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Adapting Your World for Play

by Erin

All children learn through play.[1] Play provides opportunities for children to understand environments and relationships. Playing alone with an object through experimentation helps a child learn what the physical qualities of that object are through his senses (the block is red, smooth and tasteless) and physical skills (if the block is dropped or thrown it makes a loud noise). Playing with an object with another person helps a child learn the potential uses of the object (the block can be used to build a tower) and how it relates to other objects in the world (the block is a toy). The child also learns about her relationship with the other person by observing what happens when she is unable to master a particular use of the object on her own (my parent will help me build a tower with the blocks or become upset when I throw blocks).

Children with disabilities learn through play, but the means by which they have access to objects in their environment and the assistance they need while exploring those objects may vary depending on their functioning. In some cases, a child may have difficulty seeing, hearing, reaching and holding an object without a specific degree of help from another. For this reason, assistance from others often serves a more important purpose for the child with disabilities.

That is, ***assistance helps encourage cognitive growth by setting the stage for purposeful exploration that, in turn, may help the child learn to master skills he would otherwise not be able to perform***.[2]

There is possibly no stronger need for a parenting handbook than when faced with how to help a child with disabilities learn to play. Every child learns in a distinct way and this basic fact becomes even more apparent when working with children with disabilities.

In the NICU we watched my second daughter, who experienced Hypoxic Ischemic Encephalopathy at birth, tracking my oldest daughter's mobile and naively thought that we would be well prepared because we had saved all the toys her sister enjoyed as an infant. However, once my daughter's inconsistent tracking (from Cortical Visual Impairment) and difficulty grasping objects (from Cerebral Palsy) became more apparent, we quickly realized that we would not be able to rely on many of the same toys that had encouraged my older daughter's development. Instead, we would need to find new ways to engage her.

Faced with the absence of a parenting handbook, it is helpful for parents of children with disabilities to ***become detectives and conduct their own investigations to determine the types of modifications that will be most helpful***.

Gather Information

Because the behavior of children with disabilities is often difficult to predict, it is helpful for parents to ***observe the child, looking for clues that will help them understand her challenges and interests***.

For example, when my second daughter was not snugly in a baby carrier, our entire family was on the floor with her while she laid on her back under a baby gym. Coming down to her level and watching her play helped us notice that when she reached for a toy, paradoxically her hands fisted tight and her arms locked at the elbow preventing her from doing more than batting at the toy. We also noticed that she favored toys that made noise and she sometimes looked away from the toy when she hit it, returning to look at it again once it started moving. When she was done playing and we picked her up off the floor with a big swoop her eyes opened wide. Months later her first smile occurred with similar big bounces in her father's arms.

Without knowledge of how to interpret a child's play behavior, it is helpful for parents to ***ask others (therapists, teachers, or other parents) about confusing behaviors to learn how they may have addressed them with children facing similar challenges***.

From my daughter's Early Interventionist we learned that her fisting and arm stiffening were uncontrollable behaviors associated with her Cerebral Palsy. From her Vision Specialist we learned that it is difficult for children with visual impairments to integrate sensory input so my daughter may have been looking away to focus only on her sense of touch. We also learned that my daughter would still want to and need time to explore objects with ***all*** her senses. Moving objects are often easier to see, which explained why my daughter would focus on looking at the object after it or she started moving. From her Occupational Therapist we learned that children who cannot move on their own actually crave movement and that big bouncing movements, or vestibular stimulation, can be very stimulating. Finally, from other parents we later learned how to set up an indoor swing so on rainy days my daughter could continue to enjoy big smooth bouncing movements inside.

Experiment with the Information

Much of the play behavior of children with disabilities depends on their moods and environments; therefore, it is helpful if parents learn to ***change the toys and the surroundings based on the child's demonstrated skill and current interests***.

Watching my daughter in the same place helped us learn her visual preferences and physical capabilities. We experimented with various inexpensive light-up toys found at

local department stores and discovered that she preferred toys that involved multiple senses, such as her visually interesting light-up fan that included a light breeze to stimulate her sense of touch. We also learned that she could grab thin objects, such as chains of beads, and hold cylindrical shaped objects with a certain diameter, such as the handles of small maracas, when we placed them in her hands. She also had a wider range of movement with her left arm. Using this knowledge, we were able to take calculated risks and purchase either more expensive adapted toys (preferably secondhand) or more expensive technology. Her favorites include a musical bead chain that plays cheerful music when she grabs it, or a Touchscreen Tablet PC that she can activate by swiping with her left arm. Both of these activities are also wonderfully therapeutic because they give her a sense of mastery and help encourage her range of motion.

Interacting with the child on multiple occasions and in different ways will ultimately lead to the most accurate evaluation of her responses. By letting my daughter play with the same toy repeatedly, we learned that it was important to keep toys at her arm's length. By giving her plenty of time with the toy, we also learned that she begins to explore a toy by looking at it and by touching it with her hands. By assisting her play, we learned that if she cannot pull the toy close enough to mouth it she will stick her tongue out repeatedly to communicate her desire for us to help her mouth the toy. She repeats this behavior until we respond appropriately because her exploration is often not complete

until the toy is close enough for her to mouth it.

Finally, by changing my daughter's environment and watching how she responded in various rooms of our home and in different therapy centers, both indoors and out, we learned that dim quiet areas resulted in longer and more focused attention spans. However, if it was not too loud or bright, we also learned she loved swinging and listening to other children's voices at the park; therefore, we found ways, such as strapping a special positioning seat into a Radio Flyer wagon, for her to enjoy a bumpy ride to the park with her sister.

Compare the Information

Children with disabilities are a source of very rich and often confusing information, so it is particularly helpful for parents to find ways to ***weigh all the information gathered and***

determine what play strategies and toys were the most interesting and which did not work.

Often, if no obvious preference can be noted, charting the properties of the toy, the presentation strategy used by the caregiver, and the response of the child can help identify important patterns. For example, we noticed while playing with my daughter that she loves music, light-up toys, and vibration. However, although she enjoys music and lights in combination, vibration is so stimulating she prefers it alone.

Some play strategies that work for the child may not work as well for the adult and may need creative modifications to be more effective. For example, my daughter loves swinging in her indoor swing and when she is content she does not make much noise (compared to when she is not happy and we really hear about it). Because we easily became distracted by other obligations, she was not getting pushed in her indoor swing as frequently as she would have liked. Our solution was velcroing one of her communication switches to the netting of the swing and programming it to say "more please" whenever she pressed it.

This modification was also therapeutically significant because it provided a way for her to communicate to us that she wanted a push and it helped establish an important play-based relationship expectation. Specifically, she learned to trust that she could rely on us to come and give her a push when she hit her communication switch. Indeed, she is so secure in this expectation that she smiles if she accidentally hits her switch while she is being placed in the swing. Furthermore, according to her therapist, when the swing stops she probably hits her switch just once and waits patiently because she knows she has us well-trained!

Share the Information

Observing, experimenting, and comparing the information gathered is such important work that it should not go unnoticed or fail to be utilized to its fullest potential. For this reason, it is helpful for parents to ***communicate helpful strategies with others to encourage generalization to other settings.***

This is particularly useful when the child goes to school without the knowledgeable parent present at all times. At school, a new set of caregivers and professionals will need to learn how to encourage the child to play and learn to his full potential. Without adequate communication, subtle but yet important play and communication behaviors would likely be missed, potentially frustrating the child.

Although it takes a lot of time, energy and patience, playing detective with my daughter has taught us ***to never underestimate what she can learn to do when given the right assistance.*** We share our journey learning about our daughter's capabilities online at Adapted World [http://adaptedworld.wordpress.com/] with other parents and professionals both to acknowledge the support we have received from others and to help

other parents experiencing a similar journey. Ultimately we hope everyone can witness how powerful adapting your world for play can be on the development of a child with disabilities.

Erin is a stay-at-home Mom to Brooke, a very sweet, determined, non-verbal, non-mobile and 100% G tube fed child. Brooke suffered severe oxygen loss and reduced blood flow around the time of her birth, which caused chronic kidney failure, severe brain damage, microcephaly, cortical visual impairment, mixed cerebral palsy, sleep apnea, epilepsy, and reflux. Erin has also been blessed with two very caring and entertaining siblings for Brooke, five-year-old Katherine and one-year-old Ethan.

Erin documents how Brooke interacts with her siblings on Adapted World.

Erin has a PhD in Clinical Child Psychology and although she is currently not practicing she draws upon her experience when trying to ensure Brooke obtains the services she needs.

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[1] Piaget, J.P. (1962). *Play, dreams, and imitation in childhood*. Norton, New York.
[2] Vygotsky L.S. (1978). *Mind in society: The development of higher psychological process.* Cambridge, MA: Harvard University Press.