Helping Parents with Intellectual Disabilities

Who Are Parents with Intellectual Disabilities?
Parents with intellectual disability or developmental disabilities have various levels of cognitive impairment characterized by significant limitations in intellectual functioning and adaptive behavior as expressed in conceptual, social and practical adaptive skills (AAIDD, 2011). Mild cognitive limitation describes individuals who may have been diagnosed with an intellectual disability at some time in their lives. They have lower than average learning, communication, judgment and understanding abilities (Tymchuk, Lakin & Luckasson, 2001). Their eligibility for service varies from state to state, because they do not qualify for services based on having an intellectual disability.

Parents with disabilities often lack natural parenting supports and may be reluctant to ask for help or are unaware of how/where to ask for help.

The ARC, a national organization advocating for the rights and full inclusion of individuals with disabilities, states:

“Parents who have intellectual disabilities may be closely scrutinized for any sign or symptom of abuse or neglect to their children. These parents live in fear of having their children taken away . . . Many others are not identified as having an intellectual disability and try to hide their disability, depriving themselves of any opportunity for accommodations. For those parents whose children have been taken from them, the reunification plan usually requires parents to attend counseling sessions and parenting classes that are not cognitively adapted, which dooms most to failure.” (ARC 2011)

Research shows that the ability to parent successfully depends on a wide range of factors, and parents with intellectual disabilities can be effective parents with the right kinds of supports tailored to their family’s needs.

For more information on how to support parents with ID/DD, visit the ARC Web site: http://www.thearc.org/page.aspx?pid=3195

or contact a chapter near you:
Hot Springs: (501) 625-3740
Little Rock: (501) 375-7770
Ft. Smith: (479) 783-5529
De Queen: (870) 642-6077
1. Health and Nutrition
Key policy choices in early health/development allow states to support the well-being of children. This section outlines Arkansas’ policy choices for supporting family access to and continuity of health care, including preventive screening/assessment and adherence to recommended schedules for well-child visits.

2. Early Care and Education
States’ policies affect early care and education services provided to young children and families. This section highlights Arkansas’ policy choices affecting parents’ ability to work as well as young children's development through access to childcare and states’ investment in quality pre-k programs as well as student/teacher ratios and investment in infant/toddler specialist networks and credentials.

3. Parenting/Economic Supports
Policy choices to assist low-income parents and young children’s healthy development are reflected in this section related to important economic supports for low income families with young children.

For national data, visit: http://www.nccp.org/profiles/pdf/profile_early_childhood_US.pdf
Impact of Race on National “Part C” Participation

According to the Data Accountability Center’s Part C Trend Data, approximately 3% of infants/toddlers 0-3 in the US (nearly 340,000 children) received EI in 2009. While it’s a significant increase in children served, many eligible infants / toddlers still fail to receive early intervention (Rosenberg). Recent US Dept. of Education data shows a 5% decline in the proportion of African-American children receiving services, and researchers began a national study to determine why.

National comparisons of infants receiving EI services show no racial disparity at 0-9 months. Similar results were found for infants/toddlers with diagnosed medical conditions (at any age 0-3). Researchers hypothesized that nationally, race would affect receipt of services, especially for those qualifying with developmental delay alone, which requires active screening and surveillance to detect.

“A racial disparities in EI service receipt, which were not present during infancy, emerged as children became toddlers. These disparities were found most consistently among children who qualified for services based on developmental delay alone.”

Nationwide studies support the hypothesis. At the 24 month mark, data shows a smaller percentage of eligible (non-white) toddlers are referred for early intervention. The findings suggest that minority “children without established medical conditions that cue parents and health care providers to actively assess developmental risk were less likely to receive EI services” (Feinberg). Results of the Feinberg national study show:

- Nationally, at 9 mos. (among 1000 eligible for EI), 9% received services – there were no racial differences in receipt of services
- At 24 mos., (among 1000 eligible for EI), 12% received services but African-American toddlers were 5x less likely to receive services
- There were no differences by race among children who qualified based on established medical conditions

For states wishing to improve Child Find efforts, this means analyzing the factors contributing to the disparity in order to target public awareness and education to improve referral rates among minority children. Parent interviews in the national study reveal the following possible explanations for low referral rates/receipt of EI services:

- language barrier
- family beliefs/cultural values (typical vs atypical development concerns)
- fear of blame and child protective services involvement
- maternal age (young/education level low)
- parental failure to follow up with well-baby checkups/screenings
- clinician failure to detect delay (research shows clinicians respond differently based on parent’s gender/education level and child’s behavior)

These reports suggest a need for increased public awareness of the importance of EPSDT. Also needed is increased public awareness of “typical vs. atypical” development/developmental milestones as well as clinician cultural competence training, increased use of interpreters, and routine, effective, diligent screening of minority children.

SOURCES:


Happy Birthday Baby

Healthy Families is proud to provide a reliable resource for families in Arkansas and western Tennessee to learn about the health, safety and well-being of children.

The Happy Birthday Baby Book is now in a convenient pocket size and has expanded content to give you even more information about pregnancy through age 1.

For the first time, Arkansas families also can order a second book that goes beyond prenatal care and covers information for caring for a newborn through age 5!

Individuals may order a free copy of either book or read the book online or on a Smartphone by visiting: http://www.healthyfamiliesnow.net/happy-birthday-baby-books

If your organization would like to order a FREE box of books to pass out to families you serve, contact Melody Hubbell at: 501-376-8722 or mhubbell@comgroup.com.

InfantSEE®, a public health program managed by Optometry Cares® and The American Optometric Association (AOA) Foundation, seeks to incorporate vision care as part of standard infant wellness checks. Under this program, AOA optometrists provide FREE comprehensive eye and vision assessments for infants within the first year of life regardless of a family's income or access to insurance coverage. Visit www.infantsee.org for more information. To find an InfantSEE doctor, visit the AOA Web site and use their physician finder tool (http://www.aoa.org/x5428.xml).

Carol and Terrell take their show on the road? So, if your staff is having problems using CDS, you can have help come to you to train your staff. To schedule a SITE Tech Training, call (501) 682-8699 or (501) 682-0238. E-mail carol.l.parker@arkansas.gov

Your ideas matter!
Send article submissions to ravyn.denton@arkansas.gov

Feel like you “can’t write an article?” Then send ideas and ideas to Ravyn who will write up the article for you and include it in a future newsletter. Seeking news about events hosted, parent involvement ideas, your innovative solutions to common issues.

2013 Submission Deadlines:

3 Global Child Outcomes
Percent of children who demonstrate improved:
1) Positive social emotional skills (including positive social relationships)
2) Acquisition and use of knowledge and skills (including early language/communication and for preschool, literacy)
3) Use of appropriate behaviors to meet their needs

Integrating Child Outcomes measurement into the IFSP (or IEP) process improves outcomes for children!

For online, self-guided studies, check out: