appropriate manner that aligns with the belief system of the family.
- Members perceived that there is a lack of providers who currently offer culturally-relevant services in Washington state.
- Coalition members observed that the system needs to do more outreach and support to help families overcome cultural, linguistic, and generational barriers or resistance to engaging with the service system. This includes a need for greater outreach or services to build trust between families and the system.

- Members perceived that families' immigration status can cause families to be afraid to access services. As a result, more effort needs to be made to build relationships and trust with these families.

### **More Effectively Addressing Lack of Information/Misinformation**

- Members observed a general lack of awareness of available programs or even misinformation about programs due to a lack of funding to promote programs. This can be especially problematic in rural areas, where information is often shared via word of mouth between families.
- Coalition members felt that there needs to be more emphasis on making information about programs more accessible, especially programs related to crisis prevention.
- Coalition members perceived that more effort must be made to reach out to and engage people who are isolated, people who are in denial about how much help they need, and people who want to avoid a social stigma related to services.
- Members observed that more effort must be made to intentionally connect with families at the point where families are ready and able to hear this information.
- Coalition members perceived that there is a need to provide education to medical professionals on how to take a more active role in assisting and recognizing caregiver and family support issues and connect people to resources.

### **Closing System Gaps**

- Coalition members felt that one of the greatest challenges in the system is that it is still based on the premise of institutionalization. Families must waive right to institutionalization to access services.
- Members felt that the family support system is antiquated and does not effectively leverage technology to provide services to families and to avoid unnecessary procedural hurdles (*e.g.*, too frequent care assessments, assessing when not needed).
- Coalition members felt that there is a scarcity of services available for people who do not qualify for Medicare or Medicaid and who are not considered to be in "crisis" or "badly off enough" to receive support.



- Members stated that caregivers for people who are under age 18 should be eligible to be paid. Similarly, rules making paid caregivers ineligible to access certain services should be reexamined.
- Coalition members observed that the current design of funding for services, which provides the same amount of funding regardless of the level of support received, is not flexible enough for families with greater needs and is not being well used for families with fewer support needs.
- Members perceived that the current unstable federal climate and resulting instability in the health insurance market is creating undue stress in the family support system.
- Coalition members observed that the eligibility criteria are not always clear between organizations, and that pathways to services are not always equitable for all families.

### **Providing Greater Incentives to Providers to Give Quality Care**

- Coalition members perceived that providers often face a complexity of contracting requirements, conflicting minimum wage laws, budget cuts, and a shortage of workers.
- Members perceived that direct care workers often earn wages too low to attract and retain a quality workforce and that training provided to workers does not prepare them to provide high-quality care, customer service, or address challenging behavior.
- Coalition members perceived that these challenges often mean that workers make false assumptions, are not motivated to meet families where they are, and fail to address the actual needs of caregivers and families.

During the coalition meeting, members were asked to identify the top 3 challenges that they perceive in the state. The highest rated responses included (1) providing needed behavior support to families, (2) making respite services accessible to families, (3) providing housing assistance to make families stable, and (4) providing services for people who are falling through the cracks due to service eligibility.

## Strengths, Promising Practices, and Resources

The Washington family support coalition also identified several strengths, promising practices, and resources available across the state. These include a generous system infrastructure and increasingly positive attitudes towards caregivers and caregiver support.

### Generous System Infrastructure

- Coalition members noted Washington has a generous service infrastructure. Specific provisions noted include:
  - The option to care for a family member and receive pay for it,
  - Reduced age restrictions for eligibility for aging and disability services,
  - Flexibility on how to use money from waivers,
  - Eligibility of family members to provide paid support services,
  - Increased special education support,
  - Area Agencies on Aging in every area of the state,
  - Access to the Family Caregiver Support and Lifespan Respite program, and
  - The availability of waiver services, including the 1115 Medicaid Transformation Waiver.
- Members noted that there are many programs in the state that offer caregiver support services, respite programs, caregiver support groups, and education to caregivers.
- Coalition members perceived that community organizations like churches, crisis clinics, multicultural family agencies, parent-to-parent groups, YMCA/YWCA organizations, and other nonprofit organizations provide a variety of support to families.
- Members perceived that there is are many providers and dedicated frontline staff who want to provide care to families.
- Coalition members observed there is a strong willingness of groups providing families support and the system to work together to address family support issues.
- Members perceived that there are promising models in the state for providing care. For example, there are services to provide mental health and depression screenings to a caregiver in the home; of day care centers to provide extra support and attention to care recipients so that caregivers have additional time alone.

- Coalition members perceived that the existence of 15 years of data on family support in the state is a great benefit, allowing the system to make stronger, evidence-based decisions.
- Coalition members observed that the system is focused on providing person-centered and tailored services for families.
- Members perceived that agencies often make multiple attempts to support families and to engage historically underserved communities.

### **Increasingly Positive Attitudes towards Caregivers and Family Support**

- Coalition members perceived that the public has increased its awareness about the needs of families and caregivers over the past several years, likely due to more family members being put in caregiving roles.
- Members felt that human resources departments have become more likely to have created/be open to creating resources to assist employees with the stress associated with family caregiver roles.
- Coalition members perceived that legislators have been supportive and active with advocacy groups to advance caregiver issues.

## **Strategies**

In light of the challenges and promising practices discussed, the Washington family support coalition developed six strategies to improve supports to all families of people with disabilities and seniors in the state. Many of these strategies incorporate major challenges identified or promising practices discussed in detail. Coalition members noted that the strategies recommended are in flux and will be more firmly set through discussion at the next coalition meeting, to be hosted by partner organization Dads M.O.V.E in fall 2017.

**Strategy 1:** Continue to identify challenges and available resources in Washington via engagement with experts, professionals who support the various communities, and family members who represent the wide variety of communities throughout the state. Connect with these groups to draw on lived experiences to identify barriers and expand on services needed. The coalition also recommended conducting resource mapping and literature reviews to identify formal supports available.

**Strategy 2:** Encourage greater connection among the organizations and agencies that support families by creating a culture of connecting. This culture change will be facilitated by scanning existing networks and coalitions, forming regional networks of providers/families to facilitate information between groups, providing funding/incentives for sharing of information, and providing leadership training for families to help people connect and navigate services.

**Strategy 3:** Address the needs of historically underserved communities by increasing personal engagement between families who have been underserved and professionals who support them. Steps the coalition identified included convening focus groups of consumers and providers to better understand barriers and needs, creating materials written in native language of groups, partnering with local community providers experienced in serving groups underserved by formal supports, and building intentional engagement with families as a billable expense for providers.

**Strategy 4:** Improve coordination and information-sharing to promote family support by creating a one-stop online tool and related application that provides comprehensive information on family support to families. Coalition members recommend engaging with the legislature to fund the creation of this statewide tool and require agencies to coordinate on this effort; building on existing efforts in the state; organizing resources by topic and region and ensuring all materials are translated and accessible; and coordinating marketing efforts by creating a coordinated campaign, materials, and widget for all agency websites.

**Strategy 5:** Encourage the development of a No Wrong Door system by developing trainings and resources so that professionals know how to make referrals to someone who can help families. Coalition members identified the following steps: fund a conference to make other professionals aware of information and how to navigate systems; engage local university students to engage in a data project to create materials professionals can use to make referrals; engage universities to create a course about resources; and identify partners to work with to combine resources to provide education online and in-person to medical professionals, schools, and service system professionals.

**Strategy 6:** Encourage organizations and agencies to educate families about future planning by engaging a wide variety of partners (e.g., employee assistance programs, faith-based groups, senior centers, parent groups) to offer information and expertise; conducting public awareness campaigns; publicizing the new ABLE accounts available in Washington; and collaborate with partners interested in educating the public on best practices in supporting families through a lifetime, including the Supporting Families Community of Practice being led by the Developmental Disabilities council and The Arc of Washington.

## Summary of Themes from Coalitions

While the family support coalitions in Arizona, California, Kentucky, Pennsylvania, Tennessee, Washington, and Wisconsin identified common challenges, each coalition is unique. Each state provides a different type and amount of governmental support to families of people with disabilities and seniors, and community organizations and agencies in each state coordinate with each other differently as a result of the varied service systems and other differences among the states.

Despite differences in the populations and services in each state, the 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, both families in rural areas and in 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 family needs.
- Perceived lack of resources and flexibility by employers to allow caregivers time to provide care.

### **Systemic/Coordination Failures in Service System:**

- Perceived lack of access for families, especially families of color, to available resources and services.
- Perception that too much stress is placed on families to navigate the often too bureaucratic family support system.
- Perception that families lack clarity on how to effectively enter or navigate the system.
- Perception that service providers or disability and aging organizations need to compete for resources and funding, which sometimes dissuades groups from working together.
- Perceived lack of trust by families, particularly families of color, in the service system and system providers who 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 for direct care workers.

### **Common recommendations developed across the states, including the following:**

- 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 family support in order to understand diverse needs and to determine how to improve existing programs and services to serve these families in a culturally competent manner.
- Development of groups 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 refer families to 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 education efforts aimed at lawmakers in order 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.

Coalitions also often experienced similar challenges in developing and sustaining themselves. Commonly identified challenges include:

- ***Difficulty effectively recruiting aging organizations to participate at coalition meetings:*** This difficulty has been attributed to (1) budget challenges, (2) 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 (3) the perception 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.
- ***Difficulty translating strategies into concrete actions:*** Arizona, California, and Pennsylvania reported difficulty advancing strategies identified in the action plan. Reasons reported to explain these difficulties include not being able to meet in-person with the coalition and political and funding environments unconducive to working on efforts to more effectively coordinate the service system. Kentucky was able to make significant progress after the initial meeting. This was reportedly due to the fact that they were able to keep organizations invested in the coalition due to their own assurance to coalition members that they would seek funding or provide funding to sustain the coalition through 2016. After funding ended, though, Kentucky also reported significant difficulty advancing strategies.

## Conclusion

Between 2015 and 2017, The Arc supported state coalitions that brought together disability and aging organizations to do the following:

- Discuss and better understand systemic challenges in providing family support to all families of people with disabilities and seniors in the state;
- Share existing promising practices in family support; and
- Develop and implement an action plan to address challenges in the state's family support systems.

As detailed throughout this report, each coalition convened members at an initial meeting to identify challenges and promising practices, as well as to create action plans. However, initial insights from chapters suggest that the success and sustainability of action plan implementation requires ongoing funding. Kentucky – which assured members of its dedication to funding the project for at least two years – reported significant progress in achieving its plan in the first two years. However, Arizona, California, and Pennsylvania – which did not receive significant funding beyond the first year – expressed greater challenges in advancing their action plans.

The 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 from aging organizations. These efforts met with mixed success in recruiting organizations to attend initial coalition meeting; only 24 percent of the organizations that participated in family support coalitions represented the aging community. Some aging organizations reported that they do not see significant overlap in issues that impact people with disabilities and people who are aging. Aging organizations reported differences in interests related to education and employment.

Additionally, coalitions reported difficulty recruiting organizations that represent historically underserved communities. Coalitions had mixed success identifying and reaching out to these organizations. Both Washington and Wisconsin had success in reaching out and engaging groups 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 initial success, the coalitions and host organizations remain committed to continuing their outreach efforts to these communities.



In summary, while the coalitions were successful in engaging the disability community and caregiver organizations, there is still significant progress to be made to fully engage the aging community and organizations representing historically underserved communities in state coalitions. Additionally, while the purpose of each coalition is to develop and implement an action plan, effective implementation of the action plan and its strategies depends upon the coalition's ability to successfully sustain itself after the funding from The Arc and the FSRTC project concludes.

## Next Steps

The 2017 coalition meetings were the final coalition meetings supported under the Family Support Research and Training.

In 2018, The Arc will develop a brief summarizing key findings and recommendations from coalition meetings. This brief will seek to educate stakeholders of the family support system about strategies and models that can address common family support system challenges.

To develop this brief, The Arc will review the findings identified during the state coalitions, engage host organizations and stakeholders involved in coalitions to review and provide feedback on drafts, and coordinate messaging and findings with other materials from the Family Support Research and Training Center.

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## Attachment A: Organizations in Attendance at FSRTC Coalitions

### Arizona State Coalition (44 people representing 32 organizations):

1. A.T. Still University/Arizona School of Dentistry & Oral Health
2. AARP Arizona
3. Ability360
4. Arizona Alliance of Providers for Persons with Disabilities
5. Arizona Dental Association
6. Arizona Department of Education
7. Arizona Developmental Disabilities Planning Council
8. Arizona Health Care Cost Containment System
9. Arizona Statewide Independent Living Center
10. Arizona Technology Access Program
11. AZ TASH
12. AZDES - Division of Developmental Disabilities
13. AZDES - Division of Aging & Adult Services
14. Cenpatico Integrated Care
15. Chandler-Gilbert Arc
16. Council for Jews with Special Needs
17. Dads 4 Special Kids
18. Linkages Arizona
19. Maricopa County Public Health Department
20. Morrison Institute for Public Policy
21. Northern Arizona University
22. Pilot Parents of Southern Arizona
23. Pima Council on Aging
24. Protecting Arizona's Family Coalition
25. Raising Special Kids
26. Sonoran UCEDD
27. Southern Arizona Network for Down Syndrome
28. Southwest Autism Research & Resource Center
29. Southwest Human Development
30. UnitedHealthcare
31. Vitalyst Health Foundation
32. Y.E.S. The Arc

**California State Coalition (18 people representing 15 organizations):**

1. AARP
2. Alzheimer's Association
3. Association of Regional Care Agencies
4. Autism Society San Francisco Bay Area
5. California Association of Adult Day Services
6. California Collaborative for Long Term Services and Supports
7. California Commission on Aging
8. California Congress of Seniors
9. California Council of the Alzheimer's Association
10. Department of Aging
11. Fiesta Educativa
12. State Council on Developmental Disabilities
13. Strategies to Empower People
14. The Arc Placer County
15. Warmline (Early Start)

**Kentucky State Coalition (93 people representing 63 organizations):**

1. Adanta (Service Provider)
2. Alzheimer's Association
3. Autism Society of Bluegrass
4. Bluegrass Area on Aging & Independent Living
5. Bluegrass Technology Center
6. Brain Injury Alliance of Kentucky
7. Build Inclusion
8. Cabinet for Health and Family Services - Adult Protective Services
9. Center for Accessible Living
10. Central Kentucky Educational Cooperative
11. Commission for Children with Special Health Care Needs
12. Communicare, Inc. (Service Provider)
13. Community Action KY
14. Commonwealth Council on Developmental Disabilities
15. Cumberland River Behavioral Health (Service Provider)
16. Department for Aging and Independent Living
17. Department for Behavioral Health
18. Division for Developmental and Intellectual Disabilities
19. Department of Education
20. Department of Medicaid Services
21. Down Syndrome of Central Kentucky



22. Easter Seals Society of Kentucky
23. Education and Workforce Development Cabinet
24. ElderLaw
25. Epilepsy Foundation Kentuckiana
26. Family to Family Health Information Centers
27. Family Resource Youth Services Centers
28. First Steps, Kentucky Early Intervention System
29. Goodwill Industries
30. Green River Regional Educational Cooperative
31. Human Development Institute
32. Independence Place
33. Jefferson County Public Schools
34. Mountain Comprehensive Care Center
35. Multi-Purpose Community Action Agency
36. Kentucky Assistive Technology Services
37. Kentucky Association of Private Providers
38. Kentucky Association of Regional Programs
39. Kentucky Commission on Deaf and Hard of Hearing
40. Kentucky Housing Corporation
41. Kentucky Office for the American's with Disabilities Act
42. Kentucky Partnership for Families and Children
43. Kentucky Self Advocates for Freedom
44. Kentucky Special Parent Involvement Network
45. Kentucky Sibling Leadership Network
46. LifeSkills, Inc. (Service Provider)
47. Office of Career and Technical Education
48. Office of Vocational Rehabilitation
49. Office for the Blind
50. Pathways Mental Health Center
51. Protection & Advocacy
52. Seven Counties Services
53. Southeast Kentucky Center for Independent Living
54. State Independent Living Council
55. The Arc of Barren County
56. The Arc of Central Kentucky
57. The Arc of Hardin County
58. The Arc of Kentucky
59. The Point Arc-Northern KY
60. Tri-County Community Action Agency
61. University of Kentucky Pediatrics

62. University of Louisville - Kentucky Autism Training Center
63. Wendell Foster Center

**Pennsylvania State Coalition (27 people representing 18 organizations):**

1. Acquired Brain Injury Network Of Pennsylvania, Inc.
2. The Arc of Pennsylvania
3. Anthracite Region Center for Independent Living (ARCIL)
4. Epilepsy Foundation of Western/Central Pennsylvania
5. Lehigh Valley Center for Independent Living
6. New Avenue Foundation
7. Pennsylvania Link To Aging And Disability Resources
8. Office of Developmental Programs
9. PA Elks
10. Parents Exchange
11. The PEAL Center
12. PennTeleData
13. Erie County Department of Social Services - Child Support Office
14. Saint Martin of Tours Church
15. Temple University Institute on Disability
16. The Arc of Philadelphia
17. United Cerebral Palsy- Central Pennsylvania
18. Office of Senator Bob Casey

**Tennessee State Coalition (79 people representing 34 organizations):**

1. The Arc Tennessee
2. The Arc Davidson County and Greater Nashville
3. Progress Inc.
4. Madison Haywood Developmental Services
5. PaceSetters Inc.
6. Tennessee Department of Education
7. Jackson Area Center for Independent Living
8. Family Caregiver Services
9. TennCare
10. Department of Intellectual and Developmental Disabilities
11. Family Voices of Tennessee
12. SRVS
13. The Arc of Williamson County
14. Buffalo River Services

15. The Arc of Rutherford County
16. Down Syndrome Association of Middle Tennessee
17. Emory Valley Center
18. Developmental Services of Dickson County
19. Council on Developmental Disabilities
20. United Cerebral Palsy
21. Disability Rights Tennessee
22. Center for Independent Living of Middle Tennessee
23. Vanderbilt Kennedy Center
24. Tennessee Disability Pathfinder
25. Tennessee Voices for Children
26. Habilitation and Training Center
27. Community Development Center
28. Tennessee Commission on Aging and Disability
29. Fifty Forward
30. United Healthcare
31. BlueCare
32. State of Tennessee Services for the Blind
33. Metro Nashville Social Services
34. Amerigroup

**Washington State Coalition (40 people representing 30 organizations):**

1. Aging and Long Term Support Administration
2. Homage Senior Services
3. Seattle King County Aging and Disability Services
4. The Arc of King County
5. Circle of Friends
6. Amada Senior Care
7. Crisis Clinic
8. University of Washington
9. Department of Social and Health Services
10. Open Doors
11. Full Life Care
12. Seattle Children's Autism Center
13. City of Seattle
14. Sound Generations
15. Island County
16. National Alliance on Mental Illness Seattle
17. Sea Mar Community Health Centers

18. Sound Mental Health
19. Developmental Disabilities Council
20. MCM
21. Kindering
22. Skagit Preschool and Resource Center
23. Catholic Community Services of Western Washington
24. Lifespan Respite Washington
25. Sno-Valley Senior Center
26. Dads M.O.V.E.
27. National Alliance on Mental Illness Washington
28. Washington Autism Alliance and Advocacy
29. National Alliance on Mental Illness Yakima
30. The Arc of Southwest Washington

**Wisconsin State Coalition (33 people representing 25 organizations):**

1. Wisconsin Board for People with Developmental Disabilities
2. TMG by Magellan Health
3. Living our Visions - Dane
4. Alzheimer's Association of Southeastern Wisconsin
5. Wisconsin Long-Term Care Coalition
6. Interfaith Family Caregiver Support Network
7. Kenosha County Division of Children and Family Services
8. Division of Medicaid Services, Department of Health Services
9. Disability Rights Wisconsin
10. Department of Health Services, Office of Aging
11. Easer Seals Southeast Wisconsin
12. The Arc of Racine County
13. Great Lakes Inter-Tribal Council
14. The Arc Fond du Lac
15. Family Voices of Wisconsin
16. Greater Wisconsin Agency on Aging Resources
17. Parent to Parent Wisconsin
18. Society's Assets
19. Department of Health Services, Bureau of Aging and Disability Resources
20. WisconSibs
21. ADRC of Racine County
22. Broadscope Disability Services
23. ADRC of Portage County
24. Parent University
25. Respite Care Association of Wisconsin

## Attachment B: State Coalition Framework Agenda

**Goal:** To generate and implement an action plan aimed at improving the current supports to families in Kentucky, Tennessee, and Pennsylvania.

### Objectives:

- 1) Identify challenges and available resources to support families within both formal and informal systems
- 2) Encourage greater connection among the organizations and agencies to support families
- 3) Address the needs of historically underserved communities
- 4) Improve coordination and information-sharing to promote family support
- 5) Encourage the development of a No Wrong Door system
- 6) Encourage organizations and agencies to educate families about future planning and to provide resources to support families to plan for the future

### Skeleton Agenda

- I. Introduction
  - a. Who is in the room?
    - i. Organization
    - ii. Roles
    - iii. Personal stories
- II. Identification of Strengths
  - a. Strengths in family support formal and informal systems
  - b. Potential untapped resources
- III. Identification of Problems
  - a. Status and challenges in family support formal and informal systems
  - b. Resources available in state and communities to improve/address challenges
- IV. Identifying Solutions
  - a. Addressing challenges relating to coordination or information sharing
  - b. Other ways/ideas to improve family support
- V. Create an action plan
  - a. Identify tasks and goals
  - b. Assign roles
  - c. Assign target dates for task completion
  - d. Commit to follow-up
- VI. Brief evaluation

## Attachment C: State Coalition Chapter Evaluation Plan

### On the day of the convening:

1. The Arc Staff:
  - Assist with logistics and keeping people on track to set up SMART objectives to achieve goals (see “State Family Support Coalition Objectives” attached)
  - Act as an observer floating around and listening to (but not contributing to) discussions
  - **Ensure that steps and strategies for each objectives have been identified by the end of the day OR that the coalition has determined another process to identify goals within a short-term timeline.**
  
2. Chapter
  - Facilitate and run meeting as outlined in agenda
  - Keep record of which and how many organizations attended the coalition meeting
  - Ensure facilitators in small group discussion do the following:
    - Assign one person in the group as a note taker, who will take notes on a sheet of paper or flip chart. This person should include their contact information in the form or flip chart so that they can be called upon to clarify any notes later (see “FSRTC State Coalition Note-Taker Form” attached)
    - Assign one person in the group as a reporter to report out to the larger group about what was discussed
    - Establish ground rules and are aware of best practices for facilitating groups (see “Techniques for Group Discussion”)

### Post-meeting follow-up (Annually after initial meeting)

1. The Arc staff will call chapters and ask questions to gauge how well the objectives/goals are being met as well as to ascertain any positive consequences of the coalitions (see “Post-Initial Meeting Follow-up Questions”)
2. The Arc will identify any technical assistance needs during these calls and discuss plan to address these needs

3. The Arc staff will develop a report that uses the notes and transcript from the meeting, results of follow-up, materials from the coalition application as well as any additional insights to develop a report for UIC and public consumption on the work of the coalition.

## Attachment D: FSRTC State Coalition Note-Taker Form

Please take notes on the discussion occurring at this table. Notes may be used to capture general themes of discussion, points of disagreement, or reasons people gave for supporting a particular issue, etc. Use as many sheets as you need. The facilitator will give you more paper if required. You may be contacted if needed to clarify any notes taken.

**Note-Taker Name:** \_\_\_\_\_

**Email/Phone:** \_\_\_\_\_

**Discussion Notes for Objective 1: Identify challenges and available resources to support families within both formal and informal systems**  
(space provided)

**Discussion Notes for Objective 2: Encourage greater connection among the organizations and agencies to support families**  
(space provided)

**Discussion Notes for Objective 3: Address the needs of historically underserved communities**  
(space provided)

**Discussion Notes for Objective 4: Improve coordination and information-sharing to promote family support**  
(space provided)

**Discussion Notes for Objective 5: Encourage the development of a No Wrong Door system**  
(space provided)

**Discussion Notes for Objective 6: Encourage organizations and agencies to educate families about future planning and to provide resources to support families to plan for the future**



## Attachment E: Facilitator Reading - “Techniques for Leading Group Discussion”

### Section 4. Techniques for Leading Group Discussions<sup>21</sup>

A local coalition forms a task force to address the rising HIV rate among teens in the community. A group of parents meets to wrestle with their feeling that their school district is shortchanging its students. A college class in human services approaches the topic of dealing with reluctant participants. Members of an environmental group attend a workshop on the effects of global warming. A politician convenes a “town hall meeting” of constituents to brainstorm ideas for the economic development of the region. A community health educator facilitates a smoking cessation support group.

All of these might be examples of group discussions, although they have different purposes, take place in different locations, and probably run in different ways. Group discussions are common in a democratic society, and, as a community builder, it’s more than likely that you have been and will continue to be involved in many of them. You also may be in a position to lead one, and that’s what this section is about. In this last section of a chapter on group facilitation, we’ll examine what it takes to lead a discussion group well, and how you can go about doing it.

#### WHAT IS AN EFFECTIVE GROUP DISCUSSION?

The literal definition of a group discussion is obvious: a critical conversation about a particular topic, or perhaps a range of topics, conducted in a group of a size that allows participation by all members. A group of two or three generally doesn’t need a leader to have a good discussion, but once the number reaches five or six, a leader or facilitator can often be helpful. When the group numbers eight or more, a leader or facilitator, whether formal or informal, is almost always helpful in ensuring an effective discussion.

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<sup>21</sup> This document comes from Chapter 16, “Group Facilitation and Problem-Solving”, in the Community Tool Box, a service of the Work Group for Community Health and Development at the University of Kansas  
(accessible at <http://ctb.ku.edu/en/table-of-contents/leadership/group-facilitation/group-discussions/main>)

A group discussion is a type of meeting, but it differs from the formal meetings in a number of ways:

- It may not have a specific goal - many group discussions are just that: a group kicking around ideas on a particular topic. That may lead to a goal ultimately...but it may not.
- It's less formal, and may have no time constraints, or structured order, or agenda.
- Its leadership is usually less directive than that of a meeting.
- It emphasizes process (the consideration of ideas) over product (specific tasks to be accomplished within the confines of the meeting itself).
- Leading a discussion group is not the same as running a meeting. It's much closer to acting as a facilitator, but not exactly the same as that either.

An effective group discussion generally has a number of elements:

- All members of the group have a chance to speak, expressing their own ideas and feelings freely, and to pursue and finish out their thoughts.
- All members of the group can hear others' ideas and feelings stated openly.
- Group members can safely test out ideas that are not yet fully formed.
- Group members can receive and respond to respectful but honest and constructive feedback. Feedback could be positive, negative, or merely clarifying or correcting factual questions or errors, but is in all cases delivered respectfully.
- A variety of points of view are put forward and discussed.
- The discussion is not dominated by any one person.
- Arguments, while they may be spirited, are based on the content of ideas and opinions, not on personalities.
- Even in disagreement, there's an understanding that the group is working together to resolve a dispute, solve a problem, create a plan, make a decision, find principles all can agree on, or come to a conclusion from which it can move on to further discussion.

Many group discussions have no specific purpose except the exchange of ideas and opinions. Ultimately, an effective group discussion is one in which many different ideas and viewpoints are heard and considered. This allows the group to accomplish its purpose if it has one, or to establish a basis either for ongoing discussion or for further contact and collaboration among its members.

There are many possible purposes for a group discussion, such as:

- Create a new situation: form a coalition, start an initiative, etc.
- Explore cooperative or collaborative arrangements among groups or organizations
- Discuss and/or analyze an issue, with no specific goal in mind but understanding
- Create a strategic plan - for an initiative, an advocacy campaign, an intervention, etc.
- Discuss policy and policy change
- Air concerns and differences among individuals or groups
- Hold public hearings on proposed laws or regulations, development, etc.
- Decide on an action
- Provide mutual support
- Solve a problem
- Resolve a conflict
- Plan your work or an event

Possible leadership styles of a group discussion also vary. A group leader or facilitator might be directive or non-directive; that is, she might try to control what goes on to a large extent; or she might assume that the group should be in control, and that her job is to facilitate the process. In most group discussions, leaders who are relatively non-directive make for a more broad-ranging outlay of ideas, and a more satisfying experience for participants.

Directive leaders can be necessary in some situations. If a goal must be reached in a short time period, a directive leader might help to keep the group focused. If the situation is particularly difficult, a directive leader might be needed to keep control of the discussion

[content excerpted]

## **DO'S AND DON'TS FOR DISCUSSION LEADERS**

**DO:**

- *Model the behavior and attitudes you want group members to employ.* That includes respecting all group members equally; advancing the open process; demonstrating what it means to be a learner (admitting when you're wrong, or don't know a fact or an answer, and suggesting ways to find out); asking

questions based on others' statements; focusing on positions rather than on the speaker; listening carefully; restating others' points; supporting your arguments with fact or logic; acceding when someone else has a good point; accepting criticism; thinking critically; giving up the floor when appropriate; being inclusive and culturally sensitive, etc.

- *Use encouraging body language and tone of voice, as well as words.* Lean forward when people are talking, for example, keep your body position open and approachable, smile when appropriate, and attend carefully to everyone, not just to those who are most articulate.
- *Give positive feedback for joining the discussion.* Smile, repeat group members' points, and otherwise show that you value participation.
- *Be aware of people's reactions and feelings, and try to respond appropriately.* If a group member is hurt by others' comments, seems puzzled or confused, is becoming angry or defensive, it's up to you as discussion leader to use the ground rules or your own sensitivity to deal with the situation. If someone's hurt, for instance, it may be important to point that out and discuss how to make arguments without getting personal. If group members are confused, revisiting the comments or points that caused the confusion, or restating them more clearly, may be helpful. Being aware of the reactions of individuals and of the group as a whole can make it possible to expose and use conflict, or to head off unnecessary emotional situations and misunderstandings.
- *Ask open-ended questions.* In advancing the discussion, use questions that can't be answered with a simple yes or no. Instead, questions should require some thought from group members, and should ask for answers that include reasons or analysis. The difference between "Do you think the President's decision was right?" and "Why do you think the President's decision was or wasn't right?" is huge. Where the first question can be answered with a yes or no, the second requires an analysis supporting the speaker's opinion, as well as discussion of the context and reasons for the decision.
- *Control your own biases.* While you should point out factual errors or ideas that are inaccurate and disrespectful of others, an open process demands that you not impose your views on the group, and that you keep others from doing the same. Group members should be asked to make rational decisions about the positions or views they want to agree with, and ultimately the ideas that the group agrees on should be those that make the most sense to them, whether they coincide with yours or not. Pointing out bias – including your own – and discussing it helps both you and group members try to be objective.

A constant question that leaders and members of any group have is what to do about racist, sexist, or homophobic remarks, especially in a homogeneous group where most or all of the members except the leader may agree with them. There is no clear-cut answer, although if they pass unchallenged, it may appear you condone the attitude expressed.

How you challenge prejudice is the real question. The ideal here is that other members of the group do the challenging, and it may be worth waiting long enough before you jump in to see if that's going to happen. If it doesn't, you can essentially say, "That's wrong, and I won't allow that kind of talk here," which may well put an end to the remarks, but isn't likely to change anyone's mind. You can express your strong disagreement or discomfort with such remarks and leave it at that, or follow up with "Let's talk about it after the group," which could generate some real discussion about prejudice and stereotypes, and actually change some thinking over time.

Your ground rules – the issue of respecting everyone – should address this issue, and it probably won't come up...but there are no guarantees. It won't hurt to think beforehand about how you want to handle it.

- *Encourage disagreement, and help the group use it creatively.* Disagreement is not to be smoothed over, but rather to be analyzed and used. When there are conflicting opinions – especially when both can be backed up by reasonable arguments – the real discussion starts. If everyone agrees on every point, there's really no discussion at all. Disagreement makes people think. It may not be resolved in one session, or at all, but it's the key to discussion that means something.

All too often, conflict – whether conflicting opinions, conflicting world views, or conflicting personalities – is so frightening to people that they do their best to ignore it or gloss it over. That reaction not only leaves the conflict unresolved – and therefore growing, so that it will be much stronger when it surfaces later – but fails to examine the issues that it raises. If those are brought out in the open and discussed reasonably, the two sides often find that they have as much agreement as disagreement, and can resolve their differences by putting their ideas together. Even where that's not the case, facing the conflict reasonably, and looking at the roots of the ideas on each side, can help to focus on the issue at hand and provide solutions far better than if one side or the other simply operated alone.

- *Keep your mouth shut as much as possible.* By and large, discussion groups are for the group members. You may be a member of the group and have been asked by the others to act as leader, in which case you certainly have a right to be part of the discussion (although not to dominate). If you're an outside facilitator, or leader by position, it's best to confine your contributions to observations on process, statements of fact, questions to help propel the discussion, and clarification and summarization. The simple fact that you're identified as leader or facilitator gives your comments more force than those of other group members. If you're in a position of authority or seen as an expert, that force becomes even greater. The more active you are in the discussion, the more the group will take your positions and ideas as "right," and the less it will come to its own conclusions.

#### **DON'T:**

- *Don't let one or a small group of individuals dominate the discussion.* People who are particularly articulate or assertive, who have strong feelings that they urgently want to express, or who simply feel the need – and have the ability – to dominate can take up far more than their fair share of a discussion. This often means that quieter people have little or no chance to speak, and that those who disagree with the dominant individual(s) are shouted down and cease trying to make points. It's up to the leader to cut off individuals who take far more than their share of time, or who try to limit discussion. This can be done in a relatively non-threatening way ("This is an interesting point, and it's certainly worth the time we've spent on it, but there are other points of view that need to be heard as well. I think Alice has been waiting to speak..."), but it's crucial to the open process and to the comfort and effectiveness of the group.
- *Don't let one point of view override others, unless it's based on facts and logic, and is actually convincing group members to change their minds.* If a point of view dominates because of its merits, its appeal to participants' intellectual and ethical sensibilities, that's fine. It's in fact what you hope will happen in a good group discussion. If a point of view dominates because of the aggressiveness of its supporters, or because it's presented as something it's wrong to oppose ("People who disagree with the President are unpatriotic and hate their country"), that's intellectual bullying or blackmail, and is the opposite of an open discussion. As leader, you should point it out when that's happening, and make sure other points of view are aired and examined.

Sometimes individuals or factions that are trying to dominate can disrupt the process of the group. Both Sections 1 and 2 of this chapter contain some guidelines for dealing with this type of situation.

- *Don't assume that anyone holds particular opinions or positions because of his culture, background, race, personal style, etc.* People are individuals, and can't be judged by their exteriors. You can find out what someone thinks by asking, or by listening when he speaks.
- *Don't assume that someone from a particular culture, race, or background speaks for everyone else from that situation.* She may or may not represent the general opinion of people from situations similar to hers...or there may not be a general opinion among them. In a group discussion, no one should be asked or assumed to represent anything more than herself.

The exception here is when someone has been chosen by her community or group to represent its point of view in a multi-sector discussion. Even in that situation, the individual may find herself swayed by others' arguments, or may have ideas of her own. She may have agreed to sponsor particular ideas that are important to her group, but she may still have her own opinions as well, especially in other areas.

- *Don't be the font of all wisdom.* Even if you know more about the discussion topic than most others in the group (if you're the teacher of a class, for instance), presenting yourself as the intellectual authority denies group members the chance to discuss the topic freely and without pressure. Furthermore, some of them may have ideas you haven't considered, or experiences that give them insights into the topic that you're never likely to have. Model learning behavior, not teaching behavior.

If you're asked your opinion directly, you should answer honestly. You have some choices about how you do that, however. One is to state your opinion, but make very clear that it's an opinion, not a fact, and that other people believe differently. Another is to ask to hold your opinion until the end of the discussion, so as not to influence anyone's thinking while it's going on. Yet another is to give your opinion after all other members of the group have stated theirs, and then discuss the similarities and differences among all the opinions and people's reasons for holding them.

If you're asked a direct question, you might want to answer it if it's a question of fact and you know the answer, and if it's relevant to the discussion. If the question is less

clear-cut, you might want to throw it back to the group, and use it as a spur to discussion.

## IN SUMMARY

Group discussions are common in our society, and have a variety of purposes, from planning an intervention or initiative to mutual support to problem-solving to addressing an issue of local concern. An effective discussion group depends on a leader or facilitator who can guide it through an open process – the group chooses what it’s discussing, if not already determined, discusses it with no expectation of particular conclusions, encourages civil disagreement and argument, and makes sure that every member is included and no one dominates. It helps greatly if the leader comes to the task with a democratic or, especially, a collaborative style, and with an understanding of how a group functions.

A good group discussion leader has to pay attention to the process and content of the discussion as well as to the people who make up the group. She has to prepare the space and the setting to the extent possible; help the group establish ground rules that will keep it moving civilly and comfortably; provide whatever materials are necessary; familiarize herself with the topic; and make sure that any pre-discussion readings or assignments get to participants in plenty of time. Then she has to guide the discussion, being careful to promote an open process; involve everyone and let no one dominate; attend to the personal issues and needs of individual group members when they affect the group; summarize or clarify when appropriate; ask questions to keep the discussion moving, and put aside her own agenda, ego, and biases. It’s not an easy task, but it can be extremely rewarding. An effective group discussion can lay the groundwork for action and real community change.

Contributor

Phil Rabinowitz

Online resources

[Everyday-Democracy](#). Study Circles Resource Center. Information and publications related to study circles, participatory discussion groups meant to address community issues.

[Project on Civic Reflection](#) provides information about leading study circles on civic reflection.

“[Suggestions for Leading Small-Group Discussions](#),” prepared by Lee Haugen, Center for Teaching Excellence, Iowa State University, 1998. Tips on university teaching, but much of the information is useful in other circumstances as well.



[“Tips for Leading Discussions,”](#) by Felisa Tibbits, Human Rights Education Associates.

Print resources

Forsyth, D .*Group Dynamics*. (2006). (4th edition). Belmont, CA: Thomson Wadsworth.

Johnson, D., & Frank P. (2002). *Joining Together: Group theory and group skills*. (8th edition). Boston: Allyn & Bacon.

# Attachment F: State Family Support Coalition Action Plan

*Instructions: Below, we have given you space to complete the action plan for your state coalition. This action plan includes strategies and steps that your coalition has agreed to achieve the objectives identified for the coalition. Feel free to add as many strategies or steps as needed to reflect the actions decided by your coalition.*

**Coalition Long-Term Goal:** To improve supports to all families of people with disabilities and seniors in the state

**Objective 1:** Continue to identify challenges and available resources to support families within both formal and informal systems

**Strategy 1:** \_\_\_\_\_

Action Step 1.1: \_\_\_\_\_

Completion Date: \_\_\_\_\_

Responsible Party: \_\_\_\_\_

Action Step 1.2: \_\_\_\_\_

Completion Date: \_\_\_\_\_

Responsible Party: \_\_\_\_\_

Action Step 1.3: \_\_\_\_\_

Completion Date: \_\_\_\_\_

Responsible Party: \_\_\_\_\_

**Objective 2:** Encourage greater connection among the organizations and agencies that support families

**Strategy 1:** \_\_\_\_\_

Action Step 1.1: \_\_\_\_\_

Completion Date: \_\_\_\_\_

Responsible Party: \_\_\_\_\_

Action Step 1.2: \_\_\_\_\_

Completion Date: \_\_\_\_\_

Responsible Party: \_\_\_\_\_

Action Step 1.3: \_\_\_\_\_  
Completion Date: \_\_\_\_\_  
Responsible Party: \_\_\_\_\_

**Objective 3: Address the needs of historically underserved communities**

**Strategy 1:** \_\_\_\_\_

Action Step 1.1: \_\_\_\_\_  
Completion Date: \_\_\_\_\_  
Responsible Party: \_\_\_\_\_

Action Step 1.2: \_\_\_\_\_  
Completion Date: \_\_\_\_\_  
Responsible Party: \_\_\_\_\_

Action Step 1.3: \_\_\_\_\_  
Completion Date: \_\_\_\_\_  
Responsible Party: \_\_\_\_\_

**Objective 4: Improve coordination and information-sharing to promote family support**

**Strategy 1:** \_\_\_\_\_

Action Step 1.1: \_\_\_\_\_  
Completion Date: \_\_\_\_\_  
Responsible Party: \_\_\_\_\_

Action Step 1.2: \_\_\_\_\_  
Completion Date: \_\_\_\_\_  
Responsible Party: \_\_\_\_\_

Action Step 1.3: \_\_\_\_\_  
Completion Date: \_\_\_\_\_  
Responsible Party: \_\_\_\_\_

**Objective 5: Encourage the development of a No Wrong Door system**

**Strategy 1:** \_\_\_\_\_

Action Step 1.1: \_\_\_\_\_

Completion Date: \_\_\_\_\_

Responsible Party: \_\_\_\_\_

Action Step 1.2: \_\_\_\_\_

Completion Date: \_\_\_\_\_

Responsible Party: \_\_\_\_\_

Action Step 1.3: \_\_\_\_\_

Completion Date: \_\_\_\_\_

Responsible Party: \_\_\_\_\_

**Objective 6:** Encourage organizations and agencies to educate families about future planning and to provide resources to support families to plan for the future

**Strategy 1:** \_\_\_\_\_

Action Step 1.1: \_\_\_\_\_

Completion Date: \_\_\_\_\_

Responsible Party: \_\_\_\_\_

Action Step 1.2: \_\_\_\_\_

Completion Date: \_\_\_\_\_

Responsible Party: \_\_\_\_\_

Action Step 1.3: \_\_\_\_\_

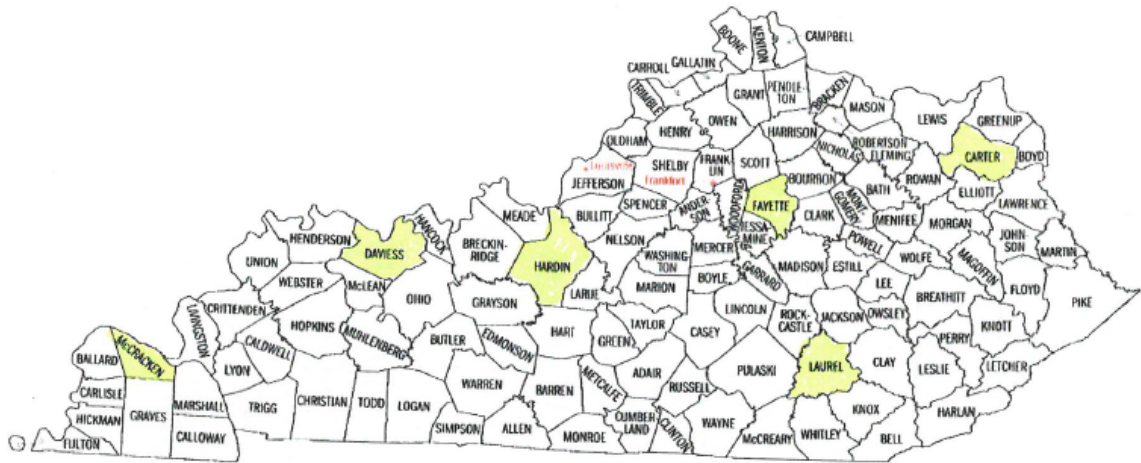
Completion Date: \_\_\_\_\_

Responsible Party: \_\_\_\_\_

## Attachment G: FSRTC Post-Coalition Meeting Follow-up Questions

1. For each of the 6 objectives:
  - a. What are the statuses of the strategies and action steps for this objective?
  - b. Do you anticipate being able to complete the progress to the objective in the estimated time? If not, what occurred to speed up/slow down progress?
  - c. Have you identified any additional steps or strategies that your coalition will be taking to achieve the objective? *If so, coalition and The Arc will need to update the state coalition objective document.*
2. How many total organizations do you now have in the coalition? *Request that chapter send a list of the organizations in the coalition.*
  - a. If coalition grew from the last count, ask:
    - i. What organization or group has joined the coalition?
    - ii. Why do you think that they joined the coalition?
  - b. If coalition shrunk from the last count, ask:
    - i. What organization or group left the coalition?
    - ii. Why do you think that they left the coalition?
3. Have you been doing any additional outreach to encourage more organizations to join the coalition? If so, what have you been doing?
4. Have you noticed any unexpected positive consequences of holding the convening and starting the coalition? These consequences may or may not relate to the family support system.
5. What challenges have you experienced in achieving the goals of the coalition and growing the coalition?
6. What can The Arc do to assist you in developing and achieving the goals of the coalition?
7. Additional Notes/Comments:

# Attachment H: Kentucky Statewide Regional Resource Fair Information, Articles, and Promotional Materials



- June 7-8 - London (Laurel Co.)**
- June 27 - Elizabethtown (Hardin Co.)**
- June 30 - Lexington (Fayette Co.)**
- July 18 - Paducah (McCracken Co.)**
- July 19 - Owensboro (Daviess Co.)**
- July 26 - Grayson (Carter Co.)**

## Join us in YOUR community!

The Family Support Coalition's goal is to improve supports to all families of people with disabilities and seniors in the state.

Join us for an afternoon of resources, networking, and learning!  
The event is FREE!!!!!!

- June 27 Elizabethtown**  
Hardin County Schools Early College and Career Center (EC3)  
200 University Dr. Elizabethtown, KY 42701
- June 30 Lexington**  
Tates Creek Christian Church  
3150 Tates Creek Rd. Lexington, KY 40502
- July 18 Paducah**  
West Kentucky Community and Technical College (ETC Building)  
4810 Alben Barkley Dr. Paducah, KY 42001
- July 19 Owensboro**  
Owensboro Community and Technical College  
4800 New Hartford Rd. Owensboro, KY 42303
- July 26 Grayson**  
Ashland Community and Technical College  
902 Technology Dr. Grayson, KY 41143

The Arc of Kentucky  
Kentucky Statewide  
Family Support Coalition  
**FREE\***

**Regional Resource Fairs**  
June & July 2016  
12:00 – 5:00 pm (local time)

\*Registration fee waived due to additional sponsorship funding.

For more information contact:

The Arc of Kentucky at  
(800)281-1272 or (502)875-6225

|            |                                  |
|------------|----------------------------------|
| 12:00-1:15 | Exhibits & Lunch                 |
| 1:15-2:45  | Breakout Sessions                |
|            | * Futures Planning               |
|            | * Behavior in the Home/Community |
| 2:45-3:00  | Break                            |
| 3:00-4:30  | Resource Roundtables             |
| 4:30-5:00  | Networking                       |



## The Arc of Kentucky Kentucky Statewide Family Support Coalition **FREE\*** Regional Resource Fair

*This statewide Coalition includes many organizations that represent people with physical, intellectual and developmental, mental health, and aging-related disabilities as well as those that advocate on behalf of under-served racial/ethnic communities.*

Please select the location you will be attending:

- June 27 Elizabethtown
- June 30 Lexington
- July 18 Paducah
- July 19 Owensboro
- July 26 Grayson

– Name \_\_\_\_\_

– Address \_\_\_\_\_

– City, State, Zip Code \_\_\_\_\_

– Email \_\_\_\_\_

– Phone \_\_\_\_\_

– Names of others attending \_\_\_\_\_

Please mail completed registration to:

The Arc of Kentucky 706 East Main Street Ste. A Frankfort, KY 40601

*The Coalition is supported by the Family Support Research and Training Center at the University of Illinois at Chicago and The Arc of the United States. These regional statewide events are also being funded by the Commonwealth Council on Developmental Disabilities.*

\*Registration fee waived due to additional sponsorship funding.

Must register before noon June 3!

FREE

## PARTNERING FOR EXCEPTIONAL OUTCOMES

JUNE 7 & 8, 2016  
SOMERSET COMMUNITY COLLEGE NORTH LAUREL CAMPUS  
100 UNIVERSITY DRIVE  
LONDON, KY

SPONSORED BY SESC EDUCATIONAL CO-OP, KENTUCKY AUTISM TRAINING CENTER, OFFICE OF AUTISM, KY-SPIN, ARC OF KENTUCKY FAMILY SUPPORT COALITION, ACTION FOR AUTISM

JOIN US FOR 2 EXCITING DAYS OF RESOURCE GATHERING, TRAININGS, AND NETWORKING FOCUSED ON PARTNERING FOR EXCEPTIONAL OUTCOMES FOR INDIVIDUALS WITH SPECIAL NEEDS.

**ALL FAMILIES ARE WELCOME AND ENCOURAGED TO ATTEND THIS FREE EVENT!**

PLEASE CONTACT HEDI COOLEY-COOK WITH THE KATC FOR MORE INFORMATION  
502-852-6401 OR HEDI.COOLEYCOOK@LOUISVILLE.EDU

Register online: <https://tinyurl.com/junelondon>

FREE

Partnering for Exceptional Outcomes  
Somerset Community College North Laurel Campus  
100 University Drive  
London, KY

Join us for 2 exciting days of resource gathering, trainings, and networking. All families are welcome and encouraged to attend the FREE Event.

TUESDAY JUNE 7, 2016

10:15 – 11:30 KEYNOTE SPEAKER

11:30 – 1:00 RESOURCE ROUNDTABLES

1:00 – 3:30 EXHIBITS/NETWORKING

\*SNACKS WILL BE AVAILABLE

WEDNESDAY JUNE 8, 2016

10:15 – 11:30 BREAKOUT SESSION

IEP BASICS

SOCIAL SKILLS DEVELOPMENT

BEHAVIOR IN HOME/COMMUNITY

11:30 – 12:30 LUNCH/NETWORKING

12:30-1:45 BREAKOUT SESSIONS

PARENT ADVOCACY

FUTURES PLANNING

BEHAVIOR IN HOME/COMMUNITY

**Deadline to register is NOON JUNE 3!**

Register online: <https://tinyurl.com/junelondon>

Sponsored by Southeast South Central (SESC) Educational Co-Op, Kentucky Autism Training Center (KATC), Office of Autism, KY-SPIN, Arc of Kentucky Family Support Coalition, and Action for Autism



Elizabethtown

Lexington

Journal Newspaper  
Articles

## Family Support Coalition to host resource fairs

The Kentucky State Family Support Coalition consists of agencies from across the state with a unified goal of improving support to all families of people with disabilities and seniors in Kentucky. The Family Support Coalition will host a series of free regional resource fairs throughout the Commonwealth to bring information and resources to families and individuals. A variety of exhibits are scheduled to participate, such as Parks & Recreation, Autism Society of the Bluegrass, Office of the Blind, Riding for Hope, Kentucky Special Olympics, Kentucky Alzheimer's Association and Down Syndrome Central Kentucky.

Call The Arc of Kentucky at 1-800-281-1272 or 502-875-5225 for more information.

The place and schedule of these fairs are as follows:

• **June 27, Elizabethtown.** Hardin County Schools Early College and Career Center (EC3), 200 University Drive.

• **June 30, Lexington.** Bates Creek Christian Church, 3150 Bates Creek Road.

The Arc of Kentucky Statewide Family Coalition Regional Resource Fairs will be from noon-5 p.m. The schedule is as follows:

Noon-1:15 p.m. Exhibits and lunch.

1:15-2:45 p.m. Breakout sessions: "Future Planning" and "Behavior in the Home/Community." Participants may choose either session. The second session is designed for ages 10 and under.

2:45-3 p.m. Break.

3-4:30 p.m. Resource roundtables.

4:30-5 p.m. Networking.



*For people with intellectual  
and developmental disabilities*

