



The Technical Assistance Center for Lifespan Respite Fact Sheet Number 62, March 2015

Respite for Family Caregivers of Children and Adults with Intellectual and Developmental Disabilities (I/DD)

Introduction

Significant policy, programmatic, and societal changes over the last fifty years have led to the deinstitutionalization of individuals with intellectual and developmental disabilities (I/DD) and to a recognition of their right to a meaningful life as active participants in families and the community. As the focus on home and community-based living grew, so have the numbers of families who chose to support their family member with I/DD at home or in the community. These family caregivers help their loved ones live in less restrictive and more person-centered environments with supports and options, which in turn, support self-determination and steps towards rightful inclusion in the community.

In the early days of deinstitutionalization, respite services and other family supports were in limited supply. Such services were most often available to families in crisis, rather than as a way to offer ongoing caregiver relief or meaningful social experiences for the care recipient. Today, the goal of respite care is to provide family caregivers a break from continual caregiving responsibilities and to improve their well-being and the well-being of the entire family. Respite allows caregivers to rest and focus on their own needs and other family relationships, while also allowing the individual with I/DD opportunities for social engagement, recreation, and other positive experiences.

Although the types of formal respite services have increased over the years with in-home respite, community-based agency respite, emergency respite, facility-based respite, and adult day

services, the need is greater than the current supply can provide, especially with limited state and federal fiscal resources. Respite opportunities through volunteer and faith-based options, family support approaches, participant-directed services, and natural community supports are being explored and expanded.

The purpose of this fact sheet is to provide a basic overview of useful information for respite providers who work with individuals and families caring for someone with I/DD. It is also meant to assist Lifespan Respite grantees and their collaborators by increasing their understanding of the unique needs of this population and their family caregivers. It is hoped that such insight and direction will help State Lifespan Respite programs and others develop strategies to increase respite options, opportunities, quality, access, and capacity for this population through partnerships with community-based services and enhanced provider recruitment and training efforts. Useful information is also provided for family caregivers.

Understanding Intellectual and Developmental Disability (I/DD)

Intellectual and developmental disabilities (I/DD) are disabilities that are usually present at birth or appear before the age of 22 and are likely to be life-long. I/DD affects physical, intellectual, and/or emotional development. According to a federal definition of developmental disability, individuals with DD must also have activity limitation in

three or more areas.¹ Examples of developmental disabilities that are largely physical include cerebral palsy or epilepsy. Some individuals may have a condition such as Down Syndrome or fetal alcohol syndrome that may include a physical and intellectual disability.

It is estimated that over half of individuals with intellectual disabilities do not meet the criteria for functional limitations (The Arc, 2011). Intellectual disability starts any time before a child turns 18 and is characterized by limitations with both:

- Intellectual functioning or intelligence, which includes the ability to learn, reason, problem solve, and other skills; and
- Adaptive behavior, which includes everyday social and life skills.

Overall, more than 4.9 million citizens with I/DD, or about 1.5% of the population, live in the United States (Braddock, et al., 2013). Among children in the U.S., about 1 in 6 have one or more developmental disabilities. The prevalence of parent-reported developmental disabilities increased 17.1% from 1997 to 2008 (Boyle, et al., 2011).

A significant number of individuals with I/DD have co-occurring conditions. An estimated 30-35% of all persons with intellectual or developmental disabilities have a co-occurring mental illness

(NADD, nd). Children with I/DD may also have complex medical conditions that persist into adulthood, and a significant percentage of adults with Down Syndrome develop dementia by age 40 (see discussion on page 3 under “Aging Individuals with I/DD and their Aging Parents”).

Individuals with I/DD exhibit a wide range of abilities and behaviors. Children may be delayed in their abilities to learn to speak, walk, dress or feed themselves. The process of learning may be slower. While some adults with I/DD may have serious, life-long limitations in functioning, most can live independently in the community with appropriate supports. Some are able to live independently without paid supports (The Arc, 2011). Assessments of an individual with I/DD should take into account the community environment typical of the individual’s peers and culture. Individuals with I/DD who are provided appropriate personalized supports over a sustained period generally have improved life outcomes (American Association of Intellectual and Developmental Disabilities, nd).

I/DD occurs among all racial, ethnic, and socioeconomic groups. Genetics, problems during pregnancy or at the time of birth, childhood illnesses such as measles or meningitis, or social conditions, such as poverty and cultural deprivation are all causes of an individual’s I/DD, but for many individuals, there is no specific known cause of their developmental delays (The Arc, 2011). Health and social factors associated with poverty, such as inadequate health care, higher incidence of childhood diseases, malnutrition, or exposure to environmental toxins such as lead, can lead to intellectual disability. Limited early intervention, cultural experiences and educational opportunities for young disadvantaged children, can also be precursors to intellectual disability (The Arc, 2011).

Understanding Family and Individual Needs

Of the nearly 5 million individuals with I/DD, 72% lived with a family caregiver in 2011 (Braddock, et al., 2013). Only 25% of individuals who are living

1 According to the Developmental Disabilities Act (Pub. L. 106-402), the term developmental disability means a severe, chronic disability that:

1. is attributable to a mental or physical impairment or a combination of those impairments;
2. occurs before the individual reaches age 22;
3. is likely to continue indefinitely;
4. results in substantial functional limitations in three or more of the following areas of major life activity: (i) self-care, (ii) receptive and expressive language, (iii) learning, (iv) mobility, (v) self-direction, (vi) capacity for independent living, and (vii) economic self-sufficiency; and
5. reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

in the community receive formal disability services and more than half of these individuals are living at home with family members. For many individuals with I/DD, this support from families is provided long-term and most likely will continue even after the individual turns eighteen years old (Hecht and Reynolds, 2011).

In a 2010 online survey conducted by The Arc, more than 5,000 parents, siblings and other caregivers or support providers of people with I/DD responded to questions about school, community and workplace environments for individuals with I/DD and supports for their families. The survey found that while the majority of families reported that they provide personal care, transportation, financial support, care coordination, and more for adults with I/DD, nearly half (46%) of parents/caregivers reported that they have more caregiving responsibilities than they can handle. In the survey:

- The vast majority of caregivers reported that they were suffering from physical fatigue (88%), emotional stress (81%) and emotional upset or guilt (81%) some or most of the time.
- More than 75% of families reported they cannot find afterschool care, non-institutional community services, trained reliable home care providers, summer care, residential, respite and other services. For respite, 38% said it was somewhat of a problem finding it while 87% said it was a major problem (The Arc [FINDS], 2011).

Aging Individuals with I/DD and Their Aging Parents

The life expectancy for adults with developmental disabilities has risen during the last 50 years, resulting in an extended period of caregiving. By 2030, the number of adults with I/DD aged 60 and older is projected to reach 1.2 million (Heller, et al., 2010). People with developmental disabilities who are aging have their own unique health and service needs. Due to biological factors related to certain syndromes and conditions, limited access to health care, and lifestyle issues, many adults with developmental disabilities have a higher risk

Jill's House Vienna, Virginia

Jill's House is a 42,000-square-foot overnight respite center for children with intellectual disabilities ages 6-17. At capacity, the program can serve 45 children for overnight care. Most children have their own rooms, though some prefer to have "slumber parties" with siblings or friends (with parents' permission). Each room is equipped with a TV and DVD player. Also equipped with an art room, a therapeutic swimming pool, and a great room with a fireplace, parents have called it "Great Wolf Lodge for Kids with Special Needs." The program was founded by the McLean Bible Church in McLean, VA. For more information: <http://jillshouse.org>.

of developing chronic health conditions at younger ages than other adults (Factor, et al., 2012).

Individuals with Down Syndrome, for example, are living longer than they did even a few decades ago and are at increased risk for developing dementia as a result, including development of younger onset Alzheimer's. Studies show that at least 25% of adults with Down Syndrome will be affected with dementia after age 40 and at least 50 to 70% will be affected with dementia after age 60 (Keller, 2013).

At the same time, the general aging population is increasing. Of the 3.5 million persons with I/DD living with family caregivers, over 850,000 are living with family caregivers who are over age sixty (Braddock, et al., 2013). Aging caregivers face unique circumstances and challenges, including the length of their caregiving experiences that may not end until their own death or incapacitation. They may face evolving health and aging issues over the lifespan of the individual in their care as well as their own aging process and diminishing health. This often leads to an overarching concern regarding the future welfare of their children with

intellectual disabilities when as parents, they are no longer alive or able to provide care (Perkins, 2011).

The aging of the baby boom generation as well as an increase in the number of aging individuals with I/DD who are living longer will result in fewer parent caregivers able to provide support. The role of siblings in providing care is likely to increase as the population of older parents increases and their ability to continue to provide ongoing care declines (Heller and Kramer, 2009).

Compound Caregivers

Longer lives for both the person with I/DD and their caregivers may result in another caregiving situation known as compound caregiving. A compound caregiver is a parent who already has significant caregiving responsibilities for their son/daughter with I/DD, who subsequently becomes a caregiver for an additional family member (Perkins, 2011).

Family Respite Services (FRS) Windsor-Essex, Ontario, Canada

FRS provides flexible respite services for families caring for children under the age of eighteen who have intellectual, physical and mental health disabilities. Their goals are to sustain and enrich a family's quality of life while seeking the fullest participation of the child in the community.

FRS, in consultation with families, offers a number of options for providing respite. Options include:

- **Community Respite:** A respite provider or "CHAP" worker (Community Helpers for Active Participation) is matched with a family and child to assist the child/youth to participate in community-based activities. The providers are self-employed and many families receive some financial assistance from FRS to pay for the service. The parent provides the training to the respite care provider. The FRS Family Coordinator provides support and resources to both the family and provider.
- **Associate Respite:** Host families welcome a child with special needs into their home, usually for a weekend each month.
- **Fantastic Fridays:** FRS works in partnership with a local parks and recreation department to provide a Friday night recreation and sports program for older youth.

- **Our Time Together:** This program features an opportunity for children with special needs and their siblings to attend an inclusive community center recreation program operated by the local municipal parks and recreation department. Parks and recreation department run the program, but FRS provides staff to support children with disabilities so that they can participate fully in the activities. Family Respite Services gives priority to families who have few other supports and families who have limited income for this program.
- **Weekend with Friends and Spago Residential Home:** FRS also maintains a weekend group respite program in a homelike environment

FRS also offers **Enhanced Respite** for children under 18 who may also have medical needs. All families work with Family Coordinators from Family Respite Services who help them determine the kind of respite that best fits their needs and help develop respite plans.

For more information – Family Respite Services Windsor, 3295 Quality Way Unit 101A, Windsor, ON N8T 3R9; Telephone: (519)-972-9688; Fax: (519)-972; Email: info@familyrespite.org; website www.familyrespite.org/contact-us.

Multiple caregiving is common across all family caregivers. More than one-third (34%) of caregivers are regularly providing care to more than one person (National Alliance for Caregiving, 2009). However, the lifelong caregiving role experienced by parents of individuals with I/DD when combined with multiple caregiving responsibilities of additional care recipients is likely to be overwhelming. In addition, new caregiving responsibilities for an aging parent or other family member may mean the loss of someone who previously assisted in the care of the individual with I/DD that could result in greater caregiving stress. In a study comparing compound caregivers with non-compound caregivers, compound caregivers reported an increased desire to place their son/daughter with ID into an alternative residential setting, which may “reflect that a tipping point has been reached from the multiple caregiving demands that results in feelings of burden and inability to cope” (Perkins, 2011).

The Benefits of Respite

Respite has been shown to have positive outcomes for parents and other caregivers of children and adults with I/DD, including improvement in social support and life satisfaction, relief of psychological stress, and even improved marital relationships (Chou, et al., 2008; Wilkie and Barr, 2008; Harper, et al., 2013). Respite and other family support services can provide the support and improved quality of life that assists families in meeting the demands of personal, family, social and work life (Caples and Sweeney, 2011).

If family caregivers are encouraged and able to use their respite time in ways most meaningful for them, research has found more long-lasting benefits in terms of stress reduction and improved well-being. Options that maximize this possibility through flexible scheduling and affordability may prove especially useful to family caregivers of individuals with I/DD. In addition, providers can help caregivers by helping them to re-capture or substitute activities during respite that have been lost because of caregiving (Lund, 2011).

Also, research has shown that benefits accrue for both family caregivers and care recipients when respite is enjoyable for the person in care and offers them opportunities for social interaction with peers (Swallow, 2011). For children with I/DD, respite can provide opportunities to engage in activities that are of particular interest to them and provide opportunities for experiences outside the family and school that will promote independence later. Respite that is provided through activities with typically developing children can offer friendships and greater engagement in the community.

For an adult with I/DD, respite can be the bridge to living outside the family by helping to build skills needed for independent living. Out-of-home respite care can enable families to test this option, explore community resources and prepare themselves and their family member with I/DD to live in the community. Social or recreational activities in mainstreamed settings can help improve peer to peer relationships for young adults with I/DD and provide respite for family caregivers at the same time (Sell, 2012). Aging parents may then see themselves as partners in care rather than as “relinquishing” care. Respite may provide the comfort of taking positive action while also allowing them to consider creation of a transition plan for where their child will live and how they will be supported once the parent is no longer able to provide care.

Respite as an Opportunity for Valued Roles

Respite can provide the opportunity for individuals with disabilities to obtain socially valued roles (Armstrong and Shevellar, 2006). Social Role Valorization (SRV) is a concept for transacting human relationships and human service formulated by Wolf Wolfensberger, PhD. His definition of SRV is: “The application of what science can tell us about the enablement, establishment, enhancement, maintenance, and/or defense of valued social roles for people.” The major goal of SRV is to create or support socially valued roles for people in society. If a person holds valued social roles, that person is highly likely to receive from society those good

things in life that are available to people who are valued (Osburn, 2006; Wolfensberger, 2013).

For example, respite programs utilizing volunteers introduce people with I/DD to unpaid freely given relationships that can assist in helping the person receiving respite to develop natural relationships and become more connected to their community. For on-site respite settings, families of people with I/DD receiving respite can see other people take an interest in and see the positive value of their child. Also, if a respite program identifies the valued roles a person receiving respite already holds, then it can help maintain those roles for the person in any respite activities. For example, if a person receiving respite has talent in art and is seen as an artist, then helping that person participate in art maintains this valued role.

There are excellent training curricula for a more in-depth understanding of the concepts of SRV. For more information on social role valorization and training materials, see <http://www.socialrolevalorization.com/training/index.html>.

Supporting Age Appropriateness of Roles and Activities

Respite is an effective way to contribute towards creating a primary view of people with I/DD as their chronological age instead of being defined by their developmental age. A way to achieve this outcome is to offer programming or care with age appropriate activities for the care recipient. For example, a 25 year old person with I/DD could learn to play board or card games typically enjoyed by adults either independently or with support within the context of the respite environment. In addition to games, other recreational or adult leisure activities such as gardening or hiking could be included as components that could provide meaningful enhancement to the respite care recipient with I/DD. Likewise, children with I/DD should have the opportunity to pursue the same activities and interests as their typically developing peers. The role of the respite worker may be to encourage the individual to engage in a current or new hobby while providing, if necessary, the support needed for

the person with I/DD to experience enjoyment and success.

A Pathway to Social Inclusion Versus Isolation/Exclusion

Respite can reinforce inclusion, integration, and a sense of belonging for the person with I/DD if it is provided in the community, among individuals and peers without disabilities, in activities and at venues where other valued citizens gather and spend their time. All too often human services (often unconsciously) promote the further segregation, exclusion, congregation and isolation of people with I/DD (Armstrong and Shevellar, 2006). Successful respite is often shaped around the individual with I/DD's interests while being mindful of support needs. Factors such as the individual's ability to manage crowds or noise, or their energy level, should be considered in addition to the respite provider's ability to communicate, comfort or soothe the individual if in distress. Respite that is mindful of the individual's specific needs and wants is often the most successful and encourages further integration, inclusion and belonging in the community.

Fostering Positive Imagery and Increased Competency

Respite can foster a positive image of people with I/DD by selecting a valued location in which to provide respite; engaging people in age-appropriate and valued activities; grouping people in integrated settings; and being mindful of language used about people in care. Also, thoughtful respite can assist people with I/DD to gain competence in areas of interest to increase the likelihood of becoming a valued community member.

Barriers to Respite Care for Families of Individuals with I/DD

Despite the benefits of respite, many families lack information about how to find, choose and pay for respite. Some may not even know such support exists. But even when families recognize the need, they may find financial barriers, or a limited supply

of well-trained providers or accessible services that meet their needs. For others, a reluctance to leave their child in someone else's care or the lack of appropriate respite options for the care recipients that promote social relationships and community engagement or offer meaningful activities can be significant barriers.

Shortages of Qualified Respite Providers and Options

As for many other populations, even when families may have the resources to pay for respite, such services for this population may be difficult to find. Respite may not be available at times families need it the most – evenings, weekends or for other extended stays – or providers may not have the training to qualify them to handle any special needs of the I/DD population. Available respite options may not be age or developmentally appropriate or desirable, especially for adults with I/DD.

Kennedy Center's Caring for the Caregiver Program Trumbull, Connecticut

The Kennedy Center's caregiver program was designed to meet the needs of parent caregivers over age 60 who are caring for individuals with intellectual disabilities at home. The model teaches younger adult children with a disability to assume a caregiving role of their aging parent by teaching them household and self-sufficiency tasks. Families receive home visits and assessments to develop an individualized plan. The senior parent receives respite services and other supports that allow families to continue to live at home together. Since the program began in 2003, 551 families have received program supports and educational services. For more information, see <http://www.thekennedycenterinc.org/what-we-do/programs-services/residential/family-support.html>.

Limited and sometimes costly training presents a barrier to ensuring a robust pool of qualified respite providers. Without appropriately trained staff, many respite providers and community-based respite programs are still hesitant to serve individuals with challenging social and communication behaviors. Consequently, there is a particularly acute shortage of providers who are qualified to serve people with autism, those who have I/DD with a dual diagnosis including mental health issues, or for older individuals with I/DD and dementia.

Barriers to the development of respite provider pools include a low pay scale with limited benefits, difficulty in recruiting direct care staff and volunteers, and an overall provider shortage for all age groups and conditions. Consumer-directed respite options, which allow families to select and train their own providers from their natural communities of support, could help alleviate this barrier. While more states and private entities are implementing this option, too few consumer-directed respite opportunities are available or supported by public or private funds.

Economic Challenges

Increased economic pressures further stress families of individuals with developmental disabilities. As a result, disposable income may not be available to pay for respite. Parental employment may be negatively affected by caregiving responsibilities. According to The Arc survey, 1 out of 5 families (20%) reported that someone in the family had to quit their job to stay home and support the needs of their family member. Moreover, families of individuals with I/DD often face higher rates of poverty than other families, while faced with considerable out-of-pocket costs for the care of their relative with disabilities (Heller, et al., 2007).

For many, limited government-funded services are available, especially for adults with I/DD, and many languish on waiting lists for years. In the survey conducted by The Arc, one-third (32%) of parents/caregivers reported that they are on waiting lists for government funded services, with an average wait of more than five years. They are waiting for

personal assistance, respite, housing, therapy, employment supports, transportation and more (The Arc [FINDS], 2011).

As a result, their financial burden is significant, with little disposable income or other resources to pay for respite. The Arc survey found that:

- 82% of families reported that their overall economic security is challenged and 80% reported that they don't have enough money to pay for the support or care their loved one needs.
- 47% of families reported that they are paying more for care out of pocket.
- 21% of families reported spending \$1,000 or more per month for services and supports for their loved ones; an additional 23% spend \$250 to \$999 per month.
- For most families (63%), the money comes from the personal income or savings of the parent/ caregiver or other family sources (The Arc [FINDS], 2011).

If a child or adult with I/DD is eligible for state or federal funding, but also has an additional diagnosis of behavioral issues or mental illness, disagreements or confusion may ensue regarding the state agency or funding stream that is responsible for covering respite expenses and other family supports. Economic challenges for these families that leave little or no resources available for respite can be especially burdensome.

Reluctance to Use Respite

Some families may feel reluctant to use respite especially if it means having a respite worker enter the family home. The imposition of a respite worker in one's home may not feel like respite at all and may add more stress to the family. Center-based or facility-based respite where providers are unknown to the family may cause similar reticence. In addition, some families may be uneasy about receiving respite care because they may have feelings of guilt or anxiety. They fear that their child may not be as well-cared for by a provider as they would be by their parent, or they are distressed because they feel they are losing control over the

child's safety and well-being (Lieberman, 2005). One way to address reluctance is to actively include parents and individuals receiving respite in any assessment process, in provider training, in decision-making, and in creating a person and family-centered respite situation that is desired.

Possible Avenues for Accessing Respite Services

Several paths to accessing respite for family caregivers exist through formal supports and services, participant-directed respite, or natural supports.

Formal Supports and Services

Case management systems may help family caregivers access respite. Therefore, registering for services is often a gateway to accessing respite programs or funding for respite care. Once engaged in a community or state office for individuals with I/DD, family caregivers may have more options for support. Those supports may include the Medicaid Home and Community-Based Services (HCBS) waivers, or state funded developmental disability services, which may provide the individual with I/DD with a menu of supports, including respite.

Family Support

Some states provide state and local family support services or funds. Family support services are community-based services that assist and support parents in their role as caregivers and support the family as a whole. Such services can take many different forms depending on the strengths and needs of the family. In many areas, respite for individuals with I/DD is frequently accessed via family support services, which may provide flexibility and a broad definition of how respite can be provided. For example, family support resources may recognize respite in a variety of settings, such as an afterschool program, Saturday drop-in activity, camp or the person's home, as well as a range of providers, from agencies to informal resources such as a neighbors, extended family members or trusted individuals in the community.

Voucher or Participant-Directed Respite

Voucher or participant-directed models, often also referred to as consumer-directed services, have been shown to result in specific benefits for both the family caregiver and the individual with I/DD. In such approaches, the family chooses and employs the care provider. Providers may be trained by a respite program, volunteer or faith-based program, or the family to provide respite care for a child/adult with special needs (I/DD) in the family's home setting or in the community. Families tend to hire friends, neighbors, and to a great extent, other family members. Hiring of other relatives to provide services has been associated with the increased community involvement of individuals with I/DD.

Also, more control by families in the management of their respite/personal assistance services has been associated with increased service satisfaction and increased employment of mothers (Caldwell and Heller, 2003).

Natural Supports

An increasing focus on the need for family-driven/youth guided and person-centered services and supports and inclusive opportunities is resulting in a paradigm shift in the way services and supports are offered and delivered. In some states and communities, a shift from formalized services to natural community supports and strategies to strengthen families is occurring. Rather than offering

The Watson Institute Sewickley, Pennsylvania

CareBreak

This volunteer respite program utilizes volunteers to provide respite for a family caring for a child (birth to 16 years old) with a variety of disabilities, including autism, cerebral palsy and other neurological impairments from Allegheny, Beaver and the southern portion of Butler counties in Pennsylvania. CareBreak provides an opportunity for children and volunteers to become close through fulfilling, one-on-one experiences, while allowing the family to regroup. Volunteers make a commitment to the child and the family – often being the first unpaid person in the child's life to do so. All CareBreak volunteers are provided with training prior to being placed with a family and have necessary clearances. Typically, CareBreak is provided in the family's home.

For more information regarding the CareBreak program, please contact MaryJo Alimena-Caruso, CareBreak Coordinator, at (412) 749-2863 or via email at maryjoa@thewatsoninstitute.org, website www.thewatsoninstitute.org/services.

Day and Overnight Respite Program

The Watson Institute has developed an inclusive respite program that creates a camp-like setting for children with and without disabilities. Children participate in small and large group activities, such as arts and crafts, music, nature hikes and sports. There are also quiet indoor activities available for those who choose not to participate in the outdoor events. The Day and Overnight Respite Programs have a high staff-to-child ratio and a nurse present at all times. The Overnight Program also consists of staff that remain awake to ensure the children are supervised at all times. All school age children with disabilities ages of 3 to 21 and their siblings ages 3 to 13 are eligible to attend the day respite. Children with disabilities ages 5 to 21 and their siblings ages 5 to 13 are eligible to attend the overnight respite.

For more information on this respite program contact Sharon Smith at (412) 749-2836 or via email at sharons@thewatsoninstitute.org, website www.thewatsoninstitute.org/services.

families a list of formalized services from which to choose, a person and family-centered approach is taken that strives to help families meet their own identified needs and the needs of the person with an I/DD. Family caregivers and care recipients are actively engaged in determination of their own needs and preferences as well as in the planning and selection of desired activities, supports and services.

Children and adults with disabilities who live and participate in their communities will have more opportunities to enhance their social lives and social skills which could be beneficial in the quality of their lives through relationships and friendships (Hewitt, et al., 2013). Respite that utilizes volunteers or friends and neighbors who freely give of their time and may have more flexibility in the range of available activities they can offer, or integrated community activities such as youth groups or sports programs, for example, may increase opportunities for children and adults with I/DD to increase their participation in the community, while providing family caregivers a break. These approaches help to develop a community of supportive relationships, improve the individual's skills and abilities, and allow them to gain greater independence. The benefits include empowerment, growth and a decrease in the need for more formal services.

Respite Options for Children and Adults

An array of possible respite options exists for consideration.

Inclusive Respite

The Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act require that reasonable accommodations required by a child or adult with a disability be made in already available services in the community. As a result, child care, after-school care, camps, community centers, and other recreation programs are increasingly serving children and adults with a range of disabilities and chronic conditions. Programs may be volunteer run or faith-based. Inclusive respite programs

can be any organized activity or setting where individuals with I/DD are receiving respite with other people who are of their age range and do not have disabilities. This model provides opportunities for people with and without disabilities to spend time together in activities along-side one another in settings that are open to the public and not disability specific. This model of respite may include family members or siblings of an individual with I/DD or be a resource to all community members rather than a segregated program. In addition, the inclusive respite model may provide the person with a disability the opportunity for friendships with a non-disabled peer, positive age-peer modeling/imitation and competency enhancing opportunities, as well as allowing families of both children and adults with and without disabilities to interact.

In-Home Respite

Using in-home respite may offer familiar surroundings that are more comfortable for the recipient of respite, the caregiver, and the family; the home may already be equipped for any adaptive or medical needs of the child/adult; a family may feel their child would be safer receiving respite in their home; and it may be more economical.

Center-Based Respite

Respite center-based models can be in existing settings that provide other support services in addition to respite. These centers may have a therapeutic or activity-based theme that allows the caregiver to take a break from caregiving while the individual with I/DD is engaged in a variety of pursuits and activities. Such respite center models allow individuals with I/DD to be in an environment/setting where they can be supervised by trained respite staff while they socialize or receive necessary treatment or other interventions, or engage in recreational or other pursuits. Some center-based respite options offer overnight or extended respite stays.

Parent/Family Caregiver Cooperative Model

The parent/family caregiver cooperative model is an informal association where families exchange respite services with each other utilizing their personal home or a faith-based or community-based center as the respite setting. This model is particularly helpful in areas where respite services are limited. It may also be beneficial in terms of peer support for families whose children/adults have similar disabilities and may also provide the option for siblings to participate in respite.

Agency Residential Setting

Some residential agencies for children/adults with I/DD provide a respite “spot” in an existing residence that already serves individuals with I/DD. Such respite can be short term or longer term depending on the type of respite service the residential agency provides. These settings may provide an opportunity for overnight or extended respite.

Emergency Respite

When a family is in crisis and can't provide care, and the above respite options are not available, emergency respite may have to be arranged. This can be a short term placement in a residential setting, private home, or other setting that can care for the person until the crisis in the family is resolved. Advance planning for emergency situations is critical and more providers are needed who are willing to provide respite on an emergency basis. For more information and examples of emergency respite, see ARCH Fact Sheet *Emergency Respite: Help for Family Caregivers in Critical Times of Need* at http://archrespites.org/images/docs/Factsheets/FS_61-EmergencyRespite.pdf.

Federal, State, and Private Funding Sources

Understanding funding for respite within a state is important for administrators, respite providers and consumers.

Administrators and providers can use this information to identify funding opportunities to

develop or enhance services. Similarly, consumers can learn about funding for the respite services they are eligible for within the local community.

Federal Funding Sources

Medicaid

Medicaid pays for medical services for individuals who are financially and medically needy. Several options currently exist for states to fund or support respite services under Medicaid.

In most states, long term services and supports (LTSS) are largely provided by Medicaid Home and Community-Based Services (HCBS) §1915(c) Waivers, which allow states considerable flexibility in the type of HCBS services offered on a statewide level. Respite is specifically supported by most HCBS Waivers, which are the leading source of federal funds for respite care. Depending on how individual HCBS waivers are written by the state, waiver programs generally are narrowly targeted to individuals of specific ages and disabilities, illnesses or conditions.

The I/DD population is one of the largest groups of §1915(c) waiver participants. In 2011, 582,470 individuals were enrolled representing 40% of national §1915(c) waiver enrollment. Nearly 70% of all waiver spending that year was for individuals with I/DD. Unlike Medicaid medical assistance, waiver services are not an entitlement and may have long waiting lists. The largest number of persons on waiting lists to receive HCBS waiver services are those waiting for I/DD waiver services. In 2013, 322,273 individuals with I/DD in the U.S. were on a waitlist for I/DD waiver services and the average length of time a person spent on a waiting list was 50 months (Ng, et al., 2014).

States may elect to fund home and community-based services as a Medicaid state plan option, specifically under HCBS State Plan Option §1915(i). Under this scenario, covered individuals would not have to meet an institutional level of care need and there would be no waiting lists or caps on services as there are for §1915(c) waiver services (Dougherty and Kagan, 2012).

In 2014, the Centers for Medicare and Medicaid Services (CMS) issued a new regulation regarding home and community-based services (HCBS). The rule streamlines the definition of HCBS across the Medicaid program and strengthens the requirements for autonomy and community integration in services. Each person receiving HCBS must have a person-centered plan. In addition, for individuals served under HCBS State Plan Option 1915(i), the rule requires that family caregivers also have an assessment of their needs. For more information on caregiver needs assessments, see resources from the *Family Caregiver Alliance* at <http://www.lifespanrespite.memberlodge.org/CaregiverAssessment>.

Another area of consideration for Medicaid funded respite is that states increasingly are moving to Medicaid managed care to provide long term services and supports (LTSS). Respite will have to be reconsidered as a benefit under many new Medicaid managed care plans. At least half the states were expected to employ managed care for long term services and supports by the end of 2014 (Caldwell, 2013).

For information on home and community-based Medicaid Waivers by state and how to access them, visit the ARCH State Resources Map at <http://archrespite.org/respitelocator/respite-locator-service-state-information-map>.

Social Services Block Grant (SSBG)

The SSBG may be used by some states to pay for support services to families caring for someone with I/DD who meets income and disability eligibility criteria. Services offered under this federal program are state specific and can often provide short-term in-home support services. Less than 1% of federal expenditures for services for the I/DD population are derived from the SSBG, but this is another potential source of funding for respite services for individuals who are not Medicaid eligible or are on waiting lists for home and community-based services (Braddock, et al., 2013).

Lifespan Respite Care Program

The Lifespan Respite Care Program, funded through the US Administration for Community Living, provides competitive grants to states in order to develop coordinated systems of accessible, community-based respite services for all family caregivers regardless of the age or special need of the care recipient. These efforts are geared to maximizing use of existing funds and leveraging new dollars for respite. As of 2015, 32 states and the District of Columbia have received Lifespan Respite grants since 2009. States conduct needs assessments and, if they are supporting direct services with their Lifespan Respite grant funds, have the option to serve unserved or underserved populations through a variety of respite options. Many elect to serve individuals currently not eligible for federal or state programs, especially adults ages 18-60 or those who are on waiting lists for other services or funding. The models for service delivery include voucher respite where families select their own providers, mini-grants to community or faith-based agencies to design innovative services, or volunteer respite.

For more information on State Lifespan Respite grantee activities, see http://archrespite.org/images/2013_Master_GraneeTable_Activities_March.pdf.

National Family Caregiver Support Program (NFCSP)

Authorized under the Older Americans Act, the program calls for State Units on Aging to work with regional Area Agencies on Aging, local community-service providers, and Tribal Organizations to offer five basic services for family caregivers: 1) information; 2) assistance accessing support services; 3) individual counseling, support groups, and caregiver training; 4) respite; and 5) limited supplemental services. Funding may be available for caregivers providing care for someone over the age of 60 or someone of any age with Alzheimer's disease or other neurological conditions. Also eligible are: grandparents and other relative caregivers (not parents) 55 years of age or older providing care to children under age 18, and

grandparents and other relative caregivers (not parents) 55 years of age or older providing care to adults age 18-59 with disabilities, to whom they are related by blood, marriage, or adoption. Tribal Organizations can set an age lower than 60 at which members can be considered as elders eligible for services. In most states, the National Family Caregiver Support Program is administered through local Area Agencies on Aging (AAA). The ElderCare Locator service at <http://www.eldercare.gov> provides links to local AAAs.

Supplemental Security Income (SSI)

Supplemental Security Income is a federal cash benefit program under the Social Security Administration (SSA). Direct monthly payments are available for unrestricted use, including for respite, for those with incomes and resources below certain levels who are blind, have disabilities, or are age 65 or older. Under the age of 18, eligibility is based

on parents' income. Over the age of 18, eligibility is based on the income of the person who has a disability.

More information on federal funding can be found in *Federal Funding and Support Opportunities for Respite: Building Blocks for Lifespan Respite Systems* at http://www.lifespanrespite.memberlodge.org/Federal_Funding_Guide.

State Funding

State Family Support Services (FSS)

Family support services are community-based resources that assist and support family caregivers of individuals with I/DD and other disabilities in their role as caregivers. Family support programs for children and/or adults with developmental disabilities exist to varying degrees in the states. Family support services may be defined differently in states and localities, but generally they provide a

coordinated system of services, resources, and other assistance for families caring for individuals with developmental disabilities who live at home.

Services may include, but are not limited to, in-home and out-of-home respite, cash stipends, assistive devices, and recreation and social programs. Some states include any service or support identified by the family. Funding is typically modest and subject to waiting lists. In FY 2011, state family support dollars accounted for about 7% of all federal and state expenditures for individuals with I/DD (Braddock, et al., 2013).

State-Funded Developmental Disabilities Respite Programs

Many states have dedicated state-only funds specifically for respite and other supports for

Participant Directed Respite South Dakota Division of Developmental Services Department of Human Services

Any family having a child or adult family member who has a developmental disability, a developmental delay (children only), a serious emotional disturbance, a severe and persistent mental illness, a chronic medical condition (children only), a traumatic brain injury, or a child they have adopted may be considered for respite care services. Respite care is available to eligible families regardless of income. There is no age limit. However, the child or adult must live with a parent or family member. A family may receive authorization to receive up to \$550.00 of Respite Care services with \$200.00 for each additional eligible child or adult, up to a maximum of \$950.00 per family, per year (June 1-May 31). Respite care can be utilized on a regular or irregular basis and can be provided by family members, friends, skilled care providers or professionals. The family selects a provider and uses the Request for Payment form to purchase Respite Care Services. The provider receives reimbursement by submitting the Request for Payment form to the Department of Human Services Respite Care Program. For more information, see <https://dhs.sd.gov/dd/respite/index.aspx>.

the I/DD population. Contact your state disability agency for the most recent information. Contact information can be found at <http://www.nasddds.org/MemberAgencies/index.shtml>.

For more information on possible state funding sources for respite, see ARCH's *State Funding Streams for Respite* at <http://archrespite.org/productspublications#StateFunding>. This information on state-by-state funding and program eligibility information is available through an interactive US map as a function of the ARCH National Respite Locator Service (<http://archrespite.org/respitelocator/respite-locator-service-state-information-map>).

Private Funding Sources

Some disability organizations such as Easter Seals, The Arc, and United Cerebral Palsy provide respite care and may offer some financial assistance. Many University Centers of Excellence in Disabilities also provide respite services. See "Resources" on page 20 for contact information. If the care recipient has a dual diagnosis of a medical, behavioral or mental health condition, they may also be able to receive support from local affiliates of the national organization that addresses the other disabilities or conditions. In local communities, some faith-based organizations, caregiver groups and volunteer organizations provide respite at no cost or on a sliding fee scale.

Considerations for Family Caregivers

When and How to Seek Referral

Caregivers should begin planning for respite by analyzing their own needs and those of their child/adult with I/DD so they can determine the type of respite, the skills needed by providers during respite, and the duration and possible location of respite. Families may initiate a referral for respite by going through a respite agency, an information and referral service, or by contacting local affiliates of condition-specific organizations, such as Easter Seals, The Arc or United Cerebral Palsy. See "Resources" on page 20 for contact information.

Aging and Disability Resource Centers are federally funded entities designed to serve as single points of entry or "no wrong door" approaches into the long-term supports and services system for older adults and people with disabilities. Many states' Aging and Disability Resource Centers that are working collaboratively with state Lifespan Respite Programs may provide a portal for respite resources. Increasingly, ADRCs through *No Wrong Door* federal grants are helping states to ensure that they have the capacity to serve individuals with I/DD and their family caregivers and a few offer assistance to families of children with special needs. ADRC locations can be found at <http://adrc-tae.acl.gov/tiki-index.php?page=ADRCLocator>.

To search for respite providers and funding sources by state, visit the ARCH National Respite Locator Service at <http://archrespite.org/respitelocator> and the ARCH State Resources Map at <http://archrespite.org/respitelocator/respite-locator-service-state-information-map>. Many Lifespan Respite programs have also developed online respite registries. Links to state registries can be found at <http://www.lifespanrespite.memberlodge.org/StateRegistries>.

Choosing and Paying for Respite

The *ARCH National Respite Guidelines* provide a summary of guiding principles addressing quality indicators, such as suggestions for provider qualifications and training, safety and privacy issues, family and provider communication, and community involvement for all respite models and services. Some sections of the guidelines may be helpful to consult when family caregivers directly recruit and hire their own respite providers. For more information on how to assess and use respite, family caregivers may want to refer to the user-friendly checklists and additional information included in the *ABCs of Respite: A Consumer Guide for Family Caregivers* at <http://archrespite.org/consumer-information>. To access the *National Respite Guidelines*, see <http://archrespite.org/productspublications/products-and-publications#Guidelines2011>.

Considerations for State Lifespan Respite Programs and other Program Administrators

Improved Recruitment, Education and Training for Respite Providers

Provider recruitment activities with ongoing support help respite programs to continue to be strong and ensure provider capacity. Specific recruitment methods can include community outreach, advertisements and informed networking.

Effective respite often begins with trained staff who are competent and confident to engage in the provision of care. Successful provider training resources often offer “toolkits” that provide support for effective implementation and sustainability, provider training curriculum, and a fidelity checklist of essential elements and ongoing technical support. This approach to starting or enhancing respite through a comprehensive training program that puts as much attention on developing core competencies as it does in training respite workers to keep individuals safe is often invaluable to state and local programs. Your local chapters of The Arc, United Cerebral Palsy, or Easter Seals may be able to provide information on provider training resources. Examples of training curricula also can be found on the ARCH website at <http://archrespite.org/training-ideas>.

A formal respite service, volunteer or faith-based respite program should provide training for respite providers that is both general to respite and specific to the needs/identities of the people and families receiving respite. Such training should impart the knowledge and skills needed to ensure safe and quality respite services and be person-centered (Edgar and Uhl, 2011). Families need to be an integral part of the training process as they understand their child’s needs better than anyone. The involvement of families in training also conveys a “sense of security” for families that the provider understands the specific needs of their child and has empathy towards the family situation.

Values: Understanding Challenges and Responding with a Person-Centered Approach

Values need to be considered when working with individuals with I/DD; this includes focusing on building on the strengths, assets and resources of people with I/DD. Maintaining confidentiality is especially important to support families and promotes trust that is central to developing and sustaining a successful relationship with the family

In accordance with requirements in the Affordable Care Act, the US Department of Health and Human Services has issued guidance on person-centered planning and self-direction. Person-centered planning should be the first consideration when addressing the respite needs, preferences and values of families and individuals with I/DD. “The person-centered planning approach identifies the person’s strengths, goals, preferences, needs (medical and HCBS), and desired outcomes. The role of staff, family, and other team members is to enable and assist the person to identify and access a unique mix of paid and unpaid services to meet their needs, and to provide support during planning and implementation.” (Administration for Community Living, 2014) This approach allows consideration of personal preferences while also protecting the health and safety needs of those in care. To access the guidance, visit <http://www.acl.gov/Programs/CDAP/OIP/docs/2402-a-Guidance.pdf>.

Maximize Flexibility and Consumer Control

Not all family caregivers or persons with I/DD have the same respite care needs or preferences. A great deal of diversity exists among family caregivers and the individuals in their care. They may have very different family relationships, caregiver resources and stressors, care recipient needs, and caregiving responsibilities. Therefore, a wide array of respite policy and programmatic options are needed to address these diverse needs. Efforts should be made to match the individual family need with available services or develop new services to meet caregiver and care recipient needs.

To ensure that families retain control and are able to maximize self-direction, individuals with I/DD and their families should be able to participate in the design of and have access to competent respite services, supports and other assistance and opportunities that promote independence, productivity, integration and inclusion into the community.

Addressing Unique Needs

As discussed earlier, some individuals with I/DD may live in families with an aging parent or a family member who has compound caregiving responsibilities. Some individuals may have a dual diagnosis of a co-occurring behavioral or mental health condition, complex medical issues, or dementia. These special needs may impose added stress on family caregivers and require special consideration when developing or implementing respite services.

For example, the unique needs of adults with Down Syndrome experiencing dementia should be taken into account when developing or referring to respite. Some respite providers or programs that specialize in dementia care for the aging population may not feel comfortable dealing with the special needs of an adult with Down Syndrome who also has Alzheimer's. Fortunately, guidance has been provided by the National Task Group on Intellectual Disabilities and Dementia Practices. *Guidelines for Structuring Community Care and Supports for People with Intellectual Disabilities Affected by Dementia* discusses respite for this population and can help providers develop the understanding and the skills needed to serve this population (Jokinen, et al., 2013).

Another example involves compound caregivers. Respite providers or programs are sometimes prohibited from providing care for more than one individual with special needs or for siblings in the same household. As a result, compound caregivers who receive respite for one of the individuals in their care, but still have significant caregiving responsibilities for another individual, may not derive the full intended benefits of respite (Perkins,

2011). Respite providers or programs who can serve multiple individuals or funding sources that allow the family caregiver to access multiple respite opportunities at one time, may improve their respite experience.

Parents of children with I/DD who also have complex medical needs often forgo their own medical appointments, nutrition, exercise, and stress reduction activities as care for a medically fragile child can be all-consuming. There may be tremendous financial strain related to extreme medical costs regardless of income or insurance status. Special consideration should be made for this group. Additional resources can be found in the ARCH Fact Sheet, *Respite for Families Caring for Children Who Are Medically Fragile* at <http://archrespite.org/productspublications/arch-fact-sheets#FS11>. Similarly, children and adults with autism may have unique respite needs. See ARCH Fact Sheet, *Respite for Individuals with Autism* at http://archrespite.org/images/docs/Factsheets/FS_58_Autism_Respite.pdf for more information.

Studies show that people who have a dual diagnosis of mental illness and I/DD are at greater risk for emergency room use, hospitalization and out of home placement than people diagnosed with an I/DD alone, suggesting that respite and family support options become even more critical for this group (North Carolina START, 2010). Improved understanding and collaboration across mental health and disability systems for the significant proportion of individuals who have co-occurring I/DD and mental health conditions would go a long way toward improving access to services, including respite, for this population.

Promote Culturally and Linguistically Competent Care

Culturally and linguistically competent care can promote respect in beliefs and practices. It is important for anyone working with a person who has I/DD to understand and respect the values, beliefs and behaviors of the individual, which are central to promoting person-centered approaches and services. Promoting cultural competence in

Cultural Linguistic Competency Resources

The term “culturally competent”, as defined by the Developmental Disabilities Bill of Rights and Assistance Act of 2000 (DD Act), “means services, supports, or other assistance that is conducted or provided in a manner that is responsive to the beliefs, interpersonal styles, attitudes, language, and behaviors of individuals who are receiving the services, supports, or other assistance, and in a manner that has the greatest likelihood of ensuring their maximum participation in the program involved.” For Cultural and Linguistic Competency Resources specifically for the I/DD population, see the Association for University Centers on Disabilities. <http://www.aucd.org/template/page.cfm?id=851>

all aspects of respite from engagement to service delivery and honoring the beliefs and practices of the families served can bring about positive outcomes.

Recommended Strategies

Expanding respite options and improving respite access, appropriateness, acceptance and cultural relevance for those caring for children and adults with intellectual and developmental disabilities (I/DD) will require collaboration between professionals and families. The expertise of individuals who work in the field of I/DD services and experts, advocates, government agencies, community providers and many others diligently working in partnership with family caregivers will be needed to fill gaps in services and ensure that meaningful respite options exist for this population. There are steps that Lifespan Respite Programs, respite coalitions, respite providers and family caregivers can take to achieve these goals.

For State Lifespan Respite Programs

Lifespan Respite programs should ensure that they are identifying available services as well as gaps in services for this population, and targeting training and recruitment resources to help meet needs.

- 1 While conducting needs assessments in your states to identify service gaps, include questions to determine the specific barriers to respite for this distinct population and work toward strategies to overcome these barriers.
- 2 Work to expand emergency, overnight and extended respite opportunities to meet family caregiver needs.
- 3 In developing materials to recruit and train respite providers and volunteers, seek expertise from the professional community who work in the field of developmental and intellectual disabilities, from condition-specific organizations such as state affiliates of The Arc and Easter Seals, UCPs, and University Centers for Excellence in Developmental Disabilities to develop training modules that will result in more respite providers able to serve this population. Include family caregivers as part of the training team for professionals.
- 4 Consider offering participant-directed respite so that family caregivers have greater choice in hiring and training their own providers from their trusted communities of support. More information on participant-directed respite can be found in *Participant – Directed Respite Guidebook*, developed for ARCH by the National Resource Center for Participant-Directed Services (NRCPS). See <http://archrespite.org/productspublications/products-and-publications#PartiDirection>.
- 5 In increasing the overall capacity of respite services and options, help develop respite opportunities that are age-appropriate, support valued social roles, foster positive imagery and community inclusion for children and adults with I/DD.
- 6 Provide training and technical assistance to local services and programs on person-

centered planning to ensure responsive and meaningful respite opportunities that promote self-direction. To access guidance on person-centered planning and self-direction from the US Department of Health and Human Services, visit <http://www.acl.gov/Programs/CDAP/OIP/docs/2402-a-Guidance.pdf>.

- 7 Train family caregivers to recognize the warning signs of tiredness and “burnout” and how to recognize when the person in their care may be in need of additional care.
- 8 Develop training programs for peer mentors to assist other family caregivers having similar caregiving roles. They understand what others caring for someone with I/DD are experiencing.
- 9 Efforts should be made to develop and maintain culturally and linguistically competent respite providers to serve people with I/DD and their families.
- 10 Grantees, charged with public education and education of family caregivers, can take the lead in bringing experts together to develop public awareness and education materials that focus on the needs of individuals with I/DD and promote expansion of natural supports for families.
- 11 Charged with developing collaborative partnerships at the state and local levels, Lifespan Respite grantees and partners are in a unique position to encourage and facilitate improved communication and joint training and service delivery options between those who work with persons with I/DD and with Alzheimer’s Association chapters, Aging and Disability Resource Centers, hospital discharge planners, area agencies on aging, caregiver support programs, and other community agencies to help in accessing supports for senior caregivers and their adults with I/DD in their care. Similarly, bring together family caregivers, state and local disability serving agencies, community mental health agencies, mental health advocates, and state mental health agencies to serve individuals with dual diagnoses.

For State Respite Coalitions

- 1 Partner with I/DD organizations, services and advocates, including self-advocates, providing information sessions for family members on I/DD, what to expect, and how to seek support and to raise awareness about the need for respite services.
- 2 Encourage respite providers and programs to allow for caregiver/care recipient feedback and input.
- 3 Work with community centers, schools, youth-serving agencies, sports and recreational programs, and faith-based organizations to engage persons with I/DD and their families in all recreational, service and educational activities, and as a result, create naturally occurring respite opportunities in the community.
- 4 Advise the state Lifespan Respite Program in identifying gaps in respite services for this population and work with them to address gaps in services for children and adults with I/DD.

For Respite Programs and Community-Based Agencies

- 1 Follow US Department of Health and Human Services guidelines on person-centered planning and self-direction to ensure responsive and meaningful respite opportunities that promote self-direction when designing and implementing respite services in the community. To access the guidance, visit <http://www.acl.gov/Programs/CDAP/OIP/docs/2402-a-Guidance.pdf>
- 2 When looking for volunteers to assist in respite service delivery, consider reaching out to university or community college students who are pursuing careers in the disabilities field, to the faith-community, and to youth-serving agencies to find volunteers to engage with individuals with I/DD in community activities or through peer relationships.
- 3 Develop and use training modules that educate the respite workforce in the needs and concerns of individuals with I/DD and their caregivers

and offer additional supports to encourage respite workers to engage with this population. For training resources, see <http://archrespite.org/training-ideas>.

- 4 Include family caregivers and self-advocates as members of the planning team and encourage their input in the development and implementation of respite services.

For Family Caregivers

- 1 Become involved with your state Respite Coalition and/or your State Lifespan Respite Program to share input regarding your specific respite needs.
- 2 Seek support and information from your state chapters of the organizations that represent I/DD, as well as information, education, and training on best practices within and outside of disability services, accessing and coordinating community supports, and advocacy and leadership skills.
- 3 If your state programs are already working on these issues, stay involved to offer your expertise and input as new respite services are developed and new providers are trained and recruited.
- 4 Connect and network with other families, including parents with disabilities, self-advocates and siblings, grandparents and other guardians for mutual support.

- 5 Involve your families in the design, implementation and funding of respite services.
- 6 Seek support and use respite early and as often as appropriate! Plan your respite time to make it as meaningful as possible.

Summary

A policy and programmatic shift from institutional care to home and community-based services, the increased lifespan of many individuals with I/DD, and the aging of the population have all contributed to a greater need for respite services and family caregiver supports for this population. Of the more than 4.9 million citizens with I/DD who live in the United States, 72% live at home with a family caregiver. Many adults with I/DD do not qualify for existing respite funding streams or are on waiting lists for respite funded by Medicaid waivers. Lifespan Respite grantees and their partners can help facilitate expansion of formal respite services as well as volunteer and faith-based initiatives, and work to improve respite quality through training and oversight. They are also in a unique position to collaborate with state and community partners to foster natural supports and participant direction that can lead to more meaningful and person and family-centered respite options.

Resources

The following resources may be helpful to Lifespan Respite Programs, respite providers, individuals with I/DD and their family caregivers.

ARCH National Respite Locator

www.archrespite.org/respitelocator

Families, care coordinators, providers and others can search for respite for children and adults with I/DD in their local communities as well as for state and federal funding sources, eligibility criteria and contact information.

Association of University Centers on Disabilities (AUCD)

www.aucd.org

AUCD is a membership organization that supports and promotes a national network of university-based interdisciplinary programs, including 67 University Centers for Excellence in Developmental Disabilities (UCEDD), 43 Leadership Education in Neurodevelopmental Disabilities (LEND) Programs, and 15 Developmental Disability Research Centers (IDDDRC). These programs serve and are located in every U.S. state and territory and are all part of universities or medical centers. Many UCEDDs provide respite or support respite services, research and training. To find a local UCEDD, visit www.aucd.org/directory/directory.cfm?program=UCEDD.

Easter Seals

www.easterseals.com

Easter Seals provides exceptional services, education, outreach, and advocacy so that people living with autism and other disabilities can live, learn, work and play in our communities. Easter Seals has been helping individuals with disabilities and special needs, and their families, live better lives for more than 90 years. From child development centers to physical rehabilitation and job training for people with disabilities, Easter Seals offers a variety of services to help people with disabilities address life's challenges and achieve personal goals. Easter Seals programs include a variety of respite services for all ages, including

adult day services, in-home support and services, and camping and recreation opportunities.

Family Support Research and Training Center (FS-RTC)

The FS-RTC is a new federally funded entity charged with undertaking research and training activities to 1) define the state of science in family support; 2) generate new knowledge in the critical policy areas of self-direction and managed care; and in culturally competent peer-to-peer family interventions; and 3) generate and implement a vision for policy and practice in family support through a national resource center. The Institute on Disability and Human Development at the University of Illinois at Chicago was funded by the National Institute on Disability and Rehabilitation Research (NIDRR), Administration for Community Living to undertake this initiative in partnership with the Lurie Institute for Disability Policy at Brandeis University, the National Resource Center for Participant-Directed Services at Boston College, the RTC on Community Living at the University of Minnesota, and the National Council on Aging.

The National Association of Councils on Developmental Disabilities (NACDD)

www.nacdd.org

NACDD is a national membership organization representing the 56 State and Territorial Councils on Developmental Disabilities. NACDD is a 501(c)3 organization with the purpose of promoting and enhancing the outcomes of member councils in developing and sustaining inclusive communities and self-directed services and supports for individuals with developmental disabilities. To contact your state/territory Developmental Disabilities Council (DDC) for information – <http://www.nacdd.org/Councils.html>.

National Association of State Directors of Developmental Disabilities Services (NASDDDS)

www.nasddds.org

NASDDDS represents the nation's agencies in 50 states and the District of Columbia providing services to children and adults with intellectual and developmental disabilities and their families.

NASDDDS promotes visionary leadership, systems innovation, and the development of national policies that support home and community-based services for individuals with disabilities and their families. To contact a state agency, visit <http://www.nasddds.org/state-agencies>.

The National Community of Practice: Supporting Families of Individuals with Intellectual and Developmental Disabilities

supportstofamilies.org/cop

The Supporting Families Community of Practice is working with six states (CT, DC, MO, OK, TN, WA) to develop systems of support for families throughout the lifespan of their family member with intellectual and developmental disabilities (I/DD). Each state team is facilitated jointly by the state I/DD service system office and the state Council on Developmental Disabilities with membership from self-advocacy and family organizations, university, education, aging and other organizations. The Supporting Families project is operated under a five year grant awarded to NASDDDS by the Administration on Intellectual and Developmental Disabilities (AIDD) beginning October 2012. Grant partners include University of Missouri Kansas City-Institute on Human Development (UMKC-IHD), Human Services Research Institute (HSRI) and the National Association of Councils of Developmental Disabilities (NACDD).

Parent to Parent USA (P2P)

www.p2pusa.org/p2pusa/SitePages/p2p-home.aspx

Parent to Parent programs across the country provide emotional and informational support to families of children who have special needs, most notably by matching parents seeking support with an experienced, trained 'Support Parent'. To find a state program: <http://www.p2pusa.org/p2pusa/SitePages/p2p-support.aspx#>

Sibling Leadership Network

siblingleadership.org

The mission of the Sibling Leadership Network is to provide siblings of individuals with disabilities the information, support and tools to advocate with

their brothers and sisters and to promote the issues important to them and their entire families. To find a state chapter: <http://siblingleadership.org/about/sibling-leadership-network-state-chapters>.

The Arc

www.thearc.org

The Arc is the largest national community-based organization advocating for and serving people with intellectual and developmental disabilities and their families. The organization encompasses all ages and all spectrums including autism, Down syndrome, Fragile X and various other developmental disabilities. To find a local or state chapter: <http://www.thearc.org/find-a-chapter>.

United Cerebral Palsy (UCP)

www.ucp.org

UCP educates, advocates and provides support services to ensure a life without limits for people with a spectrum of disabilities. UCP and its affiliates have a mission to advance the independence, productivity and full citizenship of people with a spectrum of disabilities by providing services and supports to children and adults. Contact the local UCP affiliate in your area: <http://ucp.org/findaffiliate>.

Self-Advocacy Resources

National Council of Self Advocates of The Arc (NCSA)

www.thearc.org/self-advocates

NCSA is composed of individuals with intellectual and developmental disabilities who are members of The Arc either at the local, state or national level. The Research and Training Center on Community Living (RTC) at The University of Minnesota and The Arc have partnered to support Self-Advocacy Online at <http://www.selfadvocacyonline.org>.

S.A.B.E. Self-Advocates Becoming Empowered

www.sabeusa.org/meet-sabe

S.A.B.E is a national board of regional representatives and members from every state in the US whose mission is to ensure that people

with disabilities are treated as equals and that they are given the same decisions, choices, rights, responsibilities, and chances to speak up to empower themselves; opportunities to make new friends; and to learn from their mistakes.

Autistic Self-Advocacy Network (ASAN)

autisticadvocacy.org

The Autistic Self Advocacy Network is a 501(c)(3) nonprofit organization run by and for Autistic people. ASAN was created to serve as a national grassroots disability rights organization for the Autistic community.

References

Administration for Community Living, US Department of Health and Human Services (2014). *Person-Centered Planning and Self-Direction: HHS Issues New Guidance on Implementing Section 2402(a) of the Affordable Care Act – ACL Blog of Sharon Lewis, Principal Deputy Administrator of ACL and Senior Advisor on Disability Policy*. http://www.acl.gov/NewsRoom/blog/2014/2014_07_09.aspx

American Association of Intellectual Developmental Disabilities (AAIDD) (nd). *Definition of Intellectual Disability*. <http://aaidd.org/intellectual-disability/definition#U6cicPldWfg>

ARCH National Respite Network and Resource Center (2014). *Respite for Families Caring for Children Who Are Medically Fragile*. (ARCH Fact Sheet 11). Chapel Hill, NC: Author. http://archrespitene.org/images/docs/Factsheets/FS_11-MedicallyFragile.pdf

ARCH National Respite Network and Resource Center (2013). *State Funding Streams for Respite across the Lifespan, 2013 Update*. Chapel Hill, NC: Author. http://archrespitene.org/images/docs/2013_Reports/State_Funding_Streams_for_Respite_Across_the_Lifespan_August_2013.pdf

Armstrong, J. and Shevellar, L. (2006). Re-thinking respite. *The SRV Journal*, 1(1): pp. 14–25.

Boyle, C.A., Boulet, S., Schieve, L.A., Cohen, R.A., Blumberg, S.J., Yeamgin-Allsopp, M., Visser, S., and Kogan, M.D. (2011). Trends in the prevalence of developmental disabilities in US children, 1997–2008. *Pediatrics*, 127(6):1034-42. DOI: 10.1542/peds.2010-2989 <http://pediatrics.aappublications.org/content/early/2011/05/19/peds.2010-2989.full.pdf>

Braddock, D., Hemp, R., Rizzolo, M.C., Tanis, E.S., Haffer, L., Lulinski, A., and Wu, J. (2013). *The State of the States in Developmental Disabilities 2013: The Great Recession and Its Aftermath*. Washington, DC: The American Association on Intellectual and Developmental Disabilities. <http://www.stateofthestates.org>

Caldwell, J. (2013). *Opportunities to Advance Lifespan Respite: Managed Long-Term Services and Supports and Affordable Care Act Options*. (PowerPoint Slides) ARCH National Respite Network and Resource Center, Lifespan Respite Grantee and Partner Learning Symposium, Boston, MA. <http://www.lifespanrespite.memberlodge.org/Resources/Documents/2013%20Grantee%20Meeting/Joe%20Caldwell.pdf>

Caldwell, J. and Heller, T. (2003). Management of respite and personal assistance services in a consumer-directed family support programme. *Journal of Intellectual Disability Research*, 47 Part 4/5: pp. 312–366.

Caples, M., and Sweeney, J. (2011). Quality of life: a survey of parents of children/adults with an intellectual disability who are availing of respite care. *British Journal of Learning Disabilities*, 39 (1): pp. 64-72.

Chou, Y.C., Tziou, P.Y., Pu, C.Y., C., Kroger, T., and Lee, W.P. (2008). Respite care as a community care service: Factors associated with the effects on family carers of adults with intellectual disability in Taiwan. *Journal of Intellectual & Developmental Disability*, 33(1): pp. 12–21.

Dougherty, S. and Kagan, J. (2012). *Federal Funding and Support Opportunities for Respite: Building Blocks for Lifespan Respite Systems*. Chapel Hill,

NC: ARCH National Respite Network and Resource Center. http://www.lifespanrespite.memberlodge.org/Federal_Funding_Guide

Edgar, M. (2013). *Emergency Respite: Help for Family Caregivers in Critical Times of Need*. (ARCH Fact Sheet 61). Chapel Hill, NC: ARCH National Respite Network and Resource Center. http://archrespite.org/images/docs/Factsheets/FS_61-EmergencyRespite.pdf

Edgar, M. and Uhl, M. (2011). *National Respite Guidelines*. Chapel Hill, NC: ARCH National Respite Network and Resource Center. http://archrespite.org/images/Books/NationalRespite_Guidelines_Final_October_2011_1MB.pdf

Factor, A., Heller, T., and Janicki, M. (2012). *Bridging the aging and developmental disabilities service networks: Challenges and best practices*. Chicago, IL: Institute on Disability and Human Development University of Illinois at Chicago <http://www.rttcadd.org/resources/Resources/Publications/Policy/Service/Briefs-&-Reports/Bridging-Report.pdf>

Harper, A., Dyches, T.T., Harper, J., Roper, S.O., and South, M. (2013). Respite Care, Marital Quality, and Stress in Parents of Children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, 43 (11): pp. 2604–2616.

Hecht, E. (BA) and Reynolds, M. (PhD) (2011). *Building a National Agenda for Supporting Families with a Member with Intellectual and Developmental Disabilities*. Proceedings and Recommendations from the Wingspread Family Support Summit, Racine, WI. <http://familysupportagenda.org/FSNA/files/SUPPORTING%20FAMILIES%20Wingspread%20Document%20preface%20ed%205-29.pdf>

Heller, T., and Kramer, J. (2009). Involvement of adult siblings of persons with developmental disabilities in future planning. *Intellectual & Developmental Disabilities*, 47, pp. 208–219.

Heller, T., Stafford, P., Davis, L.A., Sedlezky, L., and Gaylord, V. (Eds.). (Winter 2010). *Impact: Feature Issue on Aging and People with Intellectual and*

Developmental Disabilities, 23(1). (Minneapolis: University of Minnesota, Institute on Community Integration). <https://ici.umn.edu/products/impact/231/231.pdf>

Heller, T., Caldwell, J., and Factor, A. (2007). Aging Family Caregivers: Policies and Practices. *Mental Retardation and Developmental Disabilities Research Reviews*, 13: pp. 136–142

Hewitt, A., Emerson E., and Stancliffe, R. (2013). Introduction to the Special Issue: Community Living and Participation, Journal of policy, practice, and perspective. *Intellectual and Developmental Disabilities*, 51, No. 5: pp. 293–423.

Jokinen, N., Janicki, M.P., Keller, S.M., McCallion, P., Force, L.T., and the National Task Group on Intellectual Disabilities and Dementia Practices (2013). *Guidelines for Structuring Community Care and Supports for People with Intellectual Disabilities Affected by Dementia*. Albany NY: NTGIDDP & Center for Excellence in Aging & Community Wellness. <http://aadmd.org/sites/default/files/NTG-communitycareguidelines-Final.pdf>

Keller, S. (MD) (2013). *Caregiving for People with Dementia and Intellectual Disabilities such as Down Syndrome*. (PowerPoint Slides), ADSSP February 2013 Grantee & Partner Teleconference. <http://www.adrc-tae.acl.gov/tiki-searchresults.php?words=Keller%2C+S&x=0&y=0>

Lieberman, L. (2005) *A Stranger among Us: Hiring In-home support for a child with autism spectrum disorders or other neurological differences*. Shawnee Mission, Kansas: Autism Asperger Publishing Company.

Lin, M.C., Macmillan M., and Brown, N. (2010). The formal support experiences of mothers of adolescents with intellectual disabilities in Edinburgh, UK: a longitudinal qualitative design. *The Journal of Nursing Research*, 18(1): pp. 34-43.

Lund, D. (2011). *Making Respite More Effective*. (PowerPoint slides). ARCH National Respite Network and Resource Center Webinar. <http://>

archrespite.org/images/ARCH/Presentations/
Making_Respite_More_Effective_Final.pdf

Lund, D., Utz, R., Caserta, M., and Wright, S. (2009). Examining What Caregivers Do During Respite Time to Make Respite More Effective. *Journal of Applied Gerontology*, 28; 109. <http://archrespite.org/images/ATT00372.pdf>

Merriman, B. and Canavan, J. (2007). *Towards best practice in the provision of respite services for people with intellectual disabilities and autism*. Galway: National Parents and Siblings Alliance/DaisyChain Foundation. www.childandfamilyresearch.ie

NADD (nd). *Information on Dual Diagnosis*. <http://thenadd.org/resources/information-on-dual-diagnosis-2>

National Alliance for Caregiving & AARP. (2009). *Caregiving in the US – Executive Summary*. Washington, DC: Author. <http://www.caregiving.org/data/CaregivingUSAllAgesExecSum.pdf>

Ng, T., Harrington, C., Musumeci, M.B., and Reaves, E. L. (2014). *Medicaid Home and Community-Based Services Programs: 2011 Data Update*. Washington, DC: The Kaiser Commission on Medicaid and the Uninsured.

North Carolina Systemic, Therapeutic, Assessment, Respite and Treatment program (NC START) *Annual Report*, April 2010. http://www.ncdhhs.gov/mhddsas/statspublications/Reports/DivisionInitiativeReports/NCSTART/annual_report_nc_start_final.pdf

Osburn, J. (2006). An overview of social role valorization theory. *The SRV Journal*, 1(1), 4-13.

Perkins, E. A. (2011). *Compound caregivers: overlooked and overburdened* (White paper). Tampa, Florida: University of South Florida, Florida Center for Inclusive Communities. http://flfcic.fmhi.usf.edu/docs/FCIC_CompoundCaregivers_070811.pdf

Power, A. (2008). Caring for independent lives: Geographies of caring for young adults with intellectual disabilities. *Social Science & Medicine*, 67: pp. 834–843.

Samuel, P.S., Hobden, K.L., LeRoy, B.W and Lacey, K.K. (2012). Analyzing family service needs of typically underserved families in the USA. *Journal of Intellectual Disability Research*, 56 (1): pp. 111–128.

Sell, J. (2012). *Respite for Individuals with Autism*. (ARCH Fact Sheet 58). Chapel Hill, NC: ARCH National Respite Network and Resource Center. http://archrespite.org/images/docs/Factsheets/FS_58_Autism_Respite.pdf

Swallow, V., Forrester, T., and Macfadyen, A. (2011). Teenagers' and parents' views on a short-break service for children with life-limiting conditions: A qualitative study. *Palliative Medicine*, 26(3) pp. 257–267.

The Arc (2011). *Causes and Prevention of Intellectual Disabilities*, www.thearc.org/page.aspx?pid=2453

The Arc (2011). *Intro to Intellectual Disabilities*, www.thearc.org/page.aspx?pid=2448

The Arc (2011). *Still in the Shadows with Their Future Uncertain: A Report on Family and Individual Needs for Disability Supports (FINDS 2011)*. Washington, DC: Author. <http://www.thearc.org/document.doc?id=3140>

Wilkie, B., and Barr, O. (2008). The experiences of parents of children with an intellectual disability who use respite care services. *Learning Disability Practice*, 11 (5): pp. 30–36.

Wolfensberger, W. (2013). *A Brief Introduction to Social Role Valorization: A high-order concept for addressing the plight of societally devalued people, and for structuring human services*. Plantagenet Ontario, Canada: Valor Press, 4th expanded edition.

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