



Contacts:

Sylvia Fuerstenberg
Executive Director of The Arc
of King County
206-913-8212 (cell)
Sylvia@arcofkingcounty.org

Ellia Ryan
Development Director of The
Arc of King County
206-355-3768 (cell)
eryan@arcofkingcounty.org

New Data Reveals Our Nation is Neglecting People With Intellectual and Developmental Disabilities

Survey findings from human rights organization, The Arc, reveal nation's efforts fail to provide fundamentals for individuals and families

Seattle, WA (June 14, 2011) – Fifty years ago, President Kennedy called on the nation to bring people living with intellectual and developmental disabilities (I/DD) “out of the shadows,” to give them opportunities to lead productive, quality lives. Sadly, new data released today from The Arc’s *Families and Individual Needs for Disability Support* (FINDS) survey shows efforts have plateaued and not nearly enough progress has been made to create these opportunities. While budget cuts and economic strain have hurt all Americans, the 7 million living with I/DD and their families are among the hardest hit, with access to needed services drastically reduced. In fact, 62 percent of caregivers reported a decrease in services for their family member with a disability. Meanwhile, budget proposals in Congress threaten to dismantle Medicaid, making it even harder for people with I/DD and their families to achieve.

The Arc, the nation’s largest and oldest human rights organization for the I/DD community serving more than a million individuals and their families, conducted a national survey of nearly 5,000 respondents on educational, housing, employment and support needs. The results of this landmark survey are being released in a report today, “Still in the Shadows with Their Future Uncertain.”

According to the FINDS survey, one-third of parents and caregivers (potentially 1 million families) reported that they are on waiting lists for government funded services, with the average wait more than five years. In Washington State, 13,600 people – in King County, 3768 people – are eligible for paid services but are not receiving them due to the lack of state funding.

The survey also found that the promise of integrated, community-based employment is not being met. In fact, 85 percent of families reported that their adult family members with I/DD are not employed at all. Opportunities for inclusive education, a pre-requisite for employment, are also not being met. Too few students are completing high school – in fact, 52 percent of families reported that their family member with I/DD left school without receiving a high school diploma.

“The Arc of King County works tirelessly to be the GPS system in King County’s developmental disability community, providing essential information and support for individuals and families,” said Sylvia Fuerstenberg, executive director of The Arc of King County. “Today’s FINDS survey impresses upon us the wide gaps in equality for our neighbors, friends and families that have a developmental disability.

“To help bridge this gap, The Arc supports members of our community throughout their lifetimes by helping them navigate through a complicated network of services, and supporting individuals as they speak for themselves,” continued Fuerstenberg.

The Arc of King County is the oldest agency in the Puget Sound region dedicated to supporting individuals with intellectual and developmental disabilities. Locally, The Arc provides direct support, outreach, and advocacy for thousands of families in King County, and works to empower people, individually and collectively, to maintain and build momentum in the disability and civil rights movements.

“As senior parents and caregivers to an aging daughter with a developmental disability we rely on the support of one another and consider The Arc an added member and blessing to our family,” said Uta Tipper. “We are so encouraged by the ongoing support, compassion, understanding and advocacy from The Arc, and we rest assured knowing we aren’t walking this path alone.”

FINDS found more than 75 percent of families report problems accessing non-institutional community care, trained reliable homecare providers, services and resources. Families are shouldering tremendous financial strain as they’ve had to assume the financial and day-to-day support of their loved ones; many have even had to quit their jobs to stay home and provide care.

- 1 out of 5 families (20 percent) report that someone in the family had to quit a job to stay at home and support the needs of a family member.
- More than 80 percent of families reported not having enough retirement savings for their future as a result of using personal funds to compensate for the lack of services available to their loved ones.
- 62 percent of parents and caregivers don’t have a plan for where the person they support will live when the parent/caregiver gets older.

As a result of the report, The Arc is calling for more activism by people with I/DD and their families, launching a new effort to organize 1 million people to come out of the shadows and make their needs and concerns an issue in the 2012 elections.

To raise awareness surrounding the barriers those with I/DD face and how the organization can help individuals and families fully participate in society, The Arc has partnered with Lauren Potter, star of the hit FOX show “*Glee*.” As a successful actress with Down syndrome who is achieving her dreams, Lauren represents the spirit of The Arc’s work. Today, The Arc and Potter will kick off a public service announcement television campaign.

The Arc “Achieve with Us” Contest

To encourage people with I/DD to share their stories of achievement, The Arc is conducting a national contest via their Facebook fan page. Starting today until July 14, entrants can share a story and a photo highlighting the accomplishments of an individual with I/DD for the chance to receive a trip for two to Washington, D.C. For more information about the “Achieve with Us” contest, please visit www.facebook.com/thearcus.

For more information, or to see additional survey results, please visit thearc.org.

###

About the FINDS Survey

The web-based FINDS survey was conducted from July 22, 2010, through October 31, 2010. The survey was completed by 4,962 caregivers of people with disabilities. Families from all 50 states and Washington, DC completed the survey.

About The Arc

The Arc is the largest and oldest human rights organization serving more than 1 million people with I/DD and their families through a network of more than 700 state and local chapters across the country. The Arc is not an acronym; always refer to us as The Arc, not The ARC and never ARC. The Arc should be considered as a title or a phrase. In addition, for purposes of brevity, after the initial phrasing: intellectual and developmental disabilities you will note the abbreviation I/DD.