Quick Turn Around

Project Forum

QTA – A brief analysis of a critical issue in special education

Part C Underserved Populations: State Outreach Efforts

August 2005

by Luzanne Pierce and Eve Müller

Overview

Part C of the Individuals with Disabilities Education Act (IDEA), the federal program for infants and toddlers with disabilities ages birth through two years, was created in 1986 to establish a system of early intervention for all children in the United States. In recent years, there has been a growing focus on the extent to which state Part C programs meet the goal of serving all eligible children. In Part C state programs, data collection confirms that certain racial/ethnic groups are underserved.[1][2] This is in contrast to the widely documented overidentification of certain racial/ethnic groups in IDEA Part B programs.[3] States are aware of, and are making efforts to, reach underserved infant/toddler populations and their families. In order to reach these populations they are utilizing traditional as well as innovative strategies and resources by networking and reaching out to other state and local systems. (This is discussed in the section *Sources of Demographic Information*.)

The purpose of this document is to describe several states' practices in reaching and serving this diverse subgroup.[4] By describing examples from five states using innovative strategies to locate populations that are traditionally underserved by Part C, Project Forum hopes to inform work in other states.

Because states are only beginning to address the issue of underserved Part C populations, it will be useful to revisit this topic again in coming years to establish a more complete picture of how states are using demographic data systems, the availability of multi-lingual and multi-cultural services and the fiscal resources supporting these efforts. This document was produced by Project Forum at the National Association of State Directors of Special Education (NASDSE) as part of its cooperative agreement with the U.S. Department of Education's Office of Special Education Programs (OSEP).[5]

[1] For states' data on proportions of racial/ethnic groups served under Part C, see www.ideadata.org.
[2] For information on accessibility of services to every infant/toddler and family, see http://www.sri.com/neils/
[3] For states' data on proportions of racial/ethnic groups served under Part B, see www.ideadata.org.
[4] In some states, efforts are being made to reach out to additional underserved groups (e.g., linguistic minorities, highly mobile populations and families in poverty).
[5] Project Forum gratefully acknowledges the following individuals for sharing information about their states' Part C programs: Jan Rubinstein, Part C Coordinator, Minnesota; Terry Harrison, Part C Coordinator, New Jersey; Kay Halverson, Part C staff, Oregon; Deborah Garneau, Part C Coordinator, Rhode Island; David Steele, Part C Coordinator, South Carolina; and Joanne Moton, Part C staff, South Carolina.

Information Gathering Process

Five states recommended by the National Early Childhood Technical Assistance Center (NECTAC) participated in this study: *Minnesota, New Jersey, Oregon, Rhode Island and South Carolina*.[6] These states were selected as examples of states that have begun to address the issue of underserved Part C populations via a variety of initiatives. Based on input from NECTAC staff and the OSEP Early Childhood Portfolio Group, Project Forum developed a set of survey questions designed to highlight specific state practices and resources related to underserved Part C populations. Project Forum staff conducted telephone interviews with Part C coordinators and staff in the five states from July through September, 2004.[7] The rest of this document summarizes the interview findings.

Findings

State Definitions of "Underserved Populations"

None of the five states interviewed had specific language in their laws and regulations defining underserved populations. However, all interviewees agreed that they received some guidance from the language in IDEA:

> "The Congress finds that there is an urgent and substantial need…to enhance the capacity of state and local agencies and service providers to identify, evaluate, and meet the needs of historically under represented populations, particularly minority, low-income, inner-city, and rural populations." [P.L. 105-17 §631(a)(5)][8]

IDEA regulations also define traditionally underserved groups and require access to culturally competent services within a family's local geographical area [34 CFR §303.128].

Although none of the five states have explicit definitions of "underserved populations," several interviewees noted that shifting demographic trends mean that underserved populations are continually changing and evolving. States described the following:

- *Oregon* – Interviewees described using study groups to identify hard-to-reach populations that include working poor families, homeless families, families in emotional crises and linguistically isolated families. Part C staff said the state system is responsive to changing population trends and that service delivery could be adapted as necessary.

[6] Part C lead agencies for the five states interviewed are as follows: Minnesota, State Department of Education; New Jersey, Division of Family Health Services, Department of Health and Senior Services; Oregon, State Department of Education; Rhode Island, Center for Child and Family Health, Department of Human Services; and South Carolina, Bureau of Maternal and Child Health.

[7] The Rhode Island Department of Human Services became the Part C lead agency after interviews for this document were conducted and those policies and practices attributed to Rhode Island may no longer be in effect. For more information on current policies and practices, contact Brenda Duhamel at bduhamel@dhs.ri.gov.

[8] The 2004 reauthorization strengthens this section by adding the phrase: "and infants and toddlers in foster care." [P.L. 108-446 §631(a)(5)].

- *New Jersey* – Similarly, Part C staff reported that their system could adapt to meet the needs of children and families as demographic changes occur within the state.

- *South Carolina* – Part C programs have set a goal of serving the same percentage of infants and toddlers within each racial/ethnic group as the percentage of infants and toddlers from each racial/ethnic group – both with and without disabilities – residing within the state.

Reasons for Focus on Underserved Populations

Interviewees reported that the most common reason for focusing on underserved populations was the fact that OSEP onsite monitoring visits had reinforced the importance of doing so. Following are some examples of how states have responded to federal inquiries during the monitoring process regarding underserved populations:

- *Rhode Island* added Medicaid eligibility as a risk factor for developmental delay.
- *South Carolina* Part C staff noted a decline in early intervention program numbers following the transition of developmental screening, a component of Medicaid's Early Periodic Screening, Diagnosis and Treatment (EPSDT) Program, to the private sector. Following an investigation of the decline in numbers, the state has refocused efforts on underserved populations.
- *Oregon* developed strong interagency coordination at the local, county and state levels, allowing the state to adapt to the changing character of underserved populations.
- *Minnesota* established an interagency Child Find workgroup to implement coordination across all state agencies serving children. This workgroup's ongoing responsibilities include the development of strategies to reach underserved populations of children ages birth through two years.

Sources of Demographic Information

States reported using a number of demographic data sources in order to gather information about the racial/ethnic composition of birth through two year olds residing in the state, including those with disabilities. No single source of data was common to all states. State examples include the following:

- *Minnesota* uses a "watch list" program called *Follow Along*, which is managed by local community public health agencies, that includes 85 of the state's 87 counties and two Indian reservations.[9] *Follow Along* is a voluntary screening program of the Minnesota Department of Health in which visiting nurses assist families in monitoring their child's development. The Minnesota Department of Health and the Part C program collaborate to assure that all children in need of Part C services are located. P.L. 108-446 §638 4(C) permits the use of Part C funds for periodic screening of children at-risk. *Follow Along* data are collected and analyzed every year by the Minnesota Department of Health. In

[9] For more information on the *Follow Along* program see http://www.health.state.mn.us/divs/fh/mcshn/fap.htm. Enrollment materials for *Follow Along* are available online in English, Spanish and Hmong at http://www.health.state.mn.us/divs/fh/mcshn/ecip.htm .

addition, several early intervention programs collect additional data on demographics, race/ethnicity, assessment completion, services and exiting from the program, and have analyzed data by ethnicity and primary language. Other statewide data sources for Child Find include census information, county profiles, Department of Education data and the Minnesota KIDS Initiative.[10]

- *Oregon* has a process in place to cross-check state department of education data on racial/ethnic populations, including children served in Part C, against U.S. Census data through the Population Center at Portland State University and the Oregon Population Estimates and Projections Project.

- *Rhode Island* utilizes data retrieved from its universal newborn screening system. The screening system records APGAR scores,[11] levels of maternal education and other factors that provide some of the bases for eligibility decisions. The Department of Health also collects a set of child census data[12] and Rhode Island Kids Count[13] data provide baseline criteria for community outreach plans for each early intervention provider in the state.

- *South Carolina* uses Kids Count data as well as a unique state data warehouse that can aggregate data from the Part C program and disaggregate it to the county level in response to specific requests.[14]

These types of demographic databases provide states with guidance for developing publicity initiatives to reach diverse populations of children and families.

Child Find Publicity

States were most likely to list the following Child Find publicity strategies: information on agency websites; collaboration with racial/ethnic neighborhood organizations; and translation capabilities. Interviewees from all five states described outreach efforts to children and families whose native languages were other than English. States reported translating materials into a variety of languages, most commonly Spanish. Interviewees also acknowledged that Part C lead agencies could not do effective Child Find without the cooperation of other agencies and community groups.
States' Child Find publicity efforts included the following:

[10] A "gateway" to data information about the health, education and social well-being of children and youth in Minnesota, the KIDS Initiative is sponsored by the Minnesota Department of Health and the Minnesota Department of Human Services in collaboration with the Minnesota Department of Children, Families and Learning; Minnesota Planning; Children's Defense Fund/Minnesota; and the University of Minnesota's Center for Applied Research and Educational Improvement. More information can be found at http://www.mnkids.state.mn.us/dataset.html.
[11] The APGAR score is used to rate newborn babies' appearance, pulse, responsiveness, muscle activity and breathing on a scale of 0 -10, with 10 being an indicator of excellent health.
[12] At the time of this interview, the lead agency responsibilities in Rhode Island were about to be transferred from the Department of Health to the Department of Human Services.
[13] http://www.rikidscount.org/matriarch/ and http://www.sckidscount.org/ are state programs in the national Kids Count network, which is funded by the Annie E. Casey Foundation and others. The Rhode Island and South Carolina Part C Coordinators mentioned their state Kids Count as a useful source of demographic data. These programs are distinct from the Part C data systems.
[14] South Carolina does not send specific student identifiers to the data warehouse.

- *Rhode Island* – The state's Division of Family Health publicizes Child Find through a Family Health Information Line staffed by personnel fluent in English, Spanish, Portuguese and French. Every provider site in the state has access to linguistically and culturally appropriate referral information packets.

- *Oregon* – One county reported offering Child Find materials in Spanish, English, Russian, Vietnamese and Braille and promotes awareness of Child Find through newspapers, grocery store notices and rolodex cards.

- *South Carolina* – The Department of Education and the Department of Health and Environmental Control have pooled funds and are working together to develop a brochure publicizing Child Find for children and youth ages birth through 21 years. Each regional early intervention program team develops a public awareness plan for Child Find and outreach to physicians is a current priority. The Part C Central office has translated Child Find materials into Spanish and Korean.

- *Minnesota* – The state's Department of Human Services referral phone line offers information about early childhood programs and services in Arabic, Hmong, Khmer, Lao, Oromo, Russian, Serbo-Croatian, Somali, Spanish and Vietnamese. A local early intervention program has utilized local family service collaborative dollars to hire a Hispanic outreach worker, produced brochures and a video on child development in Spanish and developed a partnership with local clinics and physicians that includes placement of brochures in offices and other types of information sharing about the importance of early intervention. Much information for families, including American Indian families, is available on the state website.

Child Find Activities Following Publicity

States utilize a variety of strategies to implement Child Find activities following their publicity efforts. Regional management models and collaboration with public schools, other agencies and the medical community are some of the more effective strategies used. In *New Jersey* and *South Carolina*, regional teams develop locally relevant Child Find procedures. In *Oregon*, Child Find staff goes into local schools to make contact with families of hard-to-reach children and adapt their hours to meet with families after work. In *Rhode Island*, staff conducts record reviews based on information derived from the state's universal newborn screening system. *Rhode Island* staff also specifically mentioned that many of their referrals come directly from families. All states were sensitive to the need to respect cultural differences when contacting families and to work collaboratively with community organizations representing different racial/ethnic groups.

Examples of state Child Find activities include the following:

- *Oregon* maintains close linkages between all programs serving young children at the community level. Every county has an early childhood team. These interagency connections facilitate contact with families and assure that the needs of children and families are addressed through screening and home visit procedures. Local Part C staff

has worked with schools in "working poor" neighborhoods to contact parents regarding concerns about children younger than school age.

- *Minnesota* implements the following statewide Child Find activities: Universal Newborn Hearing Screening; Newborn Metabolic Screening;[15] Birth Certificate Registry; Autism First Signs Project; EPSDT; and Project Exceptional, which assists child care providers in identifying young children with disabilities (Minnesota Department of Education, 2003).

Staff Development

Although all five states interviewed are addressing the issue of underserved populations, none have conducted Part C staff development activities specifically addressing this issue. Two states described training efforts especially designed to reach underserved populations, although not specific to Part C:

- *Oregon* has two county-level study groups focusing on the characteristics of hard-to-reach populations, including those who are non-native English speakers. Training in Spanish for sign language interpreters is currently a state priority.

- *South Carolina* provides cultural sensitivity training for a region of the state that includes a Catawba Indian reservation.

Personnel Issues

All Part C staff interviewed agreed that increasing the numbers of multilingual staff is a priority. The following are examples of how some states are addressing this issue:

- *Rhode Island* has a family outreach program that employs Spanish-speaking nurses. Early intervention contract agencies recruit multilingual staff and five of the state's seven early intervention provider sites have personnel who are fluent in multiple languages. Part C programs would also like to recruit paraprofessionals from a range of cultural backgrounds.

- *South Carolina* has three program coordinators who are bilingual and the Catawba Indian Nation has provided staff to the early intervention program.

- *Oregon* places ads in ethnic newspapers to recruit multilingual staff.

Barriers Encountered

[15] According to the National Conference of State Legislatures, state laws have established newborn genetic and metabolic screening processes for some or all of the following conditions: congenital adrenal hyperplasia, biotinidase deficiency, branched-chain ketonuria, cystic fibrosis, galactosemia, homocystinuria, hypothyroidism, maple syrup urine disease, phenylketonuria (PKU) and sickle cell anemia. Many state laws include exemptions for parents who object to genetic testing for religious or other reasons.

The work of staff and agencies in these five states to reach underserved children and families is not without barriers and challenges. All states reported that budget shortfalls and personnel layoffs are barriers to serving the Part C population. Other examples of barriers include the following:

- *Oregon* Part C staff identified difficulties in approaching close-knit ethnic communities, although collaborative work with ethnic community agencies has helped reach families from diverse cultural backgrounds.

- *South Carolina* staff identified difficulties in the recruitment of related services personnel trained in multilingual, multicultural issues to work in rural areas as well as difficulties in building relationships with physicians.

- *Minnesota* staff reported that data analysis related to children's race/ethnicity and other characteristics is difficult when drawing from multiple databases (e.g., making comparisons using U.S. census data for total population data for children aged birth to five years is problematic since the categories used to determine race/ethnicity are different from those established in state education databases). Meeting the needs of highly mobile children and families, including undocumented immigrant families, was also identified as a major challenge (Minnesota Department of Education, 2003).

Success in Reaching Underserved Populations

Interviewees described a number of successes in reaching underserved populations. For instance, interagency collaboration with regard to data gathering and attention to data verification were evident in all five states. Other examples of state successes include the following:

- *Rhode Island* early intervention programs are now enrolling more children, including those from underserved populations under 12 months of age. This success may be attributable to collaboration between programs in the state's Division of Family Health and to the fact that 70 percent of all births in the state occur at one hospital.

- *South Carolina* staff reported that efforts to reach and serve more children and families overall have been successful and that numbers of children and families from underserved populations are remaining constant.

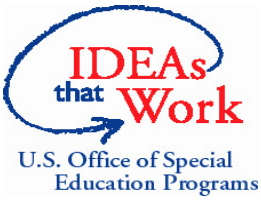
- *Oregon* has seen a steady increase in overall Part C Child Count numbers, but totals remain lower than the national average due to the state's narrow eligibility criteria. (The state does not serve at-risk infants and toddlers.) Nevertheless, efficient collaborative structures are in place for finding hard-to-reach children and their families, as evidenced by the work of the counties' interagency councils.

Concluding Remarks

Part C programs in the five states interviewed have begun to address the federal expectation that states locate and serve infants, toddlers and families from underserved populations. Key strategies include the sharing of database information across state agencies; development and sharing of language translation capacity across state agencies; and use of the Internet to share data and to disseminate Child Find information to foreign language communities and different cultures. Pooled funds and joint planning are key underpinnings for the work as is adaptability to the changing needs of children and families. Several interviewees described their state and local systems as flexible (i.e., able to identify and meet the needs of emerging populations as demographic changes occur). All five states expressed their intent to work to meet the corrective actions identified for them through self-assessment and OSEP monitoring. Reaching underserved populations and their needs was seen as one aspect of the larger mandate to fully comply with Part C of IDEA. These five states have made strides toward reaching all infants, toddlers and their families.

As part of this analysis, Project Forum staff reviewed OSEP-funded training and technical assistance projects that have a stated focus on language-minority and other underserved infant/toddler populations. The links to these projects and their abstracts were obtained from www.nectac.org and are listed below as national resources. While helpful, the emphasis of these projects is mainly on service delivery as opposed to identification and enrollment. OSEP may wish to consider creating a priority that funds targeted training and technical assistance for Child Find for underserved infants and toddlers.

This report was supported by the U.S. Department of Education (Cooperative Agreement No. H326F000001). However, the opinions expressed herein do not necessarily reflect the position of the U.S. Department of Education, and no official endorsement by the Department should be inferred.



State Resources

Minnesota

Minnesota Department of Education, Division of Special Education. (2003). *Minnesota's Self Improvement Plan – Part III.*

Minnesota Department of Human Services. (March 1, 2004). *Bulletin #04-68-02,"Refer Abused Neglected Children for Developmental Assessment."*

http://www.health.state.mn.us/divs/fh/mcshn/cdnh.htm - information regarding the Department of Human Services' multi-lingual referral lines and Early Childhood Links.

http://www.yourlink.org/ - an on-line early intervention newsletter with information about Child Find activities.

New Jersey

http://www.state.nj.us/health/fhs/eiphome.htm

National Resources

The selected links below are to Office of Special Education OSEP-funded training and technical assistance projects. These projects can offer assistance to states in addressing Child Find for underserved populations in Part C.

A Family-Centered Approach to Early and Prescriptive Assessment of Children at Risk for Learning Disabilities and Behavioral Disorders – http://www.nectac.org/search/projdetails.asp?ProjID=591

ACES: Access for Children to Early Services – http://eip.uoregon.edu/research/aces.html

Caring for Infants and Toddlers with Disabilities: New Roles for Physicians (CFIT-Physicians) - http://www.nreic.org/CFIT_Caring_for_infants_and_toddlers.htm

CASCADES Project: Creating and Sustaining Change Across Diverse Early Intervention Systems – http://eip.uoregon.edu/cascades/index.html

Creating Partnerships Between Pediatric Practitioners and Early Developmental Interventionists for Child Find (PEDI-Link) – http://www.uvm.edu/%7Ecdci/pedilinks/description/index.htm

Development PARTners: Prevention, Assessment, Referral, Transition for Adopted Infants and Toddlers – http://www.nectac.org/search/projdetails.asp?ProjID=888

Dynamic Community Connections: A Process Model for Enhancing Child Find in Rural Areas – http://ruralinstitute.umt/edu/decpchildfind/

Early Childhood Development Project for the Mississippi Delta Region: Year 5 - http://www.nectac.org/search/projdetails.asp?ProjID=793

Interagency Collaboration for Colorado Part C Child Find - http://www.nectac.org/search/projdetails.asp?ProjID=283

Strategies for Effective and Efficient "Keiki" (Child) Find (Project SEEK) – http://www.seek.hawaii.edu/

The getSET Project: Systematic Early Tracking for Effective Referral and Reporting - http://www.nectac.org/search/projdetails.asp?ProjID=1122

The National Center for Culturally Responsive Educational Systems (NCCRESt) – http://www.nccrest.org

TRACE: Tracking, Referral, and Assessment Center for Excellence – http://www.tracecenter.info/

National Parent Leadership Development Project for ICCs – http://iccparent.org/

This document, along with many other Forum publications, can be downloaded from the Project Forum at NASDSE web address:

http://www.nasdse.org > Publications

To order a hard copy of this document or any other Forum publications, please contact Carla Burgman at
NASDSE, 1800 Diagonal Road, Suite 320, Alexandria, VA 22314
Ph: 703-519-3800 ext. 312 or Email: carla.burgman@nasdse.org