

2015 SUMMER LEADERSHIP INSTITUTE

EMBRACING THE FUTURE

Treading Water or Making Waves with Smart Change?

Aging Caregivers and the Adults with I/DD who Live with Them

How do we find them? How do we talk to them? How do we talk about the critical need to support them?

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Our Challenge

- There are almost 1 million families in which adults with I/DD are living with aging caregivers
- In 2/3 of these families, there is no plan in place for the future
- Many of these families have no connection to the disability community or the disability service system

What are we doing now?

In 2014, The Arc launched the Center for Future Planning to

- Shine a spot light on the issue
- Support and encourage families to plan
- Improve resources for planning

How are we Partnering with Chapters?

- Many chapters have been working on these issues and have developed tools and expertise.
- Chapter Working Group advises us
- Family Support state convenings
- How do we gather knowledge and share it with other chapters?
- Training for chapter staff
- Newsletters, special internet groups

What tools are we using now?

- Website
 - Phase I – General Information on all aspects of future planning
 - Phase II – Build Our Plan Tool and Professional Services Directory
- Webinars
- Blogs
- Information and referral
- Exhibiting and speaking at conferences

Challenges in supporting aging caregivers

As parents and their adult children with disabilities grow older together, they develop mutually dependent relationships.

- companionship
- sharing household chores
- financially sharing household expenses

Challenges in supporting aging caregivers

Families of people with disabilities may face increasing competition for social service funding.

- increasing number of aging baby boomers
- shrinking state budgets
- waiting lists for desperately needed services

Challenges in supporting aging caregivers

Families of adult children with disabilities are frequently compound caregivers. This results in them experiencing even more stress and exhaustion, fewer financial resources and competing demands for their time.

Challenges in supporting aging caregivers

Oftentimes it is difficult to locate aging caregivers.

- socially isolated
- gave up on the “system” years ago
- tend not to utilize technology

Challenges in supporting aging caregivers

Aging caregivers are worried about:

- who will care for their family members when they no longer can do so,
- where and with whom their family members will live,
- who will advocate for them,
- what services will be available for them

Challenges in supporting aging caregivers

Although parents know they need to plan for the future, many experience sadness, fear and sometimes a paralysis when it comes to future planning.

It is very difficult to think about the day when you can no longer care for your child and you have to leave the advocacy and the care to someone else.

Solutions to these challenges

Need to provide significantly more life-span funding for family support services that are designed to improve families' ability to care for their family member with an intellectual disability in the family home:

- home modifications
- long term planning
- in-home and out-of-home respite
- emotional support

Solutions to these challenges

Ensure that in households where an aging caregiver is caring for an adult with an intellectual disability, aging and disability support coordinators are working as a team to provide all of the services that the family requires, such as:

- meals on wheels
- transportation to a senior center for respite and socialization
- day supports for the adult with the disability
- visiting nurses



Solutions to these challenges

Support aging caregivers to view future planning as an on-going process, that it will give them peace of mind and that they do not have to do this alone – include other family members, a member of the clergy, an attorney, another parent of a child with a disability as a peer supporter, a financial planner and/or trusted friend.



Born From a Tragedy

Closing the Gap Between Future Needs and Resources for
People with Intellectual Disabilities: A Joint Study by the
United Way of Allegheny County and Carnegie Mellon
University

And

A Legislative Forum on Elderly Caregivers of People with
Intellectual Disabilities

I Care

- A program that encourages local community businesses, neighborhood groups, places of worship, and mail carriers to watch for signs of distress among the elderly and other vulnerable people in their communities.
- I Care was launched in April, 2015 as a 3-month pilot project in two of Pittsburgh's lower income communities.
- 12,000 cards and posters were delivered to 100 community organizations.
- This month, the United Way will evaluate if there was a spike in calls to the Helpline from these two communities.

What Else Should We be Doing to Reach These Families?

What resources do we need at the national, state, and local, level?

What partnerships should we be developing?

- Organizations that serve seniors, e.g., NCOA, AARP, Consumer Voice
- Government agencies serving seniors, e.g., ADRCs, AAA
- Faith communities
- Neighborhood “age in place” villages
- Meals on Wheels and other community services

Outreach to Traditionally Underserved Communities

How do we Broaden our Outreach?

- Cultural Competency
- Language Barriers

What are we doing at the national level?

- NCLR Conference
- National Urban League Conference



When we reach these caregivers, how do we support them?

What tools and resources do we need to connect with them?

How do we make sure they and their family members with I/DD get the support they need?

The Media: Portrayals of Tragedy

Chicago Tribune

Woman Accused in daughter's death
devoted life to her, friends say



June 14, 2015

The Detroit News

Melvindale cops say dad killed autistic son,
himself

Melvindale – A father's apparent fatal shooting of his adult son with autism before he turned the gun on himself points up concerns in the special needs community about the stress aging parents face when caring for children as they get older.

Police believe John Richett, 58, killed his autistic son, Nicolas, 20, due to the father's health problems and concerns about his son's future well-being.

June 16, 2015

Appropriate Media Responses

In response to the recent Chicago incident:

To the editor:

The murder of Courtney Liltz by her mother, Bonnie Liltz, must be understood for exactly what it is – a crime of the worst magnitude – and her attempt to take her own life illustrates that likely she was experiencing a significant crisis in her own mental health. The act of a parent to kill or attempt to kill her own child is not a rational act, regardless of whether the child has a disability or how challenging the circumstances, and is never acceptable.

Unfortunately, far too many families with a member with a disability are not prepared for the future, or frightened by what that future may look like. Looking ahead to the day a parent or caregiver is no longer able to provide support is daunting, but when it comes to the future of a person with a disability, it is necessary, and possible.

To help families and individuals with intellectual and developmental disabilities (I/DD), The Arc has launched the [Center for Future Planning](#) – an online center to help people with I/DD, their parents, siblings, and others get started in the process. Waiting for a crisis will only make it harder, and our patchwork system of services and supports may look significantly different in the future, so The Arc encourages all families and people with I/DD to start those planning conversations as early as possible.

The future is closer than you think, and the tragic death of Courtney is a reminder that far too many people feel helpless without a plan in place.

Peter Berns, CEO, The Arc of the United States

Appropriate Media Responses

In response to Dr. Phil airing a two-part interview with Kelly Stapleton:


The Arc Weighs In on Dr. Phil Shows on the Case of Kelly Stapleton

Washington, DC – Last week, Dr. Phil aired two shows about the case of Kelly Stapleton, a mother from Michigan who attempted to take the life of her daughter, Issy, who has autism, and herself last year. The Arc released the following statement in response to the reporting done by the Dr. Phil Show.

“Kelly Stapleton’s failed attempt to take the life of her daughter, Issy, must be understood for exactly what it is – a crime of the worst magnitude – and her attempt to take her own life illustrates that likely she was experiencing a significant crisis in her own mental health. The act of a parent to kill or attempt to kill her own child is not a rational act, regardless of whether the child has a disability or how challenging the circumstances, and is never acceptable and offends our deepest values and sensibilities.

September 22, 2014





Do you think this is the right tone in response to these tragedies?

Media Portrays Proactive Planning


Nationally, we secured this Yahoo Parenting piece:



When It Comes to Her Daughter's
Future, One Aging Mom Is
Learning to Let Go

February 22, 2015





Planning is possible and necessary. We need proactive stories from *YOUR* community to pitch to the media.