Natural Environment in Illinois

Overview of Early Intervention
The Part C Early Intervention (EI) Program is a statewide program of evaluation and assessment for infants and toddlers under three years of age and of services for those who have a disability, a 30 percent delay in development in any area, or are at risk of developmental delays. Part C provides an entitlement for all eligible infants and toddlers to receive early intervention services. Services are provided to assist eligible children to develop basic developmental skills. Parents provide most of the care needed to help their children develop, guided by the therapists who serve their children.

The Part C Early Intervention Program in Illinois is federally funded, in small part, through Part C of the federal Individuals with Disabilities Education Act (IDEA). However, the bulk of funding for the EI Program comes from General Revenue funds and from the Illinois Department of Healthcare and Family Services (HFS) through Medicaid reimbursement. Additional funding comes from billing eligible family’s private insurance and charging families who have the ability to pay a participation fee – which is permissible under federal law.

In Illinois, families access the Part C EI Program through one of 25 local Child and Family Connections (CFC) offices where they are assigned a Service Coordinator. The EI Program provides 16 EI services and other family supports through a variety of individual and agency providers, some not-for-profit and some for-profit, which enroll and sign provider agreements with the Illinois Department of Human Services (DHS). The most frequently provided services are speech therapy and developmental therapy.

Illinois’ Part C EI Program is advised by a state council called the Illinois Interagency Council on Early Intervention (IICEI), which is mandated by federal law and appointed by the Governor. The IICEI works closely with the Part C EI Program to ensure that all eligible infants/toddlers and their families are receiving appropriate services and supports.

The Illinois EI program's mission is to assure that families who have infants and toddlers, birth to three, with diagnosed disabilities, developmental delays or substantial risk of significant delays receive resources and supports that assist them in maximizing their children's development.

House Joint Resolution (HJR) 50 created the Early Intervention Taskforce to partner with the DHS to undertake a comprehensive and thorough review of the EI system and develop recommendations and an action plan to address issues related to workforce, financing, monitoring and evaluation, service delivery and transitions. The Early Intervention Taskforce was chaired by DHS with membership defined in HJR 50 to include representation from state agencies, advocacy organizations, professional groups, EI training and consultation groups, the IICEI, CFC managers/staff, and parents of children in the EI Program.
The work of the Early Intervention Taskforce culminated in the submission of report to the Illinois General Assembly in July 2010. Michelle Saddler, Secretary of DHS, indicated upon presenting the report that the DHS would partner with the IICEI, the governor appointed advisory board created in the Early Intervention Services System Act (325 ILCS 20/4), to advise and assist DHS in reviewing these recommendations and identifying steps to implement an action plan.

The report was reviewed with interest by a collaborative of EI stakeholders, and in early 2011, the Early Intervention Advocacy Initiative (EIAI). Certainly this group is in agreement with many of the taskforce findings and recognition of economic and administrative realities as stated in the report: Both the growth in the EI Program and the shift in the service delivery model, as well as the explosion in our knowledge base related to early learning and development, have magnified the challenges and need for effective communication; improved collaboration and service coordination; efficient and accurate data collection, management, sharing and analysis; appropriate service provision and supervision; and qualitative assessment of child and family outcomes.

EIAI also determined that there was a need to learn more about the real and human impact of current EI practices on the lives of children and families in Illinois. EIAI wanted to provide EI with organized feedback from EI stakeholders (families, service providers, advocates, to name a few). Thus, EIAI organized a series of open forums to learn more specifically about how and whether the current interpretation and application of “natural environment” in Early Intervention effectively meet the needs of Illinois children and families. EIAI focused on this issue because of the EI Taskforce concern about improved collaboration and service coordination and appropriate service provision and supervision.

**Methodology**

EIAI chose the Chicago, Rockford, Springfield, and East St. Louis areas of Illinois because all are “hubs” of activity for large sections of Illinois, offering the opportunity to engage a demographic mix of urban, suburban, and rural health providers, family physicians, service providers, and families who might offer reflection and insight into their own personal and professional experience with service delivery.

EIAI invited a wide range of stakeholders in the four targeted areas. ICAAP also invited members of the Illinois Academy of Family Physicians (IAFP), faculty and staff from pediatric, family physician and other residency training programs, representatives of the Early Intervention Child and Family Connections (CFC) offices serving central, greater Chicago area, northern, and southern Illinois; the Illinois State Board of Education (ISBE), Illinois Departments of Human Services (IDHS) and Healthcare and Family Services (IDHFS) staff and local and regional community service providers. Other advocate groups invited include Voices for Illinois Children, the Ounce of Prevention Fund, the Illinois Maternal and Child Health Coalition, the March of Dimes Greater Illinois Chapter, The Autism Program (TAP) and the Illinois Children’s Mental
Health Partnership. Additionally, families who have younger members dealing with issues of disability were invited and in attendance.

Participants in each region explored the following questions:

- How does the Illinois interpretation and application of “natural environment” impact the IFSP team’s ability to set and achieve appropriate goals and outcomes for children?

- How does the current interpretation and application of “natural environment” impact families?

- How does the current interpretation and application of “natural environment” impact supporting service providers in their work, professional development and opportunity to participate in care coordination with colleagues, children, and families?

Ultimately all responses addressed the greater query: **Does the current interpretation and application of “natural environment” in Early Intervention effectively meet the needs of Illinois children and families?**

Generally, participants indicated that they felt heard as they participated in the Open Forum process. When we began this project there were suppositions that EIAI partners believed would be reflected in the responses to the open forum questions. Specifically partners assumed that:

1. because we asked the same questions throughout the state, we would hear that the issues were different depending on where we were conducting the open forum
2. people did not understand the intent of natural environment and wanted only to get rid of natural environment for service delivery

Concerns expressed were similar across the regions-geography does not seem to matter as much as EIAI might have thought.

Participants also expressed that services in the natural environment are important but that solely focusing on the location of services misses the point of effective and efficient EI service delivery.

**Important Findings**
Participants expressed frustration because of perceived poor or lack of communication among service providers. There was energetic discussion about promotion of a coordination of care process for Illinois children needing the support of Early Intervention and local school systems by strengthening healthcare, education, and social service systems.
Discussion about natural environment as it works in Illinois brought up areas of concern that could consistently be placed into five themes: accountability, communication and transition, connectivity and professional development, resource availability, service delivery.

**Themes**

**Accountability**
Vendor model in IL doesn’t afford collaboration, coordination, supervision and accountability Cross-over could improve professional development

- for contract service providers
- for EI and medical home staff
- for families to better understand how to support their child

**Communication and transition**
Participants expressed the idea that families may not be able to articulate who is who and what are they doing. Care coordination among service providers is often lacking. Many participants felt that there needs to be intentional organized communication with families and others to explain key principles of EI and focus on a parent’s ability to engage in the therapy process with their child.

Frustration was expressed that often the grandparents, who are either the primary care giver or certainly an important support resource for the family, are either left out of the communications process or are treated in a condescending manner.

Transition from EI to SPED or other supports and services is often fraught with challenges about information exchange related to diagnosis, service delivery, and areas of responsibility for service provision.

**Connectivity and professional development**
Stakeholders generally expressed concern about the lack of professional development opportunities for service providers indicating that if those providers were truly connected to the EI service center, they could be monitored for professional development.

Service providers and families alike shared that they often felt isolated while in the EI system. Families expressed that they were often cut off from others who were dealing with similar issues. Service providers conveyed that they were set apart with no opportunities for sharing information.
Resource availability
Many participants felt that either service delivery is limited not by lack of resources but by
distribution and limitations of service delivery within the natural environment.
There is general agreement that services for children’s mental health are very limited and that
there needs to be a concerted effort to expand those resources.

Service delivery
Families should have choice about where services are delivered and sometimes socio-economic
conditions limit choices. Some participants indicated that they would be able to deliver more
services if not limited by the need to travel from home to home over a large geographical area.

One participant left us with this thought: A therapist can go to a family’s home, but if the parent
goes into the kitchen to wash dishes while the therapist works with the child, what good is that
except that we get to count the therapy as having been provided in the natural environment? If a
parent takes a child to a therapy center and participates fully in the therapy session by actually
working with their child while the therapist coaches them and is given activities to do at home,
why is that worse than the first scenario I described?

I do understand that perhaps if a child goes to the center then it is all too easy for a therapist to
have the family in the waiting room, while if you are in someone’s home you can’t very well
banish the parent to another room!! But to me, it starts with if the therapist understands and
implements EI principles and finds ways to encourage families to participate with their children.

Next Steps for ICAAP
The conclusions drawn from the work of the open forums are important for many reasons not the
least of which is that they parallel the findings of the Early Intervention Taskforce to improve
service delivery for children and families in Illinois. This realization has informed many
taskforce recommendations. EIAI focused most specifically on the following recommendation
cited in the EI Taskforce Report (pg. 12-13):

Recommendation #7
The Bureau of Early Intervention must work to implement a comprehensive
system of qualitative monitoring, which should include:
1) consistent, comprehensive qualitative child and family outcome measurement
and analysis,
2) policies and procedures for the provision of support and technical assistance
prior to and during the IFSP meeting to better assure that IFSPs reflect EI
principles and recommended practices,
3) policies and procedures for a system of peer review/reflective supervision of
service delivery where appropriate and useful; and
4) policies and procedures for the monitoring and evaluation of Family Support
experiences.
Background
Historically and currently, the focus of monitoring and evaluation in the Part C EI Program has been based on adherence to policy and procedure and relies on the collection of quantitative information. This type of monitoring is necessary for any system and the information collected is mainly used for APR submission. Monitoring, evaluation, and improvement strategies include a system of incentives and penalties, recoupment, and corrective action based on program data and post-IFSP documentation reviews.

Rationale for Recommendation
• Due to new federal mandates for data collection, the Bureau of Early Intervention is collecting both Child and Family outcome data. CFCs also collect Family outcome and satisfaction data. These data pools are not coordinated and existing data has not been analyzed to assess the extent to which service delivery will or should be impacted.
• Due to the independent nature of providers in the Vendor model, providers regularly work alone with children and families in the home or in other community settings. These providers have little access to peers for consultation purposes. Providers report a discomfort providing services in natural environments (which is required by federal law) due to this distance from peer consultation.
• Illinois shifted from a center-based EI program to one in which the majority of services are provided in homes and other community settings. This generally means that families have fewer opportunities to spend time with other families who are sharing some of the same experiences. States, including Illinois, have struggled to replace the peer support that families used to receive from center-based EI programs. Efforts to do so should be monitored and evaluated to assess their effectiveness.

Required Actions
• The Bureau of Early Intervention will continue its work with the Early Childhood Outcome Center and with the Child Outcomes and Family Outcomes Communities of Practice to determine whether Illinois’ Child and Family Outcome data is stable and consistent enough to be a reliable indicator for monitoring and evaluation.
• The Bureau of Early Intervention will review practices currently in place in other states as well as in CFCs in Illinois for the provision of support and TA prior to and during the IFSP meeting and will encourage the widespread implementation of effective practices.
• The Bureau of Early Intervention will define peer review and, in collaboration with system stakeholders, design a system of peer review that incorporates EI policy, procedure, recommended practice, and licensure requirements.
• The Bureau of Early Intervention will review the current structure and role of the Parent Liaison in order to assure that Parent Liaisons have access to consistent training, ongoing professional development and supervision and that parents/families across all CFCs have consistent and quality opportunities for family peer support.
• The Bureau of Early Intervention will assure that as qualitative monitoring is implemented, only monitors with specific substantive training in a field will evaluate the appropriateness of services in that field, service delivery in that field, or evaluation decision in that field and such reviews should be done, if possible, during or prior to the IFSP meetings.
• The Bureau of Early Intervention will undertake 2 activities designed to inform and support families participating in the Part C Early Intervention Program:
  
  (1) assure that service providers and service coordinators are adequately prepared to train families on the Part C Early Intervention Program and their role as their child’s first teacher and primary advocate

  (2) assure that families receive information regarding quality opportunities in the community for parents/families to congregate for peer support and fellowship and if these opportunities are not available, work with CFCs to foster such opportunities with existing community resources.

ICAAP, the stakeholders of the Early Childhood Policy and Legislative Advisory Committee, and EIAI have determined that we will take the following steps as part of our advocacy for children and families who engage with EI for service delivery:

• Share information with leadership at both Early Intervention and Illinois Department of Human Services for policy change consideration
• Share recommendations from open forum work, such as allowing for a variety of modes for service delivery that work for all parties
• Participate in opportunities to review EI recommendations because of changes in federal EI regulations.
• Continue to monitor for concerns about current natural environment interpretation, especially as it relates to service delivery.

For more information about EIAI, the work of the Early Childhood Policy and Legislative Advisory Committee or the EI Taskforce Report to the General Assembly, please contact Juanona Brewster, MDiv, MTS, MJ, Director of Early Childhood Development at the Illinois Chapter, American Academy of Pediatrics (jbrewster@illinoisaap.com) .