Act Early: Concerns After the Diagnosis

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ACT EARLY: CONCERNS AFTER THE DIAGNOSIS

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Act Early is a series of posts by Utah’s Act Early ambassador, taking on hard questions about early intervention.

Today’s installment examines concerns that may continue after the diagnosis.

“I don’t want my child to be labeled!”

Sometimes parents fear that a diagnosis will bring a label that somehow limits their child’s full potential. They don’t want the label to become the child’s defining characteristic. They fear their child may be teased for being “mentally retarded” or “autistic” or “handicapped.”

No parent wants their child to be reduced to a label that can only explain part of what their child is experiencing. Such labels ignore the rest of the child’s unique personality and gifts.

A parent’s concerns in this area are valid and should not be minimized or overlooked. The disadvantages associated with labels are real. It is important for parents to realize, however, that if their child has a developmental issue, it will remain, label or not. Second, a child whose behaviors fall outside of the norm may be labeled anyway, but not so kindly, such as being called “lazy”, “dumb” or “defiant.” It can be more helpful to a child if the underlying condition receives a medical or mental health label.

At its best, a diagnostic label is a guidepost to treatment and intervention services. Diagnostic categories give definition to a child’s challenges and create a pathway to effective treatment. If a provider does not know what a child has, they cannot select the appropriate treatment. Whether or not parents choose to share that “label” with others (including their child) is a separate issue.

A sometimes overlooked reason for obtaining a “label” is because sometimes services are only available if the child has received a diagnosis. Thus, the diagnosis is key for access to treatment.

“If we start medication now, we’ll never be able to stop!”

Particularly when faced with a decision to start a child on medication, there is often the fear that once a regimen is started, it will be a regimen for a lifetime. Parents are reluctant to have their child become “addicted” and may resist what they believe is a slippery slope to a lifetime of medications and adverse side effects.

Parents need to be aware this fear is a myth. It is much more likely that a medication will be tried, adjusted, and even discontinued, depending on how the child responds to that medication. If the medication does not produce the desired results, there will not be a valid reason to continue to use the medication. It is rare that a medication could not be stopped for fear of the child being harmed; however there are protocols that some medications be withdrawn more slowly than others to prevent adverse effects.

The choice to use medication involves an ongoing dialogue between parent and provider, and the choice to stop using a medication or to reduce the levels of a medication also need to be discussed with one’s provider. But starting a child on a medication is not a commitment to a lifetime regimen.

For a more complete analysis on making the decision to put a child on medication, see this exchange between a parent and physician related to starting a child on medication for Attention Deficit Disorder.
Earlier in this series:

Learning to recognize the need

When you disagree with your pediatrician

Dr. Tracy Golden is Utah’s Act Early Ambassador for the Centers for Disease Control and Prevention’s (CDC’s) “Learn the Signs. Act Early” program. Its mission is to improve early identification practices for those providing services to very young children. Golden received her Ph.D. in Social Work from the University of Utah and has a private clinical practice for teens and adults with High Functioning Autism and Asperger’s Syndrome. She is also a staff member at the CPD.