**Parent Question List**

How old is your child?

Does your child currently receive therapy? If so, what therapies does your child receive, and how often does he/she receive them?

Has your child received or does your child currently receive physical therapy?

Where does your child receive his or her therapy (at home, at a clinic, at a school)?

If your child does not currently receive physical therapy, where did he or she receive therapy in the past? (at school, at home, in a clinic, all of these? None of these? Some of these?)

How long did your child receive physical therapy? (Or has she/he received physical therapy if still receiving PT services?)

Did you feel like physical therapy helped your child?

What about the physical therapy do you feel was most helpful?

What was least helpful?

What was the most difficult part of receiving physical therapy services?

In the different environments, what was most difficult?

If you could change anything about the therapy services you receive/received, what would you change?

Do you feel that your therapists empowered or are empowering you to take care of your child and provide for his/her future?

Do you feel like your therapist included you in the care decisions for your child and the treatment planning for your child?

Additional questions for focus groups

Do parents want a “road map” or an itinerary?

In other words, do you want specific ages or times when children accomplish milestones or do you want the order in which they happen?

Would you like a “road map” or itinerary for therapy?

Frequency of therapy is a recurring theme: Why do parents value more therapy?

Are we failing to equip you to work with your child?

What is the order of your priorities for your therapy services?

Frequency

Intensity

Convenience

Consistency of providers

Duration of sessions

Do parents need/want to know the “why” of therapy activities?

On the surface, it seems to be better for parents to have streamlined therapy; however, from interviews, parents seem to value choices in therapy providers.

Does it bother you to have multiple providers (companies) of your therapy? Or is access to therapy when it’s needed most important?

A number of parents have said “No, I don’t think I am the expert.” They express that the therapists are the expert about Down syndrome and look to the therapists for direction. In family centered care, parents ideally are directing treatment.

Would better communication with public school therapists improve your perceptions of school therapy?

Would a more thorough explanation of educationally based therapy make your perceptions more positive?

Do you feel that your care is disjointed?

Waitlist—what are your feelings about being put on a waiting list? What do you do when you are told you are going to be put on a waiting list? How can we help parents “in the meantime” when we have waiting lists for therapy?

What have transitions been like from ECI to PPCD, from home to preschool, preschool to school? Or even from one therapy provider to another

What are your feelings about being discharged?

How frequently do you get to communicate with your school therapists? Is it sufficient? How can communication with school therapists be better?

What about PT later on? Role of PT in elementary, high school?