

My name is Laura DeAngelo. I am the parent of a child on the autism spectrum. I am also an RDI® Program Certified Consultant and an educational advocate for parents of children with autism and other disabilities. I own and operate a business called Autism Family Services, LLC located in Avon.

The topic I would like to speak to you about today is choice in autism interventions for families served by the Department of Children and Families Voluntary Services Program. Currently, the DCF Voluntary Services Program provides services for children with autism, if the child also has “an emotional, behavioral or substance abuse disorder and the alleviation of such is the primary purpose of the request for voluntary services.”

The service model that is typically employed by Voluntary Services for children with autism is a direct therapy model; that is, therapists work directly with the child to address the problem areas using an approach widely used in autism treatment, Applied Behavior Analysis. Applied Behavior Analysis, or ABA, has been used as an autism therapy since the 1960’s, and research on this type of intervention is plentiful. There is a consensus in the research that this method is effective for many children in teaching particular skills, such as academic skills or language. However, research on ABA does not show consistently positive outcomes from this method in the areas of behavior and emotional control, social competence, and long-term quality of life for individuals with autism. The Interactive Autism Network, a web project of the Kennedy Krieger Institute sponsored by Autism Speaks, says this about ABA:

Many studies have shown that ABA and similar behavioral interventions can improve intelligence test scores, language skills, and academic performance of young children with ASD. Some studies have also shown some measure of improvement in behavior or personal and social skills, while others have not. One issue has been *generalization* --that is, there has not been much evidence to show that children can transfer the skills they have learned through behavioral interventions to contexts outside the setting in which skills are acquired.

In my experience, I have seen some children for whom behavioral approaches have worked in reducing problem behaviors associated with autism. I have seen others for whom behavioral approaches did not work. I work with families of some of these children.

A second shortcoming of the ABA approach to autism therapy is the service intensity required to achieve significant results. In the two studies that resulted in the “best” outcomes, the children received at least thirty hours per week of ABA therapy. To implement such an intensive program, the cost often can exceed \$50,000 per year per child.

In addition, the frequent presence of outside interventionists in the child’s home, such as occurs with the DCF voluntary services direct therapy model, can be disruptive to family life. I can relate to this issue personally. We had a home ABA program briefly through Birth to Three, before my son aged out of the program. I can remember how much our family life was disrupted by having a therapist in my home every afternoon.

And where does such an approach to therapy leave the parents? It is challenging, to say the least, to parent a child with autism. While parenting a “typical” child comes naturally to most parents, parenting a child with the severe emotional and behavioral challenges that characterize autism does not. It is critical that parents learn the skills to parent their children child with autism effectively, in a manner that will help the child to arrive at his or her full potential as a human being, a contributing member of society with a good quality of life.

I know that I felt incompetent to deal with my own child’s out-of-control behaviors, and the dependence I felt on others to help my child did nothing for my confidence. I have worked with a number of parents who echo the same sentiment. They do not know how to parent their child with autism. They are not sure how to set appropriate limits. They don’t know how to interact or communicate with their child in a way that helps him overcome his challenges. They often feel a sense of failure as parents, and they have lost hope that their child will have a positive future. They have lost the joy of parenting.

In this current economic climate, the state’s financial resources available to assist children with autism are limited. Meanwhile, the number of children with autism eligible for state-funded services continues to increase. Clearly, DCF should emphasize autism treatment protocols that:

- Are efficient in use of resources for treatment.
- Are effective in reducing or eliminating the emotional or behavioral issues associated with the autism, so that the family does not have a long-term dependence on the services.
- Contain a strong parent education component to empower parents and teach them how to control and manage their child’s behaviors themselves.
- Target remediation of the core disability to maximize the child’s long-term prospect for a quality of life, not just offer a “band aid” approach.

There is such a program available. Relationship Development Intervention® or RDI® is a trademarked program of autism intervention developed by psychologist Steven Gutstein, after he found himself dissatisfied with the results he was getting through the behavioral approaches he had been using with his clients. RDI® is a parent-centered, home-based approach that targets the core neurologic deficit areas of autism that underlie the problem behaviors. As the core issues of the autism are addressed by the parents in their everyday interactions with the child, the problem behaviors are targeted at the root. The RDI® program is more than a behavior plan for the child. It is a program that has the potential to transform family functioning. Parents learn how to parent effectively based on their child’s unique needs. Through the parents’ guidance, the child gains competence in dealing with the constantly changing world and relationships around him.

RDI® Programs involve a very specific training protocol for parents and specific developmental objectives for children. RDI® Programs are available only through RDI® Program Certified Consultants. All certified consultants have received intensive and rigorous training in administering RDI® Programs. There are currently six RDI® Program Certified Consultants in Connecticut.

The RDI® Program offers a number of benefits over the direct-therapy model, including:

1. Significant cost savings to the system. Service intensity for an RDI program over the course of a typical two-year program averages two hours per week, compared with the much higher intensity

levels that can last several years for traditional direct therapy services delivered to voluntary services families.

2. Emphasis on parent ownership of the process and parent delivery of the therapy
3. A focus on remediating the core issues behind the behaviors, normalizing family life, and creating a long-term quality of life for the child and the family.

How successful is RDI® in addressing problem behaviors in autism? In our personal situation, the program has made a significant difference for our son. Through this program he overcame bolting, wandering, and aggressive behaviors. He developed the ability to socially communicate. He developed empathy. Our family life was normalized. We learned how to interact, communicate with, and parent our child in ways that helped to develop his mind, not just produce behaviors.

Significantly, my son's diagnosis category has changed since we implemented this program. My son's original diagnosis was autism disorder, the most severe category on the autism spectrum. On the most recent triennial evaluation for our school, after about one year of RDI®, he tested with very mild autism, receiving a score of 27.5 on the Childhood Autism Rating Scale.

I have worked with a number of parents who have had success with RDI® after behavioral methods have not been effective. With my clients, I have seen the program make a difference in bolting and wandering behaviors, the need for control, social communication, and willingness to seek parents out for guidance. I have corresponded with numerous parents for whom this program has been effective, including several parents here in Connecticut.

Unfortunately, not many parents are aware that this intervention option exists. Currently, RDI® Programs are offered only on a limited basis, in some DCF regions, and then only when specifically requested by parents or when behavior programs are found to be ineffective after a long period.

Here is what one parent says about RDI®:

"Before RDI, I was a caregiver. It was lonely, exhausting and non-fulfilling. I was giving 110% and I got nothing in return. My child was 7 1/2 years old, didn't speak, wouldn't eat but 5 things, wore pull-ups and had the official diagnosis of moderate to severe autism and mental retardation. I would sit and watch him hit himself in the head and he would come home with marks on his arms where he'd bit the blood out of himself at school. He couldn't handle change....He was getting too big for me to physically control... I was crying about the situation most of the time. It was tough. RDI came along....my life changed....I became a parent instead of a caregiver. It is fun, rewarding and engaging... We are a typical family now. We can go shopping with no fears of losing our child. He...will eat almost anything now. We are able to try new things...without a meltdown...My child no longer stims. He doesn't hit himself in the head and hasn't bitten himself in years. My child appropriately orientates himself to communicate... We are able to tell jokes and he truly gets them... What RDI has given to me...is nothing short of the second chance to have a really good life. There are no words to describe what that feels like."

All parents of children with autism who are approved for DCF Voluntary Services should be provided with information about RDI® and should be encouraged to explore it, either in place of ABA-based services, or as part of a long term service plan that includes phasing out such direct therapy services.