

Still in the Shadows with Their Future Uncertain

A Report on Family and Individual Needs for Disability Supports (FINDS), 2011

Summary of Key Findings and a Call To Action

June 2011



*For people with intellectual
and developmental disabilities*

Achieve with us.

“Those of us who have seen children live in the shadows know that a country as rich as ours cannot possibly justify this neglect.”

President John F. Kennedy (1961)

50

FIFTY YEARS AGO ...

In October of 1961, President John F. Kennedy appointed a 27-member President’s Panel of outstanding scientists, doctors, and others to prescribe a plan of action in the field of intellectual and developmental disabilities (I/DD). During his tragically short tenure in office, President Kennedy called the nation’s attention to the deplorable living conditions in institutions and limited opportunities for people with intellectual and developmental disabilities in communities across the United States. At that time, it was estimated that there were more than 5.4 million children and adults with intellectual disabilities in the United States.¹

President Kennedy called on every American citizen to help bring them out of the shadows, informed, no doubt, by his own sister’s condition. It was the first time in our nation’s history where the concerns of people with I/DD and their families commanded attention at the highest level of the federal government.

It wouldn’t be the last time.

The President’s Panel produced a report with more than 100 recommendations for research into the causes and prevention of I/DD and for expanding opportunities for education, employment and community living and participation. President Kennedy advanced, and ultimately signed into law, two major pieces of legislation that established the foundation for current programs and services that support their inclusion in all facets of society.²

His commitment inspired a nation to action, fueling the growing movement of parent and family-led advocacy on behalf of people with I/DD. By the 1960s, The Arc had emerged as a strong voice advocating for community living and with it the appropriate supports and services people with disabilities needed to be successful members of their communities.

The Mission of The Arc

Established in 1950, The Arc is the nation’s leading advocacy and service organization for people with intellectual and developmental disabilities, serving more than 1 million people with I/DD and their families through more than 700 state and local chapters. The mission of The Arc is to promote and protect the human rights of people with intellectual and developmental disabilities and actively support their full inclusion and participation in the community throughout their lifetimes. •

What Are Intellectual or Developmental Disabilities?

In the years since his death, the U.S. Congress and Presidents of both political parties have carried that commitment forward. From PL 94-142, the Education for All Handicapped Children's Act of 1975, guaranteeing children with disabilities the right to a free, appropriate public education, to PL 111-148 and PL 111-152 collectively known as the Affordable Care Act of 2010, ending health insurance discrimination against people with disabilities and improving access to health care, our nation's laws promise people with I/DD that they can and should be included and fully participate in their communities.

On the Fiftieth Anniversary of President Kennedy's Call to Action ...

...is that promise being met? Today there are 7–8 million people with I/DD living in the United States; conservative estimates are that more than 1.25 million are children.

Have they achieved the progress envisioned by the President's Panel, by Congress and by ten Presidents that people with intellectual and developmental disabilities of all ages function as rightful members of our communities?

Clearly, there has been significant progress. While in 1967, there were more than 187,000 people with I/DD living in state institutions, by 2009 that number had fallen below 34,000.³ Today, most people with I/DD live with their families. Of those living in out-of-home residential settings, the number living in residences of 1-6 persons increased from 20,400 in 1977 to 321,463 in 2009.⁴ Once it was assumed that people with I/DD couldn't work, but today thousands are working. In the employment arena, by 2006 more than 117,000 people with I/DD were participating in supported/competitive employment, up from only 21,000 in 1988.⁵

Yet, is this progress continuing? Or are people with I/DD still living in the shadows?

The Arc wanted to know and, in 2010 launched a national online survey to find out. The survey of Family and Individual Needs for Disability Supports (FINDS) engaged more than 5,000 parents, siblings and other caregivers or support providers of people with I/DD. It asked how people with I/DD are faring in school, the workplace and throughout their lives. Here is what we learned.

Intellectual disability and developmental disabilities, referred to in this report collectively as "I/DD," are terms that are used to describe a subset of the population of people with any type of disability. The two terms have different definitions. Intellectual Disability is a disability characterized by significant limitations in intellectual functioning and in adaptive behavior, which covers many every day social and practical skills. This disability originates before the age of 18. Developmental Disabilities are severe, life-long disabilities attributable to mental and/or physical impairments which manifest themselves before the age of 22 years and are likely to continue indefinitely. They result in substantial limitations in three or more of the following areas: self-care, comprehension and language, skills (receptive and expressive language), learning, mobility, self-direction, capacity for independent living, economic self-sufficiency, and ability to function independently. The most well-known specific diagnoses that manifest as I/DD include Down syndrome, Fragile X, Autism Spectrum Disorder (ASD), cerebral palsy, and Intellectual Disability unspecified; there are hundreds of other specific diagnoses that also involve I/DD. •

www.aidd.org/content_100.cfm?navID=21

www.acf.hhs.gov/opa/fact_sheets/add_factsheet.html

About the FINDS Study

The Family and Individual Needs for Disability Supports (FINDS) survey was conducted online from July 22, 2010 to October 31, 2010. The survey was widely disseminated through a variety of groups, including: the Association of University Centers on Disabilities, the American Association on Intellectual and Developmental Disabilities, the American Network of Community Options and Resources, the National Association of Councils on Developmental Disabilities, Self-Advocates Becoming Empowered, the National Council on Independent Living, Best Buddies, Easter Seals, the Autism Society of America and state and local chapters of The Arc.

Families from all 50 states and DC completed surveys. Nearly 5,000 caregivers responded (4,962). The vast majority of caregiver respondents were family members (95%) who are living with their family member with disabilities (75%), and who are female (89%), Caucasian (90%) and married (75%). Additional detail regarding respondents is available in the FINDS Technical Report.

The results are representative of the people who heard about the survey and responded and may not be representative of all people with disabilities and their families. Data analysis was performed by Lynda Anderson, Sheryl A. Larson, Allise Wuorio and K. Charlie Lakin of the Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota. •

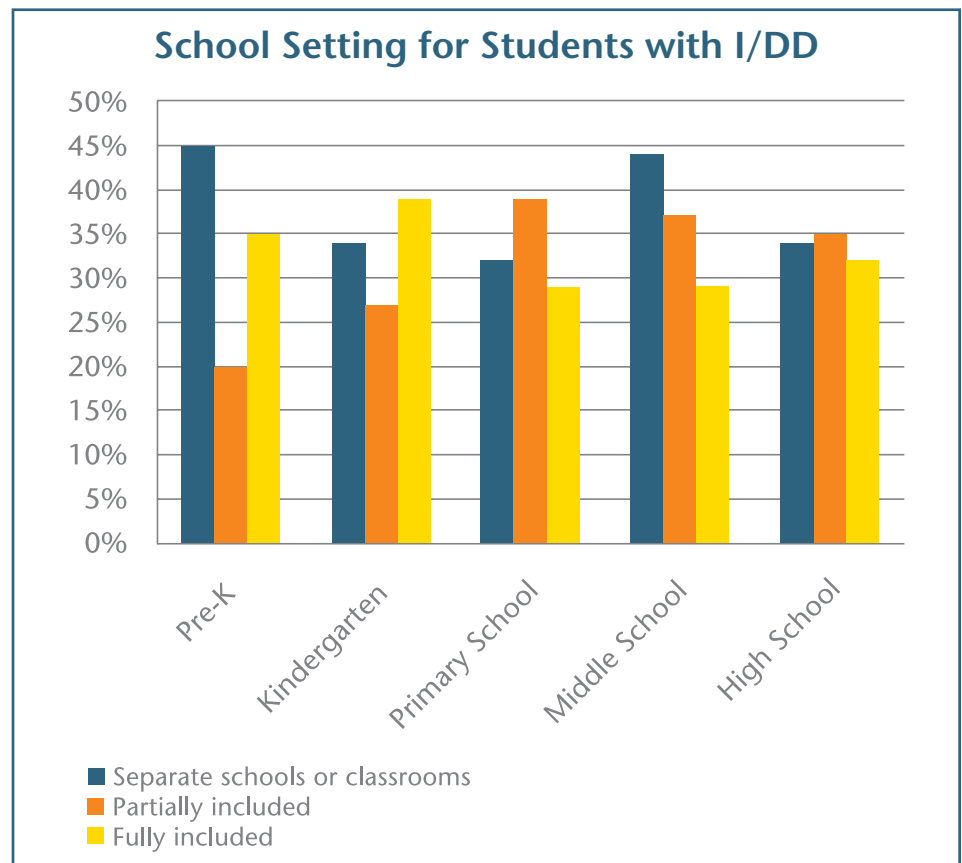
Our Nation Falls Short

Despite gains in many areas, overall the results from the FINDS survey⁶ show that our efforts as a nation have fallen short of the vision of an America where people with intellectual and developmental disabilities are accepted and have the supports they need to live to their full potential in the community.

Falling Short in Education

While the vast majority of people with I/DD attend public schools, the promise of inclusive education is not being met. Too many students with I/DD are in segregated classrooms or schools. Too few students are completing high school with a high school diploma, an important prerequisite for further education or employment. Despite their interest in continuing with their education, very few are moving on to receive post-secondary education. For those who have stopped going to school:

- 52% of families reported that their family member with I/DD left school without receiving a high school diploma, including 10% that never finished high school.
- Only 8% report having any college level experience.



While in school, too few students with I/DD are reported to be fully included in their schools and too many are dissatisfied with their school experience.

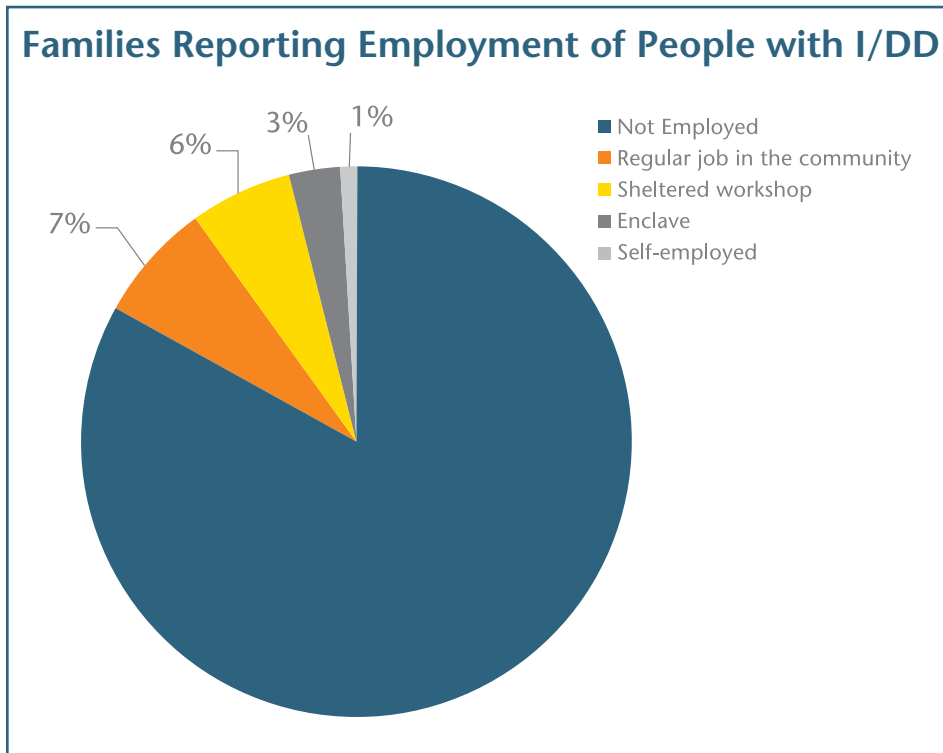
- Fewer than one-third of students with I/DD are reportedly fully included in regular classrooms in regular schools in primary/middle (29%) or high school (32%).

- 4 out of 10 parents report being dissatisfied with the quality of education their students with I/DD received in primary/middle (40%) or high school (38%).

Falling Short in Employment

While the majority of people with I/DD want to have a regular job in the community just like everyone else, the promise of integrated, community-based employment is not being met. In fact, the vast majority of people with I/DD are not employed at all.

- 85% of families reported that their adult family members with I/DD were not employed, either part-time or full-time.



Among the 15% that report their family members with I/DD are employed, regular jobs in the community with competitive wages remain elusive.

- Only 41% report that their family member works in a regular job in the community, while 1% are self-employed. 54% work in sheltered workshops and enclave settings.
- Only 57% report that their family member earns at least minimum wage.

For those who are unemployed, too many can't find jobs or get the supports they need to be successfully employed.

- 52% report that their family member with I/DD is unable get the job training or other assistance they need to find and keep a job.

At present, there is no system in place that guarantees that young adults with I/DD will have the support they need to live in the community and to find and keep a job after the school bus no longer comes. Their future is uncertain.

85% of families reported that their adult family members with I/DD were not employed

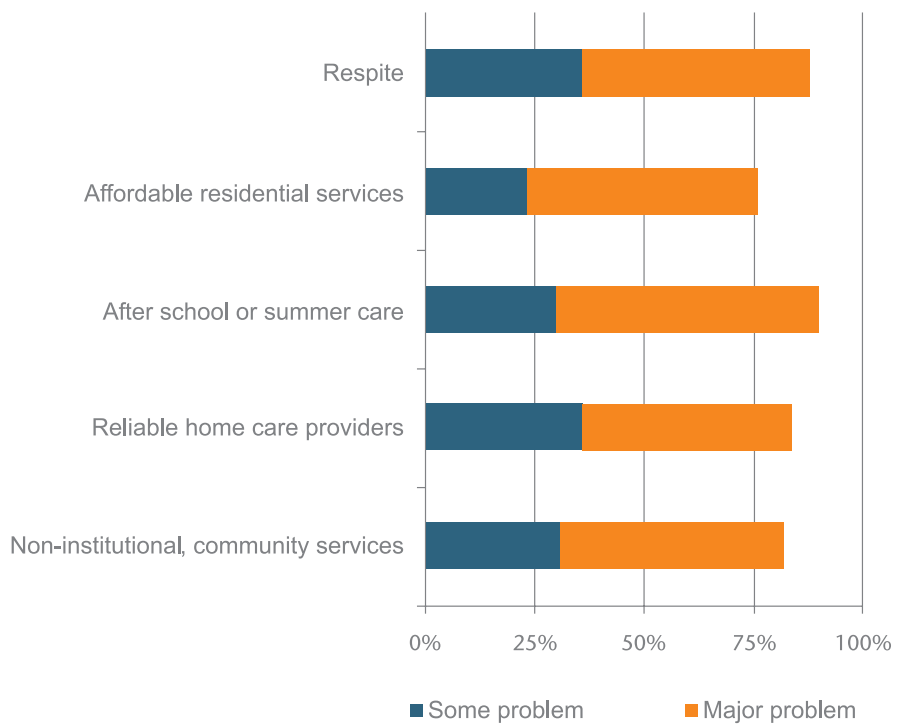
Falling Short in Providing Services and Supports for People with I/DD and Their Families

While families continue to be the primary source of support and care for people with I/DD, the promise of community support to lighten the load is not being met. Parents, siblings and family members struggle mightily so that their family member with I/DD can continue to live at home, or independently, and have a typical life. The majority of families report that they provide personal care – such as bathing, feeding (61%), administer medications (69%), provide direct financial support (72%), maintain the home (74%), manage financial affairs (78%), arrange/monitor outside services (76%), make social arrangements (76%), cook, clean and do laundry (80%), provide transportation (84%) and emotional reassurance (86%) and more.

- 58% of parents/caregivers report spending more than 40 hours per week providing support for their loved one with I/DD, including 40% spending more than 80 hours a week.
- Nearly half (46%) of parents/caregivers report that they have more caregiving responsibilities than they can handle.
- The vast majority of caregivers report that they are suffering from physical fatigue (88%), emotional stress (81%) and emotional upset or guilt (81%) some or most of the time.
- 1 out of 5 families (20%) report that someone in the family had to quit their job to stay home and support the needs of their family member.

46% of parents and caregivers report that they have more caregiving responsibilities than they can handle

Challenges Finding Supports & Services



Meet Analee and Nicky

For some, family efforts have been bolstered by a variety of government funded programs and services delivered through school systems, state developmental disabilities agencies that use Medicaid funding to support an extensive network of community-based nonprofits and for-profit service providers, as well as individual direct support workers. But necessary supports and services are hard to find and the situation is getting worse.

- More than 75% of families report they can't find afterschool care, non-institutional community services, trained reliable home care providers, summer care, residential, respite and other services.
- 62% of families report that services are being cut in the community, limiting or eliminating access to community life and opportunities for their family member with I/DD.
- 43% report that schools have cut back on services, such as physical, occupational or speech therapies.

For many, no government funded services are available and people with I/DD and their families languish on waiting lists for years.

- One-third (32%) of parents/caregivers report 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.

A conservative estimate is that there are more than 1 million people with I/DD waiting for services that may never come.

Analee lives with her 21-year-old son Nicky, who has autism, in North Carolina. She quit her job three years ago to stay home with Nicky after he graduated from high school with no real idea of what would come next. Meanwhile, money is tight and Nicky's dad has taken work in Florida to support the family. They would like to be together, but after checking into the possibility, they realize that the situation in Florida would be even worse than what they face in rural North Carolina. Recently Analee found a small group home that she feels would be a good place for Nicky to make the transition from his family's home to living semi-independently as an adult. That would also allow her to go back to work. She says, "It felt just right! I just couldn't believe we had lucked out to find such a right fit for Nicky!" As luck would have it, though, the home is covered by a different Local Management Entity (LME) than where Nicky currently lives and each LME feels the other should cover the costs. While the bureaucracy sorts out whether state funding is "tied to the bed or tied to the client," Nicky and Analee wait. The LMEs have told them they should complain; there are 100 other cases just like theirs waiting for a solution that is not coming anytime soon. ●



◀ Nicky relaxing at home

► David
with his
mother
Charlotte



Meet David

David, who was born with Down syndrome, is a friendly, engaging man. On the job at McDonalds, where he worked for almost 30 years, he was called the Mayor because he could always be relied upon. Because of his intellectual disability, David needs help with his money, meal preparation, and some self-care. His health has declined in the last year and he is having some trouble walking and using his hands. When his father died two years ago, his mother Charlotte, who is in poor health at the age of 94, began to worry about what will happen to David when she is unable to help him. They recently looked into a DDA waiver for David that would allow him to live independently in his community, but were told applications were not being accepted, due to lack of funding. "This breaks my heart," says friend and mentor Jenn. "Charlotte and David have contributed to their community for decades and taken care of themselves and done everything right. And this is what they're left with." •

These circumstances are imposing an enormous financial burden on families and have negative consequences for their family members with I/DD, but also for the families themselves and the communities in which they live.

- 47% of families report that they are paying more for care out of pocket.
- 21% of families report 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.
- 80% of families report that they don't have enough money to pay for the support or care their loved one needs.
- 82% report problems balancing other family responsibilities (e.g., marriage, other children, housework).

The long term economic stability of families, as well as their ability to contribute to the economy as taxpayers and consumers of goods and services, is threatened as well. Income for people with intellectual and developmental disabilities remains low, with most people reporting that they live in poverty with Supplemental Security Income or SSI (33%) or Social Security (21%) as their only source of income; 25% have no income. Sixty percent (60%) rely on Medicaid for their health insurance; only 50% benefit from Medicaid funded home and community-based services.

- 82% of families report that their overall economic security is challenged.
- 81% of family care providers report that they don't have time to attend to their personal needs.
- 73% report that they don't have adequate savings for retirement.

And the future is uncertain. Nationally, more than 700,000 people with I/DD are living with caregivers who are 60 years or older.⁷ With 58% of family caregivers between the ages of 51 to 79, where will the individual with I/DD live and who will support them when their family members are no longer able to do so? Housing is unaffordable to individuals who have no outside income or who rely on safety net programs to live. Outside services and supports are hard to find to help people live in the community. Unfortunately, most families don't have a plan.

- 61% of parents/caregivers tell us they worry that the person they support might have to go live somewhere they don't want to.
- 62% of parents/caregivers say they don't have a plan for where the person they support will live when the parent/caregiver gets older.
- 59% report they don't have enough information to make good choices about housing options.
- 65% report that they don't have enough help in planning for the future.

At present, there is no system in place that will guarantee older adults with I/DD the support they will need to continue to live in the community. A return to institutionalization in nursing homes, hospitals or other state facilities may be their only alternative to homelessness. The implications for catastrophic societal failure for this population and for America are serious if efforts are not taken now to ensure their future.

...With Even Greater Threats on the Horizon

The challenges facing people with I/DD and their families, if not bad enough already, threaten to become much worse as a result of the recent recession and the current federal and state budget crises. Recent actions by Congress and in the states raise the specter that our country is renegeing on its 50 year long commitment of support for people with I/DD.

At the national level, House Concurrent Resolution 34, developed by Congressman Paul Ryan (R-WI) and adopted by the House of Representatives proposes to:

- Cut more than \$770 billion over the next ten years from the Medicaid program — the federal/state program that provides the majority of funding for services for people with I/DD — while also capping future expenditures.
- Cut an additional \$2.1 trillion dollars from Medicare, low-income housing, education funding, food stamps and other programs of importance to low and moderate income families, including people with I/DD.
- Repeal the new healthcare reform law known as the Patient Protection and Affordable Care Act of 2010, including provisions that prevent people with disabilities from being denied health insurance coverage, provide for a new insurance program for long term services and supports, and provide incentives for states to expand home and community-based services.

At the state level, according to the Center on Budget and Policy Priorities, since 2008 at least 46 states and the District of Columbia have made budget cuts that affected healthcare, services for people with disabilities, education and other areas. Programs and services for people with disabilities and the elderly have been cut in at least 29 states and DC.⁸

The states continue to face substantial budget deficits, with many proposing deep cuts in social services spending for 2012 as well.⁹ For example, in New York alone approximately \$2.3 billion has been cut from the Medicaid program for FY 2012, with \$200 million cut from programs and services for people with I/DD. In Kentucky, approximately \$75 million has been cut from programs and services for people with I/DD. The prospect of additional budget cuts looms indefinitely into the future.

The pattern of reduced funding for services and supports in education, employment, personal supports, and residential services, will be devastating for the millions of people that have no other means of obtaining the services and supports they need.

Meet Tammie and Maurice

Tammie has turned to her faith to help her son Maurice, a 21-year-old with an intellectual disability and epilepsy. In May of this year, Maurice will no longer be able to continue his education in the public school system. He has “aged out” and Tammie is concerned about what’s to come. She’s a single parent and sole provider for their household and has to work to keep the two of them afloat. When Maurice is no longer able to go to school, she will be forced to leave him unattended at home. He’s on a waiting list for services through the Department of Intellectual and Developmental Disabilities in Tennessee, but so far has not received any services. Tammie says she is “physically, mentally and emotionally drained” and no longer knows who to turn to “except my Heavenly Father” since she has not been able to get any support from her state. Her greatest fear is that without supervision, Maurice will become a victim of the state’s judicial system rather than a recipient of the state’s care. She says Maurice simply doesn’t understand or comprehend the results of his behavior and she’s not sure what will happen when she’s forced to leave him alone all day. •



◀ *Tammie and Maurice before an ROTC function*

► *Earnest dancing at The Arc's National Convention*



Meet Earnest

Earnest and his wife both have intellectual and developmental disabilities and have lived in institutions. Of their institutionalization, Earnest recalls that if you escaped, “they’d shock you.” Earnest and his wife married about ten years ago. He wore a tux and she wore a white gown. “I was the King!” he says of that day. Then, with a wry smile, he says “Now, she’s the boss of the house.” That house is a condo which they own together and which they pay for in part with the income Earnest earns doing maintenance work at a large university in Maryland. Earnest is very involved with his local chapter of The Arc, having served on their board and now named Director Emeritus. They are both attending community college classes. Now that they are homeowners, employed and living productive lives in their community, Earnest and his wife are looking into what it would take for them to adopt a child and have a family. ●

Fifty years later, while great progress has been made, people with intellectual and developmental disabilities and their families are still living in the shadows and their future is uncertain.

- **While budget cuts and economic strain have hurt all Americans, people with intellectual and developmental disabilities and their families are among the hardest hit.** Due to limited and decreasing funding for critical services, families are taking on more caregiving responsibilities for their family members with I/DD and are experiencing tremendous economic and personal stress, threatening the stability of families and communities all over the United States.
- **While The Arc has succeeded in removing many barriers to education, employment and independence for many people with I/DD, millions are still waiting to realize their full potential.** Too many people with I/DD still confront barriers that stop them from receiving education, including post-secondary education, having a regular job in the community that pays a livable wage, and exercising their rights to fully participate in the communities where they live.
- **The unmet needs of millions of people with intellectual and developmental disabilities and their families demand immediate and sustained solutions to prevent major societal consequences.** A renewed and ongoing commitment is needed from our federal and state government leaders, from business and community leaders, from religious leaders and from members of the public, to assure that people with I/DD have the opportunity to achieve the acceptance and inclusion they deserve.

We can do better! *Today, there is no doubt that people with I/DD can live in the community and fully participate in society.*

The FINDS survey confirms the extraordinary progress that has been made from the days of social isolation and segregated institutions. Today, the vast majority of people with I/DD report living in the community.

- 98% live in the community, with 78% living with family members, 9% in group homes of six or fewer people and 7% in their own

Families express a clear preference for their family member with I/DD to live in the community with people they choose.

- While many families favor their family member with I/DD continuing to live where they live now, others identified the ideal living arrangement as an apartment or house that the person with I/DD owns or rents (20%) or a group home of 3 or fewer people (16%).
- Families identified ideal roommates as people that were chosen by their family member with I/DD (36%), one or both parents (28%), living alone (10%) with siblings (10%) or others (10%). There is little interest in living with an assigned roommate (7%).
- There is virtually no reported interest in living in large (7 residents or more) congregate housing (1%) or state institutions (0.2%).

The majority of people with I/DD receive their education through public schools and share the dream of life-long learning.

- 83% - 86% report that they attended public school, while 12 -14% attended private school and 3% home school, depending on the level of school (e.g. primary, middle or high school).
- 84% of family members believe that it is important for their family member with I/DD to continue their education after high school or go back to school as an adult to learn a job-related skill (73%), to learn about things they are interested in (72%), to have experiences that will help them get a job (66%), as well as other reasons.

People with I/DD are making their way into the workforce, albeit slowly, and like being employed.

- While only 15% are employed, either full-time or part-time, those that have a job report being happy with what they do (82%) and their work hours (78%).
- The majority (63%) would like their family members with I/DD to have a regular job in the community; 7% would like their family member to be self-employed.
- 82% of families believe that employees with I/DD should be paid at least the minimum wage.

Meet Adrian

As Adrian would tell you, he is “brave” and “confident.” Maybe that’s why he aspires to be an actor. He has no fear of walking out on stage in front of an audience. And he has no fear of pursuing his goals on a college campus. Although Adrian has Down syndrome, he is not so different from other students in acting classes at George Mason University, or from his brother who also attends college there and does not have a disability. He goes to class, rooms with a group of buddies, and clowns around during rehearsals with his fellow students. He lights up when he is on stage and can hear the applause. He has chosen his path in life as we all have the right to do and The Arc helped him obtain scholarships to pursue his dreams. Adrian wants to find a real job in the community, and he knows he can do it. ●



◀ *Adrian, left, on stage*

Fifty years ago,

President John F. Kennedy called us to shine the light on people who were living in the shadows.

A New Call to Action

The Arc invites all people with I/DD, their parents, siblings, other family members and friends, their employers, government, business and community leaders and all people of good conscience to join together in a new movement to promote and protect the rights of people with I/DD to live, to learn, to work, and to participate, alongside people without disabilities, in all aspects of community life.

Out of the shadows ... into the light

1. The Arc is calling on 1 million Americans with I/DD, their parents, their siblings and other family members, their colleagues at work, their neighbors and friends, and other people of good conscience, to join our movement by signing up at www.thearc.org/join-withus.
2. As part of this movement, The Arc is establishing:
 - a. **National Self-Advocates Council** to enlist people with I/DD to speak out for themselves and support them in doing so.
 - b. **National Siblings Leadership Council** to enlist the involvement and leadership of their brothers and sisters.
3. The Arc is calling on people with I/DD and their families to tell your stories. Tell your neighbor, tell your friend, tell your congressman. Tell your story on our website at www.thearc.org/sharewithus.
4. Participate in The Arc's social media contest, by submitting a brief story and photo or video on The Arc's Facebook fan page (facebook.com/thearcus) now through August 14, 2011 that chronicles the success, as well as the challenges faced, by people with I/DD.

Out of the shadows ... into the voting booth.

In preparation for the November 6, 2012 election, there's a lot of work to do to put the issues and concerns of people with I/DD on the agenda of all candidates for public office. The Arc is calling on people with I/DD and their families to:

1. Visit and deliver a message to their Member of Congress at their district offices and in Washington, DC that Congress shouldn't try to balance the budget on the backs of people with I/DD.

2. Show up at every town hall meeting, candidate forum and debate and ask incumbents, as well as candidates for public office, what they are going to do to support the right of people with I/DD to live in the community.
3. Ask candidates to promise to actively support the right of people with I/DD to live in the community.
4. Register to vote.
5. Volunteer for and donate to candidates who are committed to upholding, protecting and supporting the rights of people with I/DD to live in the community.
6. Vote on Election Day.

Out of the shadows ... into the workplace

The Arc is calling on people with I/DD and their families to reach out to individual employers, as well as chambers of commerce and other business and professional organizations, and seek their commitment to dramatically expand employment opportunities for people with I/DD.

1. Ask every employer who is not currently employing anyone with I/DD to hire at least one worker with I/DD in the coming year.
2. Ask employers who currently are employing people with I/DD to tell their stories about how employing people with I/DD has enhanced their workforce and improved their business performance by visiting www.thearc.org/workwithus. We will share success stories and promote businesses hiring individuals with I/DD through our publications and social media.

The Arc invites businesses to work with our 700+ state and local chapters throughout the U.S. to increase employment for people with I/DD until the rate of employment is comparable to that for the adult population as a whole.

Out of the shadows ... into the halls of government

The Arc is also calling on Congress, the Administration, and the States for immediate action on several fronts. There are a number of legislative and regulatory actions that can have a significant positive impact on the lives of people with I/DD. The following are the highest priorities:

1. **Congress and the States should not balance their budgets on the backs of people with I/DD and their families. Funding for programs, services and supports for people with I/DD must be sustained and expanded.** People with I/DD and their families have much to lose if the social safety net is dismantled. Federal safety net programs such as Medicaid, Medicare, Social Security, Supplemental Security Income (SSI), food stamps and others must be protected from deep cuts. Medicaid, in particular, is a lifeline for people with I/DD and the individual entitlement to the program must be maintained. Nationwide it provides 78% of the long term services and supports for people with I/DD. It provides access to health care for the majority of Americans with I/DD.
2. **In any reform of Medicaid, Congress should reverse the institutional bias in Medicaid and make home and community-based services mandatory, and institutional care the exception.**
3. **Congress should reject any attempt to repeal the Patient Protection and Affordable Care Act and states should move forward to implement the law.** Maintaining the critical health insurance reforms, expansion of eligibility for Medicaid to 133% of poverty, health insurance coverage expansions, prevention and public health improvements contained in the Act is of paramount importance to people with I/DD. In fact, the Affordable Care Act is the single most important piece of legislation for people with I/DD since passage of the Americans with Disabilities Act more than 20 years ago.
The Administration and Congress should support full implementation of the Community First Choice Option and other provisions of the Affordable Care Act that will expand home and community based services under Medicaid. The States should take advantage of these new options. The Community Living Assistance Services and Supports (CLASS) long term insurance plan must be fully developed and put into place so that workers can pay premiums and be fully covered (without impoverishing themselves for Medicaid eligibility) in the event they need long term services and supports.
4. **Congress should reintroduce and enact into law the “Achieving a Better Life Experience” (ABLE) Act.** Families of people with I/DD should be allowed to save for the long term support needs of their loved one with disabilities with the same tax advantages that are available for families to save for their children’s college education.
5. **Congress should fully fund the Individuals with Disabilities Education Act (IDEA), and the Elementary and Secondary Education Act (also known as No Child Left Behind) and the Higher Education Act.** This means increasing the funding for early intervention services, special education services, teacher training, parental support, transition and other education services. **Congress should also amend IDEA to make it easier for parents to challenge schools** when they are not living up to their obligations to provide appropriate education to all students with disabilities. **And Congress should expand federal support for programs helping students with I/DD attend colleges and universities.**
6. **Congress should dramatically expand the availability of employment support strategies such as supported employment and customized employment** to achieve more community employment, including fully funding employment and vocational rehabilitation programs. Vocational Rehabilitation Agencies, the state workforce programs and the state Developmental Disabilities programs must **develop the infrastructure to support transition from school to work** and community life. Congress and the Social Security Administration should improve and **simplify work incentives** for people with disabilities so that it is easier for more people to try to work while maintaining health care and some income support if needed.
7. **Congress should expand the availability of housing supports** by adequately funding and implementing the Frank Melville Supportive Housing Investment Act of 2010 and increasing funding for Section 8 Housing Choice Vouchers and other federal housing programs.
8. **Congress should help people with I/DD and their families to address their unmet needs by establishing separate federal funding for family supports and for self-advocacy under the Developmental Disabilities Act.**

Over the longer term, there are a number of other federal laws and programs that support education, employment and community living for people with I/DD that need to be strengthened. The Arc’s detailed Legislative Agenda for the 112th Congress is at www.thearc.org/page.aspx?pid=3084

Information about state laws and programs is available on the websites of state chapters of The Arc. To find a state chapter visit www.thearc.org/page.aspx?pid=2214

► *The Hage sisters together*



Meet the Hages

When identical twins Annika and Maya were born in New Jersey with an unknown genetic syndrome, their parents weren't sure they'd walk. Or do much of anything. "They weren't moving, they had no expression..." their father, Bob, said. Seven years later, they enjoy books, music, running around in the yard, and playing on the trampoline. Still, their parents worry. "You know your children are different, they'll have different lives than what you envisioned. You feel very alone." The Arc helped The Hages by offering them a community of support, giving them the information they needed and providing a map of the services they may need in the future. "The biggest unknown is the future," says their mother Odette. "We don't know that the girls will ever be able to provide for themselves. It's so frightening because when we're older we're not going to have the ability to look after the children." But, thanks to The Arc, they have hope for the future and don't feel quite so alone knowing they can count on The Arc. ●

A New and Reinvigorated Movement for People with Intellectual and Developmental Disabilities and Their Families.

It is up to all of us!

Can we make quality inclusive education a reality for children with intellectual and developmental disabilities?

Can we make supported and independent housing readily available for people with intellectual and developmental disabilities?

Can we make employment and small business entrepreneurship a real possibility for people with intellectual and developmental disabilities?

Can we open up the hearts and minds of the American people so they see the need to fully include people with intellectual disabilities in schools, the marketplace, places of worship, our clubs and recreational programs?

Can we go beyond mere inclusion to achieve meaningful participation in all aspects of society, to achieve true acceptance and respect?

Together, we can.

Achieve with us.

Credits:

The FINDS survey project was a collaborative effort that involved many members of The Arc's national headquarters staff. Thanks in particular to the following staff members for their contribution at critical stages of the project (listed in alphabetical order): Annie Acosta, Peter Berns, Ann Cameron Caldwell, Ph.D., Shelly DeButts, Dee Dee Eberle, Laurie Ertz, Maureen Fitzgerald, Marty Ford, Trudy Jacobson, Julie Ward, and William Washington.

Data analysis was provided by the Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota. Thanks (listed in alphabetical order) to: Lynda Anderson, M.P.H., K. Charlie Lakin, Ph.D. Sheryl A. Larson, Ph.D. and Allise Wuorio.

The Family and Individual Needs for Disability Supports Technical Report, 2011, including data tables, is available at www.thearc.org



This report has been supported in part by Ecology and Environment, Inc.

Special thanks to the End the Wait Now Campaign for David's story. Visit www.endthewaitnow.com for more information.

Endnotes:

¹"Report to the President, A Proposed Program For National Action to Combat Mental Retardation," The President's Panel on Mental Retardation, October 1962, p.1.

²PL 88-156 Maternal and Child Health and Mental Retardation Planning Amendments of 1963 (October 24, 1963); PL 88-164 Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963 (October 31, 1963)

³Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2009, Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota (2010), Table 1.4.

⁴Id., Table 2.2

⁵The State of the States in Developmental Disabilities, 2008., Braddock, D, Hemp, R. & Rizzolo, Mary C., Coleman Institute for Cognitive Disabilities (2008), Fig.15.

⁶Except where otherwise indicated, the data reported are the responses of parents, siblings or other caregivers or support providers describing the lives of the individual with I/DD. The majority (95%) of respondents were family members of an individual with disabilities and are referred to as "families."

⁷The State of the States in Developmental Disabilities, 2008., Braddock, D, Hemp, R. & Rizzolo, Mary C., Coleman Institute for Cognitive Disabilities (2008)

⁸www.cbpp.org/cms/?fa=view&id=1214

⁹www.cbpp.org/research/index.cfm?fa=topic&id=40



Washington, D.C.
1-800-433-5255
www.thearc.org



