



“The diagram charts with the yes/no questions, within the **On Track Study** classification package, were really helpful in determining where my child fit” *parent participating in the study*

Family Newsletter

Third Edition, June 2015



Wow, things are really rolling! Our study team is very busy keeping the project moving forward. We have wrapped up our study recruitment – with a final, wonderful achievement of 711 families from Canada and the US in the On Track study!

Visit <http://bit.ly/1k8uJ7Z> to see a map of all the study sites across Canada & the US.

Thank you so much to everyone involved in this important step – it was a huge team effort. We are very excited to now turn our focus a bit to make sure we **stay in touch** with all of our families throughout the study and that we **keep our momentum**. We are working on our plans for getting information out to all interested parties as soon as we possibly can, in ways that are most meaningful and helpful. We welcome ideas from one and all, so please feel free to contact us to share your thoughts.

What are the assessments in the On Track Study? (the first in a series):

Early Clinical Assessment of Balance (ECAB): When your assessor is doing the visit, you will see her working with your child to examine his/her head and trunk control and balance while sitting and standing. The assessor may place your child in a variety of positions, including sitting on her lap, lying on their back, lying on their stomach, sitting, and standing. She may ask your child to do certain actions in these positions, such as rolling over, holding their hands up, turning around, or closing their eyes. These actions tell the therapist more about your child's balance.

What are some things we are hearing from parents in the study?

Comment from a parent: "I wish health care providers would think outside the "text book" box. Parents don't know what questions to ask and I really learned a lot this year by researching and looking up information myself. If there was ever a change I would like to see, it would be health care professionals



engaging in more details with parents so they can actually help parents help their kids rather than leaving parents feeling lost and confused."

One of our goals with this research is to share ideas with therapists and families on various approaches to exchanging information. If parents have general ideas or suggestions for the study or specific ideas about how we provide information to families or therapists, please feel free to contact your regional coordinator. Contact information is listed on the last page.

One of the great parts of doing research is the learning exchange between parents and therapists/researchers. The Child Engagement in Daily Life Measure asks about participation in family and community. A parent recently wrote a note asking about how we define participation. One question asks about active physical recreation such as riding a tricycle or running outside. The parent asked whether riding in a bike trailer or going hiking in a jogger should be counted as participation even when the child isn't the one riding the bike or doing the running. **ABSOLUTELY!** Participation comes in so many different forms and we were happy to hear about this family's experience.

Parent Researchers

The parent researchers working on the project are very invested and they are continuing to work with us as valuable collaborators, adding fresh insights and real life experiences to help shape, define, and guide the study. Their valuable perspectives are having a



tremendously positive impact overall. The parent researchers help us to make sure that the work we are doing is meaningful, thoughtful, and practical – they keep the study "On Track."

The investigators continue to look for ways to involve our parent partners. As the study moves forward, parent team members will be more and more involved in helping the researchers figure out the best ways to share what we are learning with healthcare providers and families.

Parent Investigator Profiles

In each newsletter we are featuring two of the parent researchers. In this issue, we would like to introduce you to: Nancy Ford and Paula Drew.



Nancy Ford lives in Atlanta, Georgia with her husband Marshall and their four children. Anna, Noelle, and Sydney are 14 year old fraternal triplets and are currently in 8th grade. Harrison is 12 years old and is currently in 7th grade.

Anna, Noelle, and Sydney were born very prematurely at 25 ½ weeks gestation and weighed less than 2 pounds. Anna and Sydney required a three month stay in the Neonatal Intensive Care Unit and Noelle required a four month stay. Sydney continues to have minor eye complications due to retinopathy of prematurity. Noelle was diagnosed with hydrocephalus, which requires a shunt, and has cerebral palsy, and learning delays. Harrison was born full term, weighing more than his triplet sisters' combined birth weight.

Nancy is a graduate of Clemson University with a BS in Finance. She works in Corporate Finance at The Coca-Cola Company on a flex-time schedule to allow her to spend more time with her family. Marshall is CFO at Yancey Brothers, the Caterpillar dealer for the state of Georgia. The Fords enjoy numerous sporting activities including running, soccer, football, swimming, and basketball. They are active members of their community and All Saints Catholic Church. The family also works very closely with several not-for-profit organizations and is actively involved with FOCUS and Lekotek, both of which focus on children with special needs and their families.



Paula Drew is the mother of a miracle. Dillard, her 21 year-old son, has spastic diplegia cerebral palsy, vision, and hearing impairments. He is a happy, healthy and most of all, loving young man; a

gift from God. Paula is a Registered Dental Hygienist, now retired. She has been married to Dillard's dad for 28 years and lives in Edmond, Oklahoma. Paula credits Dillard's physical therapist with supporting her family through the everyday life of cerebral palsy, all for the good of Dillard. She hopes that her experiences as the mother of a young adult with cerebral palsy will provide guidance and help to others. Paula is a board member of Coffee Creek Riding Center. The Center provides therapeutic horseback riding for children with developmental challenges. She is a member of a parent/advocacy group, The Oklahoma Family Network, in which parents experiencing the NICU life are mentored. Paula states that being Dillard's mother is to always nurture, guide, and love him.



Parent to Parent



Talking With Others About Your Child and CP

All parents of children with cerebral palsy (CP) remember the moment they learned the diagnosis. Whether it was shortly after birth or sometime after, once the diagnosis is applied a lifelong learning curve begins. One of the first and most challenging aspects of that learning curve is how to talk with others about your child's disability.

As parents of young adults (Dillard, age 21, and William, age 24), we want to share things we wish we had understood better when our children were young!

Keep it simple. Parents often learn a great deal about CP while consulting specialists and determining options for therapy. But caregivers, acquaintances, and parents of other children don't need medical information; it's fine to share the basics directly and factually.

"CP is caused by a brain injury; most likely it happened during William's birth."

Especially when responding to young children, give them answers in terms they understand.

Q: "What are those things in her ears?" A: "Hearing aids—they help her ears to hear better like glasses help eyes to see better."

Q: "Why can't he walk?" "What are those things on his legs?" A: "Dillard was born extremely early and was very sick, so he needs help with balance. His orthotics support his legs to be stronger."

If your child communicates directly, encourage him or her to take the lead.

"I need support with my balance because an area of my brain was injured when I was born. I have cerebral palsy; that's all."

The more matter-of-factly questions are answered, the better other people understand that CP is a fact of your child's life—a challenge, not a tragedy.

Emphasize the positive. When people hear the words "neurological injury" or "brain injury" they may assume CP is progressive or even life-threatening. It's helpful to say up front that CP is not a degenerative disorder such as ALS.

"Once the brain injury happens, it's done—the brain injury doesn't get any worse."

Help people understand that human development is a process. The consequences of CP may intensify as a child grows taller and heavier (e.g. spasticity may appear more severe, low tone in the torso may make it harder to sit upright). But it's a comfort to us, as well as others, to say how amazingly adaptable our brains are and that many children continue to gain skills into adulthood.

"Over time, it's likely that her brain will adapt and find ways to continually improve."

Use person-first language. Let others know how to describe your child, i.e. a "child with disabilities" rather than "a disabled child." It's more than political correctness. Person-first language

reinforces that our kids do everything other kids do, just in unique ways.

Acknowledge how your child is specifically affected. Sometimes people try to compare the capabilities of one person with CP to another; they may also assume a child with motor disabilities also has intellectual disabilities. It's helpful to say that CP manifests in unique ways in each person, and spell out how your child functions.

"CP affects everyone differently. For William, it means he isn't walking yet and it helps him if you ask simple yes-or-no questions."

"She has to work hard to sit up and use her computer, but she understands everything you say."

Disability does not equal illness. When your child looks visibly different, people may assume that she is sick or medically fragile. If that is not the case, people are relieved to know for sure.

"She's perfectly healthy—she just needs extra time to crawl over to that ball."

Suggest ways to promote your child's progress. An unspoken question may be, "How should I relate to this child?" Remind others that your child is a child first, and a child with disabilities second.

"Treat him like you would any child, and encourage your child to do the same."



"If you don't believe she can, then she won't—because you may not do the things that will help get her there. So believe she can and that will help her make progress."

Model inclusive behavior. If people talk about your child in her presence as if she's not there, they need you to educate them out of excluding her. Show them how. For example, say your son has dropped a toy and the man in the store next to you starts to pick it up. You can demonstrate your child's independence.

"Oh, William can pick that up himself. William, pick it up please. But thank you so much for offering!"

If your child genuinely needs the help to retrieve the toy, involve him in the interaction.

"Oh, thank you so much. William, can you say thank you yourself to this man?"

Remember: all your communications about CP help build a more welcoming world. Of course, having a child with CP is exhausting and frustrating at times for our kids and for us; we don't always have the energy to educate other people about CP. However, it is an effort very much worth making. We are all working to prepare our children for the world; but we can also help prepare the world for them. Whenever we share the joy we have in our kids and our pride in their hard-won accomplishments, we are helping to create the fully inclusive world we want our kids to live in.

Written by Barbara Sieck Taylor and Paula Drew

Input from: Marquitha Gilbert, Lisa Diller, Nancy Ford, Tina Hjorngaard, and Kimberly Rayfield



Summer is coming! Try to think ahead, figure out vacation time, structured time, and plenty of free time too. Days with no planned activities can inspire creativity and encourage us to follow our children's lead for fun things to do. Now is the time to start planning for fun activities, including summer camp. If your child is old enough, interested, and ready for camp, start doing your research now for summer camps in your area that are suitable for children with special needs.

For families in the Pacific Northwest, a great online resource is The Center for Children with Special Needs at Seattle Children's Hospital, which provides lots of good ideas and summer camp opportunities:

<http://www.cshcn.org/resources-contacts/summer-camp-directory>.

Fun Activities to Do in the Summer

- 🏊 Swimming - warm water helps to reduce stiffness; some hotels have warm pools - good to do year round
- 🎡 Local amusement parks with rides or water fun or both- use wagon to get about vs. stroller, wheelchair, or crutches
- 🦒 Zoo - take train ride to view entire area
- 🐟 Fish - at a lake, pond, river, ocean - might try a guide
- 🏖 Beach - use 2 man inflatable raft "to ride the waves" with sibling or friend; parasailing - allow 2 people to sail at a time depending on total weight

- 👉 Golf - riding or driving the golf cart can be just as much fun as golfing; miniature golf is also fun
- 👉 Accommodations - always ask for accessible room or at least one on the first floor close to an exit

The American Camp Association has information on accredited camps across the US and beyond, serving people with special needs: <http://www.acacamps.org/>

Check out your local children's hospitals, community centers, YMCA's, Boys and Girls clubs. Ask your therapists – they often are in the loop about fun activities (and let them know if you have any gems to pass on)! Share, share, share 😊

Going to the beach and need a wheelchair? Many destination beaches have free access to wheelchairs. One of our parent team members has this helpful tip – contact the nearest fire station or Chamber of Commerce.



So many choices, how to decide? Here are a few tips derived from Dr. Toy (Stevanne Auerbach):

Most important - Is the toy safe? Are there any potential hazards? Is it nontoxic? Will it take rough treatment? Can it be easily cleaned?

Is it fun? A toy is supposed to entertain. It should amuse, delight, excite, be enjoyable, and provide skills' practice.

Is it appropriate? Does the toy fit your child's age, skills, and abilities? Will it hold his/her interest?

Is it well-designed/versatile, easy to use? Does it look and feel good?

Will it help your child expand creativity? A great toy can expand imagination in art, crafts, hobbies, language, reading, music, movement, and drama.

Will the toy frustrate or challenge your child? Will s/he know how to use it, or will it be too difficult to use without adult assistance? Does the toy offer something new to learn, to practice, or to try?

See more at:

<http://families.naeyc.org/learning-and-development/child-development/why-toy#sthash.D4HTNM4J.dpuf>

Resources



The Family Resource Network is a leading provider of family support services to individuals with intellectual and developmental disabilities and their families in NJ. Check out their terrific Resources page <http://www.familyresourcenetwork.org/resources/>



The Center for Parent Information and Resources (CPIR) serves as a central resource of information and products to the community of Parent Training Information (PTI) Centers and the Community Parent Resource Centers (CPRCs), so that they can focus their efforts on serving families of children with disabilities. <http://www.parentcenterhub.org/>



CEC works to improve public policy affecting children and youth with disabilities and gifts and talents, their parents and the professionals who work with them, at all levels of government.
<http://www.cec.sped.org/>

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THANKS
For all you do