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A Parent's Guide for a Special Journey

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Being a parent is an emotionally charged experience, often joyous, but also fraught with worries. As you hold your newborn in your arms, your instinct is to love and protect him, but you are also concerned about the best way to fulfill his needs.

At the very beginning of his life, you already have aspirations and dreams for your child and you believe he is destined for greatness. As you watch your infant develop, you are captivated by each connection he makes—how he smiles, gazes at you and enjoys the warmth of your touch. You celebrate every milestone—when he first babbles, sits up and crawls and, eventually, talks and walks.

Unmet Milestones

However, imagine that your child is delayed in meeting his milestones. You begin to get concerned and you seek out your pediatrician's advice. Perhaps you are told you are “worrying for nothing.” Or you might hear, “it's not a bad idea to investigate further,” in which case you might be referred to a developmental pediatrician or neuropsychologist to perform testing.

If the clinician validates your concerns, you are suddenly faced with a range of frightening possibilities. As hard as you try to stay in the moment, your mind races years ahead and you wonder: “Will he be happy? ... Will he go to college? ... Will he be independent? ... Will he get married?” After one doctor's visit, your aspirations and dreams for this child are now in doubt, and you would give anything for an average trajectory, rather than “greatness.”

Instead of words like “smart,” “sharp” and “social,” your new vocabulary is “dysregulated,” “delayed” and “deficits.” Instead

of gym, music and Mommy and Me classes, your new normal is special instruction, and occupational, speech and language therapy. While you are often told to enjoy every moment because “they grow up so quickly,” you can’t wait to see your child as an adult, so you can finally know that he is fine.

Soon after accepting that your child will be on a different path than you had hoped, you and your child embark on the long journey ahead: it is unique to you and your child, and it will not be predictable.

At first, you are filled with fear, second guessing, confusing messages, rejection and isolation. But suddenly you kick into gear and begin to intervene and advocate for your child with all of your energy. You arrange for a full battery of services and supports for your child.

Then something happens. It could be as simple as fitting a puzzle piece into its proper place or stringing together a few words to form a sentence. Your whole world changes. And these turning points help you to understand that greatness comes in different forms.

Evaluations: Only Snapshots

Most families begin their journey with an evaluation provided by a developmental pediatrician or a neuropsychologist. As informative and valuable as these evaluations are, they can also be somewhat limiting as they only represent a snapshot in a child’s development. As your child grows, you need to update this testing every two to three years, and also when contemplating a school change, in order to continue to confirm the continuing accuracy of the evaluation and to assess the effectiveness of the services and supports being applied.

So, what happens in between evaluations?

Preschool Options

There are a number of preschool options to consider, depending on your child’s needs. They range from center-based preschools, where children with developmental delays receive appropriate services in a self-contained school; to integrated settings, where

children with an Individual Education Plan (IEP) learn and play together with “mainstream” children within the same class setting; to “mainstream” preschools that welcome the support of a Special Education Itinerant Teacher (SEIT), as well as other appropriate services for your child.

Preschool is an opportunity to play, and to develop language, socialization and classroom-readiness skills. The selection of an appropriate preschool depends a good amount on your child’s emerging communication, self-help, social and self-regulation skills, as well as his ability to function independently. It is also important to consider other key factors: class and school size, the frequency of schedule changes, whether a school is a SEIT-friendly environment, and the flexibility of the staff to meaningfully include your child and offer additional attention and support.

Kindergarten and Beyond

As your child progresses to kindergarten and beyond, you are again faced with a number of options: public or private, day or boarding, as well as special needs, mainstream or integrated environments.

Updating testing at this juncture will assist you to identify your child’s current abilities and needs, as well as to understand which type of school setting and supports would be most helpful for him.

The Road Ahead

While you travel on this long journey, it is important to remember certain guiding principles:

- Provide your child with support as early as possible—studies show that early intervention can result in significant advancement in a child’s development. But balance these services with opportunities for your child to play and have fun.
- Understand that certain behaviors may be engaged in by all children and may not be indicative of a developmental concern.(He may be wiggling in his seat just because he is a 3-year-old.)
- Engage in honest conversations with potential schools,

explaining what your child needs in order to be successful—this will help you determine if the setting is appropriate for your child.

- Periodically monitor your child’s progress. Frequent team meetings, evaluations and teacher conferences will keep everyone informed and connected—and prepared when it is time to consider a change in schools.
- When it comes to your child’s development, there is nothing to be gained from shame or blame, and there is certainly no room for complacency. Connect with other parents and professionals through support groups and informational gatherings.
- Stay in the moment, knowing that each day is a new opportunity for your child to grow and learn.
- While it would be wonderful to imagine that a perfect school exists where your child can remain from kindergarten through 12th grade, the reality is that your special child may need to change schools several times—each of these changes being entirely appropriate and beneficial.

Becoming a parent and ushering a child through his formative years is incredibly rewarding. But parenting a child with special needs redefines that role. You relentlessly advocate for your child, love and celebrate him, and provide him with support and services to help him to be successful. As the parent of a child with special needs, you forge a path that is unique and special.

You are nothing short of a trailblazer.

Chantal Aflalo is a special needs school advisor at Parents League of New York. Parents League school advisors are knowledgeable about programs for children with special needs, including preschools, day schools in the city and boarding schools. In addition, the Parents League holds special needs workshops that follow a support group format.