Act Early: Learning to Recognize the Need

Center for Persons With Disabilities

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ACT EARLY: LEARNING TO RECOGNIZE THE NEED

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This article is the first in a series on overcoming barriers to early intervention for young children with disabilities.

You notice as your child is developing that they do not appear to be acquiring language at the rate of your neighbor's child. Or perhaps your other children walked between 12 and 13 months, and your 16 month-old is still crawling. Even more concerning, you have a child who seems disinterested in you as a parent, not noticing when you come and go, and having little interest in playing with you.

These are the scenarios that confront parents with children who may later be diagnosed with a developmental delay or disability. These scenarios do little justice to the fear and anxiety that can grip a parent when faced with these events unfolding in their daily lives. As humans, we are generally never more vulnerable then when something threatens our own children.

Logic suggests that if we have a concern, we act early and take our concern to our pediatrician. Despite the simplicity of that suggestion, there are enormous obstacles, even when parents have the best intentions. In this article, I will review two of those obstacles and suggest strategies for overcoming them.

“He (or she) is just fine!”

When parents first have concerns, it is most natural to turn to friends and family for consultation and reality testing. Especially as new parents, it is easy to wonder whether we are neurotic first time parents about every single thing our child does or does not do. We have to remember, however, that it is just as natural for friends and family to want to reassure us.

Their well intentioned advice can lead a parent to avoid an early screening or assessment, which might have resulted in critical early intervention services. It is OK for parents to turn to family and friends, but if concerns persist, it may be more beneficial to seek out the advice of a pediatrician or speak to a child's pre-school teacher or childcare provider. These professionals may give parents more objective feedback about a child’s possible delays. A parent can also contact early intervention services, speak with professionals at their child's school district or contact their local health department for further feedback on their child's development.

“There's nothing wrong with my child!”

Perhaps the most difficult barrier to overcome in seeking early identification of a developmental delay is the parent who struggles with acknowledging that there might be a problem. Noticing that one's child is developing differently can bring up tremendous anxiety, fear and unwarranted self-blame for the parent.

In this case, those around the child such as teachers, babysitters, family and friends all seem to recognize that the child might need to be assessed, but the parent resists or denies the child's struggles. This may be prompted by fear, misunderstanding or lack of access to education and resources.

This is a tricky situation and generally produces significant stress in all those affected. Family, friends and childcare providers may be reluctant to bring up their concerns with the parents for fear of offending or alienating them. Outside observers might also fear that their hunches are invalid and might not want to offend the parent with their suggestions.
There is no right answer in this case. Friends and family will have to decide how to approach the situation, which may range from gentle, ongoing support and education to a more direct confrontation to simply leaving the matter alone.

Five suggestions that may bring about a more positive outcome include: (1) approaching a parent with empathy, (2) asking the parent first if they are open to feedback about their child, (3) focusing on tangible concerns (such as underdeveloped speech or frequent meltdowns) rather than suggesting a “diagnosis” (4) sharing similar challenges you may have had with your own child; and (5) providing resources on developmental milestones so the parent can be empowered to make their own decision.

Regardless of approach, friends and family need to be prepared for a possible negative reaction from the parents and must realize the parent will need continued support if they begin to acknowledge and address their child’s delays.

Coming up:
How to resolve disagreements with a pediatrician about acting early
Concerns that may linger after the diagnosis

Dr. Tracy Golden

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.

Additional resources:

Utah Act Early webpage
Early Childhood News article: What do I say to parents when I am worried about their child?
Utah’s Baby Watch webpage
Directory of Utah School Districts
Directory of Utah’s Local Health Departments