

# The Infant and Toddler Pilot Project: An Update

Mike Stolte

*A shorter version of this article originally appeared in the Winter 2010 issue of Autism Now*

Last winter (2009) I wrote an article introducing the Infant and Toddler Pilot Project to the readership of Autism Now. This project is funded by Family Support for Children with Disabilities (FSCD) and implemented by the Centre for Autism Services Alberta. The Centre is a non-profit organization that has been providing comprehensive supports to children and families that have been impacted by autism for over 10 years in the Edmonton region, and currently offers a wide array of child focused, specialized and Program Unit Funding (PUF) supports.

## **History of the Project**

In early 2008, the Centre was approached by FSCD to develop a model of intervention for newly diagnosed infant and toddlers with Autism Spectrum Disorder (ASD). This was due in part to the decreasing age of diagnosis (as low as 18 months in some cases), as well as the increased diagnostic skill developing at the Glenrose Hospital and the arrival of the Autism Center of Excellence to Edmonton. In consultation with numerous professionals involved in autism treatment and support, along with an extensive literature review, the following elements were highlighted as integral to the program. More detailed information on guidelines / best practices are available in the reference list in the online version of this document, available at **ADDRESS**.

Here are the highlights:

- Parents and children benefit from having parents involved at the centre of all early intervention, and on-going parent training is required to make that successful. This is particularly important for newly-diagnosed younger children as parents adjust to the diagnosis, and intervention is more focused on the parent-child dyad, rather than just the child.
- Early intervention is better, though intervention can be effective at any age. Intervention is recommended as soon as an ASD is suspected (not necessarily confirmed as a diagnosis).
- Intervention is ideally led by a multi-disciplinary team of individuals with expertise in the area of autism and who are, optimally, collaborative in practice.
- Intervention must be based on established rehabilitative practices, and must utilize the latest research in established best practices for autism intervention.
- Intervention must be age-appropriate, provided in digestible “chunks” based on what a child can manage, and must not overly interfere with a child’s ability to participate in the daily flow of life. At the same time, it is necessary to provide a sufficient level of intensity to make a difference. The intervention should be structured, occur across multiple settings, and involve daily individualized attention from an adult.

- Intervention should be fun, as play-based as possible, be developmentally appropriate, and focus on specific goals that will increase child skills, decrease behavioral rigidities, and increase overall family life satisfaction
- There should be regular opportunities for the child to engage with typically developing peers, ideally out in the community.

### **Program Launch**

The pilot project was officially launched in September 2008. By February 2009 the program was full, with 10 children and their families enrolled. Detailed data was collected on all of the families pre- and post-intervention to assess the effectiveness of the intervention. The model consisted of parent training, in-home modeling of skills, play-based inclusion opportunities in the community, bi-weekly professional consultation, and behavioural aide supports to maximize intensity beyond immediate parental availability. All program decisions and structure sought to match the ideals in best practices identified above.

The parent training component was extensive and included:

- An Introduction to Autism (diagnostics, history of the condition, what it is and isn't, best practices for intervention, 1 evening)
- An Introduction to Pivotal Response Treatment (PRT, 3 evenings). PRT is a naturalistic, play-based strategy that is a form of contemporary applied behavior analysis (ABA).
- Completion of the Hanen "More than Words" program (MTW, 8 evenings). MTW is a formalized parent training course designed by the Hanen Centre for caregivers of children with autism. The course focuses on training parents to maximize communication opportunities with their child on a daily basis, thus improving interactions with their child and building receptive and expressive language skills. Each lesson concentrates on a different skill. The program is led by a specially trained speech pathologist. There are also three home visits included in the course in which the parents are video-taped interacting with their child while doing specific tasks. The parent(s) then watch the tape and help to make suggestions on how to improve their interactions with their child.
- In-home modeling and mentoring of skills by a multi-disciplinary team that consisted of a behavioural specialist, occupational therapist, speech-language pathologist and specially trained behavioural aides.

In addition to the above, a team of highly trained behavioral aides worked one-to-one with the child, providing play-based, behavioral intervention in both the home and community for up to 9 hours per week. Specific hours varied from child to child: some children had minimal aide involvement (as parents wanted to provide almost all of the intervention), while others had more aide support. The aides also assisted the children in becoming included in community based play groups with other children, and also provided "hands on" mentoring to parents of skills being learned in the evening sessions and home visits by the professionals.

## **Program Outcomes – Child Measures**

In order to evaluate the program, all of the children were administered a battery of standardized tests and questionnaires at both intake and discharge. Parents were also given feedback evaluation forms at the end of the program to assist the program in identifying what parents found most beneficial and what they would like to see changed. At the time of this summary, seven of the ten children had been discharged, so only the general results will be reported.

The overall results indicated that all of the children made broad based gains in adaptive skill, most of the parents reported learning new skills to work with their children, and all of the children had a positive increase in their ability to functionally communicate with others. That being said, the gains varied widely depending on the specific child and their family situation. As an example of the variance, I have highlighted some of the observations made in communication, social skills, self help skills, sleeping and feeding concerns, and anxiety. Additional areas that are not summarized below involve increased behavioral flexibility, play skills, and motor development.

Two children went from being primarily non-verbal to engaging in full-fledged spontaneous speech, utilizing appropriate phrases and questions, whereas three others had a much slower acquisition of language, learning new words and phrases supplemented by a communication system such as PECS. The remaining two children made gains in language, but due to on-going family circumstances it was difficult to evaluate how much of an impact the overall program made on the children's gains per se.

Regarding self-help skills, six of the seven children had difficulties with feeding that needed to be addressed. Two of the children were only able to take in liquids or purees, and the remaining four had excessive food rigidities, only tolerating specific foods or displayed high rigidity around their foods. Systematic desensitization, a strategy based on slowly exposing the children to anxiety inducing stimuli, coupled with sensory based coping strategies and positive praise, was the primary means of addressing these concerns. All of the children responded positively to this style of intervention, though again the gains varied widely depending on the child and his/her family.

Sleep was another widespread concern by the families, with four of the seven families reporting difficulty in this area. Feedback was provided in stabilizing sleep schedules, using behavioral strategies to reinforce positive behavior, decreasing napping time, and ensuring that positive sleep hygiene strategies were followed. Again, all of the children did respond positively to the sleep based interventions, though some more successfully than others.

Separation anxiety was another concern. Many of the children had never been separated from one of their caregivers and this was an initial goal for many of the families. One child's separation anxiety was so severe, he would begin to bite, scream

and hit those around him even when the parent just went to the washroom. As with the feeding skills, systematic desensitization was a dominant strategy, slowly exposing the child to additional caregivers and teaching them alternate coping strategies. Parents also required support in learning not to “give in” to their child’s escalating demands, and to provide praise and attention at alternate times. Overall, once positive expectations were put in place, along with specific strategies, all of the children responded quite positively and many of these aggressive behaviors decreased.

### **Program Outcomes – Family Measures**

The majority of the families participated in all aspects of the training provided, with one family having to withdraw from much of the parent training due to extenuating personal circumstances. Of those families that did participate, all of them displayed additional skill in maximizing communication opportunities with their children, modifying language and environment to ensure communication occurred, and demonstrated increased understanding of applying behavioral principles in order to shape their child’s behavior. Additionally, they also got to know and socialize with other parents going through the same experience, gained awareness of autism intervention and best practices, and perhaps most importantly, they had **a lot of fun** with their children during the intervention period!

Though most parents initially found quite intimidating to be videotaped and given feedback from a group of professionals, they soon became accustomed to it and found the experience to be beneficial. As one parent outlined in the feedback forms, the parent training/mentoring “has greatly changed the way we interact with our child and also how our child interacts with us”. Overall, of those parents that participated fully, they reported a general increase in overall confidence and skills in working with their children.

### **Lessons Learned / Looking Forward**

At the end of our first year of delivery in this model, we have learned a number of key lessons about the benefits and drawbacks of this model of service delivery. Primarily, for the family, the drawbacks included the time commitments required, the additional stress of working with a team of professionals, some of the ambiguities involved in a pilot, the difficulties in finding inclusion placements in the community, and coming to terms with the reality of the diagnosis. The primary benefits for the children included an overall increase in their ability to communicate, increased social and play skills, improved feeding and sleeping, and a general increase in behavioral flexibility. The primary benefits for the parents were the opportunity to get together with other parents facing the same challenges, and an increase in their skills and confidence in playing with and parenting their children.

For the clinical team, we found it very rewarding to work so intimately with these families, but also found it difficult to ensure we weren’t being overly intrusive in the family’s lives, were appropriately matching their energy and availability, were

maintaining reasonable expectations for the families, and were supportive at the appropriate times, in a reasonable manner. However, the personal benefits far outweighed any of these negatives and we felt privileged to be so intimately involved in these family's lives.

We are deeply appreciative and respectful of all the families that have participated in the project thus far, as well as the foresight and financial support of FSCD for supporting this project. We are also thankful for the research relationship that has been established with Dr. Veronica Smith of the University of Alberta, who is independently examining interactions between many of the parents and their children utilizing digital language processing technology.

Looking forward, we have decided to expand the program to 12 children for this upcoming year. We will have a rolling intake throughout the year, have added a workshop on sensory processing, and will look at generalizing the program to other children and families that might benefit from this type of format. If you have any additional questions on the pilot project, please contact Mr. Michael Stolte, Clinical Director / Registered Psychologist (AB) at 780-488-6600 ext. 234 or [mstolte@centreforautism.ab.ca](mailto:mstolte@centreforautism.ab.ca).

Bryson, S.E., Koegel, L., Koegel, R., Openden, D., Smith, I., & Nefdt, N. (2007). Large Scale Dissemination and Community Implementation of Pivotal Response Treatment: Program Description and Preliminary Data, *Research & Practice for Persons with Severe Disabilities*, 32(2), 142-143

Chawarska, K., Klin, A., & Volkmar, F. (Eds., 2008), *Autism Spectrum Disorders in Infants and Toddlers: Diagnosis, Assessment and Treatment*, New York, NY: The Guilford Press.

Koegel, R., Schreibman, L., et al (1989). *How to Teach Pivotal Behaviors to Children with Autism: A Training Manual*, Santa Barbara, CA: University of California.

National Research Council. (2001). *Educating Children with Autism*. Washington, DC: National Academic Press.

O'Brien, M. & Daggett, J.A. (2006). *Beyond the Autism Diagnosis: A Professional's Guide to Helping Families*. Baltimore, Maryland: Paul H. Brookes Publishing Co.

Simpson, R., de Boer-Ott, S., et al. (2005). *Autism spectrum disorders: Interventions and treatments for children and youth*. Thousand Oaks, CA: Corwin Press.

Stolte, M. (2009). Infants and Toddlers with Autism: An Intervention Pilot Project, *Autism Now*, 21(4), Edmonton, AB: Autism Society of Edmonton.

Sussman, F. (1999). *More Than Words: Helping Parents Promote Communication and Social Skills in Children with Autism Spectrum Disorder*. Toronto, ON: The Hanen Centre.

Vismara, L.A. (2008). *The Early Start Denver Model Parent Coaching Program*, The 2<sup>nd</sup> International Conference, Signs of Autism in Infants: Changing Outcomes through Early Identification and Intervention, Yorba Linda, CA: Child Development Media, Inc.

Volkmar, F., Rhea, P., Klin, A. & Cohen, D. (Eds., 2005), *Handbook of Autism and Pervasive Developmental Disorders*, Hoboken, New Jersey: John Wiley & Sons, Inc..