

What do researchers need to do to support parents as partners in research?

Lynda:

Early intervention is an important stage, however, this is a time that moves quickly and takes place when many families are learning about cerebral palsy for the first time. Families are bonding with their new family member while adapting their life, learning about disability, and seeking medical help. Their minds may not be thinking about research as a participant.

Family engagement in research, for me, is about having a partner on the team that represents the balance required in a project during a sensitive time. A partner is a face who understands the emotional sensitivity and also the value of research.

For this reason, I feel that FER in this particular area would be a benefit. It is a fragile and fast paced time for a family. Yet, it is a crucial time that could use more research to back practices and protocol.

Creating an atmosphere where FER is more common place will be a challenge. However, if done in an approachable and informative way, families will have the knowledge base needed to look forward to opportunities when they come available. Maybe, with enough common-place language, families can seek out and help create opportunities.

