

## **The Family Role in Part C Webinar Participant FAQs**

1. **Question:** Mark question: What is the role of your State ICC and what is the funding source for the local ICCs and who collects and monitors the information from each ICC?
  - **Debbie Jackson:** Washington State ICC is funded by our lead agency (ESIT). Most counties have 4 meetings a year and are given a certain amount of money in their contracts to conduct these meetings. The ICC is a representation of the EI system in a local community. The providers, stakeholders and hopefully families provide input in an advisory capacity to the local system. The state lead agency monitors the local lead agencies.
  - **Mark Smith:** Our state ICC has multiple roles. It advises our Part C Program, but was combined several years ago with the state advisories for our Childcare Block grant and Head Start. My role is primary to Part C, but I work in collaboration with our early childhood partners on issues that affect all young children who might be at-risk and their families. Our Local ICCs are funded in 2 ways; first, services through Part C are provided by school districts since we are a birth mandate state. Second, are local ICCs are funded through our federal Part C funding, which is supplemented by Medicaid funds derived from our Medicaid in Public schools program (these funds were set aside in statute for this purpose.) Local ICCs submit Systems Support Grant proposals to the Lead Agency team describing their past and planned activities each year; this allows the Lead Agency team to focus efforts and supply discretionary funds for projects to address systemic concerns (like family involvement) and monitor the activities of the local councils.
2. **Question:** How are Washington and Nebraska helping / supporting families who do not still have internet access?
  - **Debbie Jackson:** Materials were developed in written form as well as being available on the internet.
  - **Mark Smith:** We are seeing an increasing trend towards more families having internet access. However, we provide all of our information in hard copy whenever requested and we do a lot of our work with families either by phone (our state council parents participate routine conference calls as regards their work on the state council) and our services coordinators meet with families face-to-face routinely as well.
3. **Question:** As someone who serves a rural area, how do you support families who live in far rural areas? (internet, transportation to doctors etc.)
  - **Debbie Jackson:** We encourage our Family Resources Coordinators and service providers to make information available to families as much as they possibly can. I do my best to visit the more rural areas of our state and provide trainings as I can. We provide scholarships to our Washington State Infant and Early Childhood Conference so that families that don't have as many opportunities to participate in information and training forum can attend. As most state our funding is stretched very thin and we are always being asked to do more with less so we do the best we can and support as much as we can with the resources that are available in our more rural areas. Family Resources Coordinators are invaluable when it comes to helping

families solve issues like transportation, doctor appointments, food, housing. They know their local resources and we count on them to help families access these services.

- **Mark Smith:** That is certainly an issue here, and our EI staff refer to it as “windshield time” that is we work as best we can to insure services are delivered in natural environments for example the family home – we try to come to the child and family whenever possible. It is a challenge, but our rural providers have maintained a fairly low rate of services occurring outside of natural environments. We do try and insure, for example, rural parents have the opportunity for training (again, we come to them) and, for example, opportunities to serve on, for example, our state ICC so that the issues and challenges of serving rural families remain in front of policy makers and providers.

4. **Question:** edn? ecicc?

- **Mark Smith:** Early Development Network (our EI system’s title) and Early Childhood Interagency Coordinating Council, our state ICC.

5. **Question:** Are your EI providers on the same page and understand the importance of family participation? How did you train the providers?

- **Debbie Jackson:** We have done a lot of training around the importance of family involvement and participation. We have a lead agency and a State program coordinator that believes in family participation. Our providers seem to have the same understanding.
- **Mark Smith:** At the state level, I can say they certainly are. At the local level, it is a little more heterogeneous. We do open our family involvement and leadership training to professionals, and have had some attend. We primarily provide feedback to local providers through our monitoring process and our Systems Support Grant process. Local ICCs provide their rosters as part of the grant proposal so that we can ascertain whether they have at least 20% family representation. Members of the Lead Agency team also attend a sample of local ICC meetings each year as a means to support communication with the councils and monitor participation.

6. **Question:** Do you have a training geared towards the Service Coordinators?

- **Debbie Jackson:** We have used our family curriculum to train our providers about family involvement. I believe that the providers need to know what we want families to know so that we are all on the same page. When everyone is coming from the same place. We have emphasized different aspects of the training for providers such as the importance of drawing the family into the process and steps to make the family feel valued.
- **Mark Smith:** We have an annual 2-day EI Summit that is geared towards EI professionals, in particular Services Coordinators. In addition, we have routine trainings that are available to EI personnel and families on a variety of topics annually – Positive Behavioral Supports Coaching and the Primary Provider Model, Language Acquisition, the effects of Abuse in Early Childhood and the neurological and developmental outcomes as some examples. We also have a training series for the Court System on legal issues in EI called “Helping Babies from the Bench” that has supported our CAPTA efforts.

7. **Question:** WHAT IF FAMILIES CANNOT READ?

- **Debbie Jackson:** we try to find someone who can read it, another family member, volunteer etc.
- **Mark Smith:** We try to insure our written information is developed in as “reader friendly” formats as possible. Families who have members who are illiterate would receive the same accommodations as, for example, the same as English as a second language families like having an individual dedicated to reading information to them as needed.

8. **Question:** What are some suggestions you have to help families that may not have had the best early childhood intervention, but have teens or older children with disabilities like autism? How can they improve their children’s abilities later in life?

- **Debbie Jackson:** It’s always a disappointment to hear that a families experience in EI wasn’t good. It’s never too late to turn things around thought. There are family’s supports organizations like Parent to Parent (national organization) that can help families connect with other families walking the same path as well as your state’s “PTI” (parent training and information center) that can usually help families with older children get the help and resources that they need to succeed.
- **Mark Smith:** We assume any individual has the capacity to learn. Through my role at my University Center as well as Connie’s role at our Parent Training and Information Center, we refer children and families to programs that can address their developmental needs regardless of age. If they did not have a positive experience in EI, we would take that information back to our Lead Agency Team to try and address the reasons they did not have a more positive experience in EI.

9. **Question:** WHAT IF FAMILIES DO NOT HAVE ANY COMPUTERS?

- **Debbie Jackson:** Our information is in written form.
- **Mark Smith:** See the response to question #2 above.

10. **Question:** HOW EXACTLY ARE YOU CREATING CULTURALLY SENSITIVE COORDINATORS AND STAFF MEMBERS?

- **Debbie Jackson:** We have and continue to engage in cultural competency training at a community and provider level as well as a state level, it’s ongoing. We have several agencies in our state that do a really good job with training.
- **Mark Smith:** Training on cultural competence is routinely provided to our EI personnel as it is a significant concern given we are seeing significant changes to the demographics in our state. We also try and insure the composition of our family representatives to local councils and the state ICC reflects the diversity of cultures and ethnic make-up of the state population. Our population is becoming increasingly diverse; we are experiencing an influx of Latino, African, Vietnamese families and other ethnic groups along with addressing the issues of typically underserved

groups: African-American, Native American, etc., which is an ongoing challenge to our state program .

**11. Question:** How do you find the families who are interested in training for leadership?

- **Debbie Jackson:** That's always the million dollar question. We look to our providers and family resources coordinators to identify families that show leadership potential. We host a state wide early childhood conference every year and we typically have a large number of families that attend. We use this venue to recruit and talk with families about leadership roles in the state.
- **Mark Smith:** We advertise our trainings through our state information networks as well as approach Services Coordinators in areas we plan to provide training. Often, Services Coordinators are aware of particularly good candidates and will approach them for us. This frequently involves caregivers who have children who may have recently completed EI – they've been through intake, worked with Services Coordinators and other professionals, transition, etc. and often have more perspective on their experience than families in EI.

**12. Question:** Why do I, as a parent, want to spend my time reading/viewing videos in a situation where we know the child with disabilities takes more time to care for, where I might be stressed, where there may be impacts on my mental health and marital satisfaction?

- **Debbie Jackson:** As a parent myself I want to know all that I can do to help my child be successful. I want to be active in my child's ability to succeed. Not all families will feel that way but a provider has the ability to draw a family member in slowly and show how the activities and routines they are working on are making the life of the child and family better, maybe not perfect but better. Even parents with the most severe disabled children want to learn how to improve access to services and learn advocacy skills for their children, don't limit the will of a parent! We always find a way!! Families that struggle with mental health issues need be able to access resources for themselves as well. Service coordinators can often help them do that. Not all marriages will survive disability but studies have shown no more than marriages with non-disabled children. Working with a fragile families isn't easy but as a service provider or resources coordinator develops a relationship with the family hopefully they can help them access resource for the good of the entire family.
- **Mark Smith:** Good question. We do not assume all families have the interest or capacity to become involved in advocacy or other activities related to EI. We really leave it up to the families as to whether they want to be involved and to what degree if they do. We try to provide options so that if a family has significant stressors present, they can choose to either be involved to a degree that they can or to discontinue their involvement if need be. We try to be certain to recognize that "life happens," and that family representatives need additional supports to maintain an involvement in, for example, their local ICC, etc. We believe this support has to be intentional and insure that families have the flexibility they need. We often have had to honor the fact that their spouse and children must come first; it creates a challenge in terms of turnover in representatives, but that's part of the process.

**13. Question:** Are initial contacts with families for the ICC made through Service Coordinators?

- **Debbie Jackson:** They can be and often that is the best way since they see the families on a regular basis and can often identify leadership skills. Often family leaders will refer other families as well.
- **Mark Smith:** Once the initial referral comes in (which can come from a diverse list of possible sources,) yes.

**14. Question:** What does family participation/involvement mean operationally?

- **Debbie Jackson:** for us it means that the family voice is always at the table for policy changes and improvements for state performance plans for quality program monitoring. We value the voice of the family and want and need their input about how the policies and procedures that are implemented translate to real life.
- **Mark Smith:** Much of operationalizing the concept of family participation is qualitative, but there are certain components that need to be present to insure family involvement is realized at a functional level. First, there is the matter of families being “at the table;” one has to insure families are supported in their involvement in ways that assures they’re able to participate to an optimal level. Supports can be financial but also can involve services like childcare, transportation, etc. Second, families have to be informed to the extent they can effectively participate and represent the family perspective as regards activities and discussions related to services, supports, and policy. Families need to have a reasonable awareness of the different aspects of the EI system as it operates, but also what constitutes best practices in these same aspects, particularly in terms of what constitutes: “family-centered care”. In other words, family representatives need to ideally be able to see beyond the current to what may be possible. Also, the make-up of family representatives should encompass the diversity of the area they represent. It is, for example, significantly more effective to the process to have a Latino family speaking to the concerns Latino families have. Families also need the means to be representative; they need to be supported in terms of understanding the concerns that families have in the area they represent in general. While it is reasonable to assume they can represent their own family’s experience from the outset, they need the means to move beyond that in terms of all families. Regardless, family representatives need support in “finding their voice,” that is support in how they can best communicate their feedback to the team or council.

**15. Question:** I UNDERSTAND THAT YOU WANT TO GO NATIONAL, BUT HOW ABOUT IMPROVING THE QUALITY OF SERVICES THAT ARE BEING PROVIDED BY PROGRAMS LIKE EARLY STEPS?

- **Debbie Jackson:** I’m not familiar with Early Steps. I would encourage you to be a voice at the table and talk to families that have participated in the program and bring their voice to the table. Change doesn’t always happen fast but as they say the squeaky wheel gets the grease! Don’t give up on advocating for high quality services for the children in your community!
- **Mark Smith:** Our state Council covers programs birth through age 5, and we intentionally include partner organizations basically across the board in early childhood in Nebraska. We don’t have an Early Steps program, but there are numerous initiatives, programs, and agencies that utilize our state ICC as their advisory. We encourage information sharing and collaboration across programs which minimize the “silo effect,” that was the status quo when we started, so

to speak. As such, any efforts we undertake tend to benefit other partners at the table. The national aspect comes from the fact that during the implementation of Part H, now Part C, there was significant outreach to families as programs were being designed and implemented at the local, state, and national level (for example, I served on the Federal ICC for 3 years; also, funds were designated to assure families were able to attend national conferences, etc.) Over time, this emphasis has waned as budgets have tightened, etc., yet family advocates in EI still see this as a needed practice to insure the best program outcomes. As such, we try and promote family representation (and presentations) at the OSEP Leadership conference, the ECO conference, DEC, and others. I'm happy to say that these organizations have welcomed family involvement, but resources to sustain this involvement will likely remain an issue.