

Why should I do it as a researcher or as a parent?

Lynda:

As a parent of a child with cerebral palsy, we face many decisions for treatment plans that will affect not only their current quality of life, but their future as well.

As any parent, we want to make the best decisions possible, but there isn't always an easy answer. Some of the decisions are based on 'anecdotal' evidence.

When we asked our clinical staff why there wasn't more research, they asked us, 'how comfortable would you be signing your infant up for a study at this stage?'

I think families of young children would be more willing to participate in research if they knew about family engagement and that a project was using it.

Early intervention is a short window. It is a busy time for a family and there is a lot of pressure to get the correct treatment. It is not an easy time to reach beyond your day to day.

However, more research of pregnancy, preterm, infancy, early years and transitioning out of early intervention would be such a benefit.

Once you have been through something, and you have a better understanding of it, as a family member you can give back to the community you are now a part of. You can help with the whole process with a valid voice.

If a family representative had asked me how comfortable I would be signing up my infant for a project... I think I would be more willing to hear the details and see past our day to day.