Promising Practices and Challenges in Family Support

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Outline

1. The State of Family Support in the United States
2. National Family Support Research Efforts
3. The Arc’s Family Support Federal Advocacy Work
4. Family Support Initiatives in The Arc Chapter Network
   - Support for Aging Families
     • State chapter initiatives: Tennessee, California
     • Outreach to aging caregivers
   - Support for Younger Families
     • State chapter initiatives: Kentucky
     • Financial literacy training for human service professionals
5. How You Can Help Support Families
The State of Family Support in the United States
Supporting Families is Critical - The Underlying Facts

- Roughly two-thirds of adults with I/DD live with their parents or other caregivers.

- Over 860,000 adults with I/DD are living with caregivers 60+ (Braddock).

- According to AARP and the National Alliance for Caregiving’s 2015 report, *Caregiving in the US*,
  - 43.5 million family caregivers
  - Spend 24.4 hours a week providing support
  - Nearly one-quarter provide 41 or more hours of care a week
Supporting Families is Critical - The Underlying Facts (cont’d)

• According to The Arc’s FINDS study:
  – There are approximately 3.5 million caregivers of people with I/DD
  – Most of these caregivers provide more than 40 hours of support per week
  – 40% of caregivers provide more than 80 hours of support per week

We need to improve our formal and informal systems to better support families throughout the family’s lifecycle.
Medicaid Home and Community Based Services (HCBS) Waiver programs finance the majority of support services

- 82% of all family support services paid via the HCBS waiver
- Only 13% of families of people with I/DD received any support
The National Family Caregiver Support Program provides grants to states to provide 6 types of services. Services include:

1) Information about services to caregivers
2) Assistance to gain access to services
3) Individual counseling
4) Organization of support groups and caregiver training
5) Respite care
6) Supplemental services (on a limited basis)

The program recently expanded eligibility to include older caregivers (55+) providing support to adults and children (18-59) with disabilities.
Our Patchwork Family Support System (cont’d)

The *Aging and Disability Resource Centers Program/No Wrong Door System* provides awareness, assistance, and access to services

- Only a few states receive any ADRC funding
- Service system continues to be focused on the aging population and adults with physical disabilities
- ADRC staff need more training and experience working with people with I/DD
- Services focused heavily on assisting clients with hospital discharge after an acute care episode
The *Lifespan Respite Care Program* was created in 2006 to increase the availability and coordination of respite care services for family caregivers of individuals with disabilities, regardless of age or type of disability.

Program received a small increase to $3.36 million in 2016, but never received more than $2.5 million per year from 2009-2015.
Our Patchwork Family Support System (cont’d)

*Developmental Disabilities Assistance and Bill of Rights Act of 2000* (DD Act) - title for family support was never funded

*Family-to-Family Health Information Centers* (F2Fs) - information and referral centers (in each state and DC) that help families of children with special health care needs or disabilities learn to navigate the health care system so that their child can get needed care
National Family Support Research Efforts
We Need to Know More About Families

Three national research goals were identified in 2015 to help us learn more about families:

1. Develop a Better Understanding of the Complexity of Families in the United States
   - Ethnic, racial, and linguistic diversity
   - Families include more than mothers
   - Socioeconomic diversity
   - Family structure
   - Transition points across the life cycle
We Need to Know More About Families (cont’d)

2. Extend our Knowledge to Understand the Experiences of Families and Communities Outside the Purview of the IDD systems

- Where do families encounter other individuals and groups that constitute supports?
- What do families actually find supportive in these connections?
- How do these sources and types of supports shape individual well-being and family quality of life?

- Discovery and Navigation
- Connecting and network
- Goods and services

We Need to Know More About Families (cont’d)

Major Projects/Research:
- Developing a strategic plan for family support research
- Identifying promising practices in family support services
- Family member roles and well-being in self-directed waiver programs,
- Understanding experiences, trends, and needs in managed care,
- Family support in managed care, and
- Parent-training programs for Latino families who have a child with autism spectrum disorder
We Need to Know More About Families (cont’d)

The Arc’s work as a Family Support Research and Training Center Partner

- Disseminate information about family support research efforts to network
- Host family support research webinars for professionals, family members, and other interested stakeholders
- Support the development of family support state coalitions to develop action plans and strategies to address statewide systemic family support issues.
We Need to Know More About Families (cont’d)

• Coalitions bring together cross-disability, aging, and caregiver organizations; organizations that advocate on behalf of racial/ethnic minorities; government agencies; and others who play a key role in providing support to families.

• Coalitions have been developed in Arizona, California, Kentucky, Pennsylvania, and Tennessee. Coalitions have brought together 224 people from 157 organizations in these 5 states.

• In 2017, we will be supporting the development of 3 more state coalitions.
The Arc’s Family Support Federal Advocacy Work
Overall Objective: Services must be made widely available to family caregivers, especially those who are aging, and who provide supports in the community.

This will help avoid costly and unwanted institutional placements of individuals with I/DD.

Services include:

- Counseling,
- Support groups,
- Respite,
- Training,
- Cash assistance, and
- Information and referral
Specific Items:

- Supporting federal initiatives that recognize the important role of families and the need for comprehensive family supports and ensuring that any such initiatives explicitly recognize that they cannot be a substitute for creating a national solution to provide appropriate long term supports and services for persons with disabilities;

- Significantly increasing, expanding, and/or continuing funding for:
  - the Family Support Program under Title II of the DD Act
  - the Lifespan Respite Care Act
  - the National Family Caregiver Support Program to include funding for caregivers of children and adults with disabilities
  - the Child Care and Development Block Grant (CCDBG)
  - Social Security Act Title V Maternal and Child Health Program
The Arc’s Legislative Agenda
Calls for Ways to Improve Supports (cont’d)

• Expanding access to paid and unpaid leave by enhancing covering through the Family and Medical Leave Act and by providing incentives for businesses to offer employer-provided individual and family supports for employees that have a family member with I/DD as part of employee-assistance programs

For more details:
http://www.thearc.org/what-we-do/public-policy/legislative-agenda-full#family-support
Family Support Initiatives and Promising Practices Throughout The Arc Chapter Network

Support for Aging Caregivers

The Arc of Tennessee
The Arc of California
The Arc of the United States
Supporting Aging Caregivers - It Begins with the Waiting List for HCBS

• Tennessee has a waiting list of nearly 6,000 people with ID who need HCBS services
• Tennessee’s waiting list lawsuit ended in 2011 and only 100-200 people were being enrolled into HCBS each year - primarily those in crisis
• The Arc Tennessee initiated a campaign to address Tennessee’s Waiting List for HCBS for people with ID called “It’s Not Too Late...End the Wait”
Laying the Groundwork

• In 2012, The Arc Tennessee crisscrossed the state, hosting 12 community forums to bring family members up to speed on the waiting list situation - and the funding challenges facing our state
• These family forums laid a foundation for advocacy around the waiting list issue
• During the 2013 legislative session, The Arc Tennessee educated elected officials on the waiting list crisis and introduced a $5 million budget amendment to enroll more people from the waiting list into services
• It didn’t pass
Regroup and Refocus

- The Arc Tennessee realized that the waiting list was too large and a general budget amendment too vague to get the full support of the General Assembly.
- Borrowed a concept from Indiana and narrowed the focus to people on the waiting list with aging caregivers (landed on an age of 75).
- Drafted legislation that would require all eligible people on the waiting list with primary caregivers aged 75 and older to be enrolled into the state’s $30,000 capped waiver and introduced it in the 2014 session.
- This legislation garnered strong philosophical support from the General Assembly, but still didn’t pass.
Never Give Up

• The Arc Tennessee continued its work on the legislation by gathering family stories of aging caregivers, meeting with legislators and securing new sponsors
• Armed with new sponsors and plenty of stories, what became known as the “Aging Caregiver” legislation was reintroduced in the 2015 legislative session
• Collaborative effort of The Arc Tennessee, other disability advocacy organizations and the Department of Intellectual and Developmental Disabilities (DIDDD)
• Strong support insured it would pass in some fashion, but budget limitations resulted in an amendment that raised the age to 80
• The legislation did pass and had the potential to enroll about 200 additional individuals off the waiting list that year
Capitalizing on the Momentum

- Tennessee’s finances continued to improve
- Took advantage of the “Aging Caregiver” momentum and introduced the legislation again in 2016 to get the age down to the originally intended 75 years old
- It passed
- TN code now requires that every eligible individual with ID on the waiting list for HCBS with a primary caregiver aged 75 and older be enrolled into an available waiver with a $30,000 cap
Lessons Learned

• If at first you don’t succeed - try again but with a different angle
• Legislators couldn’t wrap their brain around a 6,000 person waiting list
• Legislators could fully understand the challenge of older parents providing direct care and support to an adult child with ID
• Families provided many stories and pictures
• Be realistic and willing to compromise
Resources

http://vkc.mc.vanderbilt.edu/assets/files/resources/kindredaging.pdf
2016 California State Family Support Coalition

- Background
- Challenges
- Lack of Awareness or Education
- Community Awareness
- Strengths, Promising Practices and Resources
- Emerging Opportunities
- Action and Strategy
Background

• 5,189,558 Californians over the age of 65 and 3,851,442 Californians with a disability
• There are over 93,000 people with IDD living at home with an aging caregiver in California
• Expected to grow more than twice as fast as the total population
• 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).
Challenges

• There is a shortage of high-quality medical care resources, care providers, opportunities for respite and supervision, mental health services, transportation services, and behavior-based projects that serve people who are aging or who have disabilities and their families.

• The amount and timing of services provided to families is often driven by crises rather than by the person’s and family’s current needs and desires - often inadequate planning

• Members perceived that high staff turnover hurts both communities

• The coalition perceived that Proposition 98 - the regulation that mandates that 39% of the state’s seniors and people with disabilities are in competition with other groups and it often makes it difficult for agencies and groups (e.g., aging and disability groups) to come together and advocate for services that all families need in a unified manner.

• Disparate points of services and different points of entry to the service system
Challenges (continued)

• Very uneven access to services and supports for families from diverse ethnic or cultural groups - because of lack of accessible resources and technology tailored to these families as well as the family’s lack of access to technology necessary to access resources.
• Family support system is often challenged by the state’s geography and changing demographics.
• State isn’t recognizing growth of aging population
• Caregiving is increasingly occurring across generations and with more diverse and often intergenerational families than the 2-parent nuclear family.
• Support system has not recognized the growth in need for autism support as a result of a failure to recognize the large growth in people who have been diagnosed with autism in California.
Lack of awareness or education

- Caregivers and staff providing services often need education about what resources (including financial planning, benefits, and services)
- Regional centers and AAAs often have a knowledge gap around the resources available to families.
- Staff providing services often need more training to provide effective services to families.
- Because of high staff turnover, coalition members perceived that this training is not provided as often as needed.
- Families often get information from other families; however, this information can be inaccurate or anecdotal.
Awareness

• Coalition members perceived that community members often have a negative perception of people who are aging or who have disability.

• The coalition perceives that there is a cultural tendency to blame people who access public benefits or services.
Strengths, Promising Practices and Resources

• Significant infrastructure to provide support.
• California also has legislation in place that guarantees services and support.
• However, while the infrastructure exists, there aren’t enough resources available within the system to provide support needed and families don’t often have the money to access the supports on their own.
Strengths, Promising Practices and Resources

• Coalition members also mentioned that it may be beneficial to further consider the following practices or models:
  • 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 health care and service coordination program for seniors so that they may live in their home rather than receive care in a nursing home (CalPACE, 2016).
Emerging Opportunities

• CBAS and PACE service expansions; The group discussed that there are currently discussions on the national level that could expand the scope of population in their charge and that developmental disabilities could potentially be a new population.

• Caregiver Task Force: The IDD community was not included in the appointments of the Caregiver Task Force and they can participate more in the policy conversations to support California caregivers.
Action and Strategy

• **Strategy 1:** Public policy forums and collaborations that discuss the implications and resolutions for the challenges family caregivers face.

• **Strategy 2:** Encourage greater connection among organizations that support family by maintaining effective collaborations in a variety of policy areas important to all California caregivers (i.e. California Collaboration for Long Term Supports and Services and the Aging and Disability Resource Connections).

• **Strategy 3:** Participate in forums and community groups representing underserved populations.
Action and Strategy (cont’d)

• **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 and 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.
September 22, 2016, Follow-up Meeting

After another full day session, we came to an agreement that the pressing issue that both the senior and IDD caregivers face is the lack of qualified, well-trained, well-paid staff.
What is The Arc Doing to Improve Support to Aging Caregivers?

In 2014, The Arc created the Center for Future Planning to encourage adults with I/DD and their families to plan for the future.

In 2016, The Arc launched an intensive effort to reach out to aging caregivers in North Carolina and Tennessee.
Outreach to Aging Caregivers

**Goal:** Engage caregivers over the age of 65 who are providing direct support to an adult son or daughter with I/DD in a future planning process.

**What We’re Doing:**

- Conducting a training for 56 human services staff in Tennessee & North Carolina to conduct outreach to seniors over the age of 65
- Providing information and resources to caregivers over the age of 65 in Tennessee and North Carolina
- Engaging caregivers over the age of 65 in Tennessee and North Carolina in initiating a future planning process during the course of the project year.
Family Support Initiatives and Promising Practices Throughout The Arc Chapter Network

Support for Younger Families

The Arc of Kentucky
The Arc of the United States
2015-2016 Kentucky Family Support Coalition Efforts
Goals and Objectives

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.

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

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

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

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

**Objective 6:** Encourage organizations and agencies to educate families about futures planning and to provide resources to support families to plan for the future.
Special Education Training Camps

• The Arc of Kentucky, Protection and Advocacy and KY-SPIN (Parent Training and Information Center) partnered to provide Special Education resources to families across the state.

• These camps provided information to families which empowers them to be a better advocate for their child.
Special Education Training Camps (cont’d)

The Parent
Special Education Training Camp
Free Training

Who Should Come?
The target audience for this one day training camp are parents, grandparents, family members, guardians and others interested in learning about special education topics.

Why Should I Come?
This free workshop will help you understand the basic rights and protections of Special Education Law (IDEA) including how the Individualized Education Program is developed. Tips and strategies will be discussed to help you when working with the school as part of the ARC team.

You will leave camp with a better understanding of your rights as a parent and the rights of your child as a special education student. You will also learn tips and strategies on how to work with the schools so that you can become an effective part of the ARC team that plans your child's education including what to do if things are not going well.

Camp Topics Include
- Overview of Individuals with Disabilities Act (IDEA)
- Understanding the IEP Process
- KY-SPIN will present Kentucky Department of Education's IEP Guidance Document Training
- Working Effectively with Your School Team...tips and strategies
- Preparing for Admission and Release Committee (ARC) meetings from a parent's perspective
- Understanding your rights as a parent and the rights of your child as a special education student.

Lunch will be provided.
Door Prize drawings will be held.

Workshop sessions are presented and sponsored by: The Arc of Kentucky, Protection and Advocacy and KY-SPIN.

Camp Times and Locations
2016 Fall Locations
Free Training

Northern Kentucky
Saturday, September 17, 2016
9:00-3:00 p.m. E.S.T.
Hampton Inn Cincinnati Airport S.
7393 Turfway Road
Florence, KY
(859) 283-1600
Co-Sponsor: The POINT, Arc of Northern Kentucky

Paducah
Saturday, October 15, 2016
9:00-3:00 p.m. C.S.T.
Hampton Inn & Suites
3901 Coleman Crossing Circle
Paducah, KY
(270) 442-0200
Co-Sponsor: Commission for Children with Special Health Care Needs

Come spend an interactive day of learning with time to share and network with other parents!
Special Education Training Camps (cont’d)

Guidance Document for Individual Education Program (IEP) Development

We also train parents on the IEP Guidance Document (Individual Education Program). This is the document that Kentucky Special Education teachers are trained on to write IEP’s. We also train parents on partnership with the schools and Advocacy. This is an all day training and it is free to anyone who attends. Lunch is provided.
2-Day Statewide Resource Fairs

- The Coalition agreed to sponsor a two day Resource Fair and partner with various agencies to provide resources for families.

- The two day event was scheduled in June 2016 and was free.

- We had various agencies represented and also had 2 breakout training sessions.

- We had families attend.

- The Coalition decided summer months were not the best time to host fairs so this will be considered for future fairs.
1-Day Statewide Resource Fairs

- The Coalition agreed to have five 1 day events across the state during the months of June and July.
- These events were designed to improve supports to all families of people with disabilities and seniors in the state. The events were free!
- These events also had breakout session on behavior and future planning (Objective 6).
Roundtables

• The Resource Fairs included agencies from around the state that participated in roundtable discussions.
• Participants visited each table for 5 minutes, then switched tables.
• Agencies involved included: Office of Vocational Rehabilitation, First Steps, Human Development Institute, The Arc of Kentucky, KY-SPIN, KY Autism Training Center, Department of Medicaid (Waivers), Social Security Office, Commonwealth Council on Developmental Disabilities, Center for Accessible Living, Protection and Advocacy, Department for Aging and Independent Living and Commission for Children with Special Health Care Needs.
Exhibitors

- Local agencies also invited to be exhibitor at booths.
- Exhibiting agencies included: YMCA, Local Health Department, Special Olympics, Department of Housing, Kentucky Guardianship, Career Tech and Workforce and various local disability support groups.
Next Steps....

- Google Calendar - All coalition members have access to add their upcoming dates of trainings, meetings in one location. Access to this calendar can be shared with non-members to keep families/agencies updated on various events.
- Coalition Facebook Page and Twitter - A KY Family Support Coalition Facebook page will be created and shared with other agencies. A Twitter account added in the future.
- Additional future planning trainings regarding Social Security benefits and working.
- Mailing resources to those on Medicaid waiting lists.
- Reach out to homeless population, medical communities and faith based communities.
What is The Arc Doing to Improve Support to Younger Families?

In 2016, we began developing a new financial literacy training for families that include a child with I/DD.
Financial Literacy Project

**Goal:** This project will provide financial education training to low-income families to help them achieve financial stability through planning, accessing public benefits available to people with disabilities, and building assets that will not jeopardize public benefits.

**Objectives Include:**
1. Develop a financial literacy training curriculum that includes information about public benefits available to people with I/DD, as well as information about special needs trusts and the ABLE Act.
2. Pilot the training with 3 chapters, serving at least 30 low-income families.
3. Based on feedback from the Year 1 pilot, The Arc will modify the curriculum and train 5 additional chapters to work with low-income families.
How You Can Help Support Families
Get Involved!

• Attend our upcoming family support webinars
  • November 15th - Developing Positive Relationships
  • November 29th - Family Support Coalitions: Strengthening Support to all Families
  • February 7th - Tips to Interact Effectively with Law Enforcement

• Apply this fall to develop a Family Support state coalition

• Connect with us to find out more about how to bring the training for human services professionals to conduct future planning for aging caregivers to your chapter
Get Connected!

• Sign up for the Center for Future Planning listserv at futureplanning@thearc.org to keep up-to-date with The Arc’s family support initiatives

• Join the FSRTC listserv to stay on top of research developments in family support: http://fsrtc.ahslabs.uic.edu/join-our-listserv/
Contact Us!

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Questions?

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Upcoming Webinar Information

Family Support Coalitions: Strengthening Support to ALL Families

November 29, 2016, from 2:00 pm–3:00 pm Eastern Time

Join state chapter executive directors Jon Meyers, Tony Anderson, and Stella Beard to learn about their efforts to improve support to families by creating statewide coalitions of organizations advocating for people with disabilities, seniors, and caregivers.

In 2016, The Arc of Arizona and The Arc of California convened organizations to identify challenges in their state family support system and develop an action plan to address them. The Arc of Kentucky reconvened the coalition it created in 2015 to review accomplishments and challenges and plan for the year ahead.

These coalitions were created through the Family Support Research and Training Center (FSRTC) at the University of Illinois at Chicago (UIC). The FSRTC explores supports needed by families of people with disabilities and seniors and promising practices in family support around the country.

Register for this session: https://thearc.webex.com/thearc/k2/j.php?MTID=tb0d81bf848eb6e80acb30143123452e5
Upcoming Webinar Information

Fear that bad things could happen to people with intellectual and developmental disabilities (I/DD) can create a barrier that stops families from planning for full and independent lives in the community. Building skills that promote safety can help families overcome this barrier and move forward to create a robust future plan.

Developing Positive Relationships
Tuesday, November 15, at 2:00 pm EST
Speakers Theresa Fears and Leigh Ann Davis will provide strategies that help people with I/DD develop the skills to understand and fully participate in healthy relationships. The speakers will also describe how to build skills to recognize when a relationship is unhealthy, exploitative, or abusive and provide concrete steps to take in those situations.
Register: https://thearc.webex.com/thearc/k2/j.php?MTID=t2bc7783c9e0b50d190cb7a960144ddc5

Tips to Interact Effectively with Law Enforcement
Tuesday, February 7, at 2:00 pm EST
Speakers Leigh Ann Davis and Jessica Oppenheim will explore skills needed to engage effectively with law enforcement officers, the criminal justice system, and other authority figures as a witness, victim, or offender. This webinar will provide practical tips for people with I/DD, families, and professionals on how to support people with I/DD to advocate for themselves and engage with authority figures effectively.
Register: https://thearc.webex.com/thearc/k2/j.php?MTID=t75562b8a5d640502efb61f8544fb70c4