

Program Recommendations for Children Diagnosed with Autism Spectrum Disorder

June 16, 2014

Introduction

This document has been prepared by ADAPT (the Association for Developmental Autism Programs and Therapies), a group consisting of both parents of children diagnosed with autism spectrum disorder (ASD) and concerned professionals. The goal of the group is to inform and advocate for greater choices within the current structure of family and school programs - with a particular focus on therapies based in developmental psychology. Developmental therapies for the purpose of this document include Developmental Individual Differences® (DIR/Floortime) and Relationship Development Intervention® (RDI). In Winnipeg, the Autism Outreach program follows the DIR model and the Relate program follows the RDI model.

About Developmental Therapies

“Developmental therapies are intended to directly address autism's core deficits. To achieve this goal, they recommend that therapists and parents work with the child's own interests or actions to slowly build engagement, interaction, communication, affection, and then specific skills such as logical reasoning, symbolic thinking and more. It's important to note that developmental therapies are extremely child-oriented, which means that there is no one-size-fits-all approach. In addition, they demand a great deal from parents. Developers of these therapies see the family as the key to an autistic child's development, and they want to see parents take on the lion's share of actual, day-to-day intervention.”¹

From the description of developmental therapies above, it is clear that this approach represents “**family-centered service**”, which was recently described by Dr. Peter Rosenbaum (CanChild Centre for Childhood Disability Research) during his speaking engagement in Winnipeg. At the core of family-centered service is the recognition that the family is the constant in a child's life - therefore, the service is built upon partnership between parents and professionals.

Another term that fits with developmental therapies is “**client self-management**”. This is the ability of the client and his/her family to collaborate with professionals in order to make informed decisions about the challenges associated with their diagnosis. There is a growing body of research on developmental therapies, as well as the childhood attachment principles upon which they are based.

1. about.com - <http://autism.about.com/od/treatmentoptions/a/devtherapies.htm>

Recommendations for Enhancing Service

Like the developmental therapies approach itself, solutions to the needs and gaps in service are not “one size fits all”. Our recommendations span the scopes of several Ministerial portfolios, including:

- Department of Family Services
- Department of Education and Advanced Learning
- Department of Health, Healthy Living and Seniors

Through combining the resources of all three departments, the positive changes proposed in this document can be realized.

This document focuses on four main stages where families need support, and where change will be most effective: Time of Diagnosis, Transition to Preschool, Transition to School, and School Age Diagnosis.

I. Time of Diagnosis

What’s Going Well

- Let’s Get Started Program (based out of the Child Development Clinic, Health Sciences Centre) – for children and families newly diagnosed.
- Autism Outreach (offered by Manitoba Family Services and Consumer Affairs) Children are eligible until they enter Kindergarten. They offer an evening series on autism and parenting, and a one-day Floortime® training session.
- The Relate Program (Rehabilitation Centre for Children) offers a 7-week evening parenting seminar to introduce ideas and strategies for promoting their child’s development.
- Hanen Training for Speech-Language Pathologists (with the understanding that those being trained will be offering parent seminars – as explained in a meeting with T. Moore).
- Parent Support Groups (Manitoba Families for Floortime®, Autism Society Manitoba, RDI® parent support group, etc)

Greatest Needs/Gaps

- Most parents have no idea what "autism" means for their child, but they do know the importance of early intervention. Accurate information regarding implications, prognosis and available services and supports is crucial.
- Lengthy wait-lists for support and therapy are frustrating. Any wait time for the introductory supports (Let’s Get Started, CSW worker, SMD Outreach) is unacceptable. Current wait times:
 - Let’s Get Started (5 months),
 - Children’s disAbility Services worker (2-3 years),
 - SMD Outreach - Speech/Occupational/Physical Therapy (8+ months),
 - Child Development Counselor (6+ months)

Recommendations:

1. At the time of diagnosis, parents need:

- Reassurance about their child's future - information about the possible range of abilities and outcomes should be balanced with empathy and hope.
- Basic information and parenting tips - given the wait-lists for parent training and child therapy.
- Access to professionally-led seminars – possibly provided through the support of a Child Development Counselor or Children's disAbility Services. Private therapists might also be encouraged to partner on this – eg: SpeechWorks has offered such support. Offering contact with a parent volunteer/mentor or inviting a seasoned parent to speak would also be helpful.
- A "self-help" website outlining: services available, information about professionals and programs, the philosophical basis of different interventions, how the process works [ie referral → assessment → children's disAbility → j intervention], estimated wait times, stop-gap programs, support group links, social media support, events and seminars, etc).
- Information regarding the complete range of interventions available - including developmental therapies, occupational therapy, physiotherapy, speech and language therapy – and the process for registering for such services. Include options for on-line parent training – eg: DIR Parent Course

2. "Let's Get Started"

- Needs to begin as soon after diagnosis as possible - Building capacity of parents through hands-on training. Parents getting educated and feeling supported is key.
- Fundamentals of a developmental program should be explained in a child- and parent-friendly manner:
 - suggest no one-way mirrors
 - therapist should coach and support parent directly (feedback, not evaluation)
 - Drop-in program at set times (eg MWF 9-1), rather than setting three 1-hour appointments.

3. Offer Group Support

- Offer drop-in/support groups where resource information is shared, similar to Let's Get Started but at a community level.
- For example, offer group play times with a single child development counselor or occupational therapist to provide feedback and suggestions; this can double as a support group for the families. Use community drop-in play programs as inclusive locations, or more clinical locations like the play area at the Rehabilitation Centre for Children.
- Liason with university practicum programs: To help provide more support but keep costs down, in addition to a fully-trained coordinator, students (eg: pediatrics, education, disability services) could be enlisted to volunteer "staff" the sessions, which could result in more people being trained as support workers.

4. Equip Daycares and Nursery Schools
 - Ensure training in developmental therapies is part of the education process for early childhood care providers. This will provide support for children with potentially emergent issues, as well as children already diagnosed.
 - Provide an option for children with special needs, such as Autism, to be fast-tracked to attend a day care facility where staff have developmental training.
 - Create a pilot project with perhaps 5 daycares to meet the needs of children with developmental disorders; Seven Oaks is already working from a developmental perspective and could be a model or perhaps spearhead the effort.
5. Shorten wait times for support services. As said above, any wait time for the introductory supports (Let's Get Started, CSW worker, SMD Outreach) is unacceptable.
 - Parents who are on wait lists for intensive therapy (Autism Outreach, Relate) need access to supports so they can implement what they learn while they wait.
 - Parenting seminars such as the ones offered by Autism Outreach (currently open only to families actively enrolled in the program) and Relate (open to any interested families)
 - Parent support groups, which provide information from parents already in intervention programs. Sharing of strategies may be beneficial to those who are feeling helpless. Information about existing parent support groups can be made available.

II. Transition to Preschool

What's Going Well

Several programs work together to meet the needs of young children with autism. The staff implementing these programs represent a significant pool of experience, training and expertise, and should be considered as experts in their fields, with the potential to bring about innovative change:

- Child Development Counselors,
- Family Service Workers,
- POTC (Provincial Outreach Therapy for Children) for speech, occupational, and physical therapy,
- Autism Outreach (JoAnne Sobczak and Andrew Robson)
- Relate Program at the Rehabilitation Centre for Children (Lianne Belton and Stephannie Motuz)

Greatest Needs/Gaps

- The many service providers supporting children with autism is very confusing for parents. It is hard to know whom to seek out for support and who is responsible for what. There are many organizational and professional titles to understand.
- The wait lists for all early childhood autism services are so long that many children are being missed, or given ineffectively short terms of service.
 - Autism Outreach (10+ months),

- Relate Program (6+ months).
- Frequency of family visits: Twice per month works well; once a month or less isn't sufficient.
- Program quality assurance and accountability:
 - There should be a strategy in place to measure how well and in what ways each child is progressing, and whether the program is effective for that child.
 - It should be possible to switch programs, if parents or professionals feel the child's program isn't a good fit.
 - Parents should also have a way to measure their own learning. For example, a journal or a list of goals for parent strategies can be helpful (as provided in the Relate program).

Recommendations:

1. Expand the Autism Outreach and Relate programs to reduce the wait list to no more than six months, and accommodate monthly appointments (at a minimum). Feedback from parents has been that visits are not frequent enough to assist in a positive way with changes (resource needs, emerging developmental issues, continued skill development, etc).
2. Offer optional home or clinic visits – clinic appointments may facilitate serving a greater number of clients.
3. Developmental therapy training for daycare workers (see *Equip Daycares and Nursery Schools* in Section I).
4. Require daycare/nursery staff to collaborate with Family Services staff as a condition of inclusion funding.
5. Review effective service models in other places:
 - PLAY Project in Ann Arbor, Michigan (www.playproject.org)
 - Dr. Shanker's research project at York University (www.mehri.ca/research.html)
6. Analyze what has been effective locally:
 - Relate Program at RCC
 - Previous structure of Autism Outreach and SMD: It is our understanding that Autism Outreach and SMD services were once more extensive; what has been lost?

III. Transition to School

What's Going Well

- Growing networks among teachers:
 - Brent Epp's seminar series
 - Manitoba Families for Floortime TeachMeets
 - Manitoba Alliance for Universal Design for Learning

Greatest Needs/Gaps

- Children continue to grow and develop, but with Autism Outreach service ending during the Kindergarten year, parents feel abandoned.
 - The transition from early intervention to education support programs is neither smooth nor consistent.
 - Parents must “start over” with professionals who don’t know their background, and often find a separation between home needs and school needs

Recommendations:

1. Extend Child Development Counselor’s follow-up to the end of grade 1 or longer- to assist with the transition to school.
2. Extend Autism Outreach follow-up to grade 5:
 - School visits 3x/yr;
 - Home visits/appointment 2x/yr.
 - Staff available for advice in emergencies.
 - More training for school staff (teachers, educational assistants) - invite teachers, resource teachers and educational assistants to Autism Outreach seminars.
3. Increase Speech, OT, PT support in the schools. Incorporate the therapy of choice whenever possible into the school day.
4. Provide appropriate funding for students on the autism spectrum to ensure the guidance they need in their daily routines.
5. Base school support funding on program needs. If Autism Outreach recommends that a child needs support throughout the day, funding should be available to support that programming.
 - There is something strange about Level 2 and 3 funding: ABA children generally get level 3; few children from Autism Outreach do. In fact, some are finding it hard to get level 2. This places a much heavier burden on schools running an intensive program if their students are from Autism Outreach rather than ABA. And some ABA children do not require the level of support they are getting. This disproportionate funding means some children who really need it in fact do not receive it. This is not a reflection of the level of functioning of children in each program - ie: there are children with milder and more severe forms of autism in both programs.
6. In the case of insufficient funding for educational support staff, parents should have the option to donate money to the school for that purpose.

IV. School Age Diagnosis

What’s Going Well

For Teachers:

- Brent Epp is spearheading some training/networking efforts.
- Manitoba Families for Floortime is working on developing a network for teachers working with Autism Outreach and similar approaches.

For Parents:

- The Relate Program opens their workshops to parents whose children received later diagnosis (about 10 families over the past year). Unfortunately, many whose children are able to speak, are ineligible for follow-up in the program.

Greatest Needs/Gaps

- A significant gap exists for those parents who were not part of the Early Intervention structure. Current programs (eg: Autism Outreach) focus on families whose child received early diagnosis, and are unavailable to those who received a later diagnosis.
- The wait-list to access a Children's disAbility Services Worker, means that families are left unsupported for a considerable time.
- MATC offers short-term consult to address a specific issue – and is not structured as a generalized parent support, with general training and long-term follow-up options. Professionals at MATC are seeking to learn more about developmental therapies (however, they are limited in their ability to help families apply developmental principles by the program capability and the goals of the program).
- School personnel have varying levels of experience, support and expertise in working with children and families affected by Autism. Often, there is a patchwork of developmental and behavioural approaches being used – which can become an ongoing struggle for parents who desire a consistent developmental approach for their child.

Recommendations:

1. Wait List Support:
 - Initial triage of families and their needs by a CDS "intake worker" - *with appropriate informational support and possible fast-track for service*
 - Periodic meetings or "check-ins" with someone while you are on the CDS wait list, to evaluate short-term needs *and suggest strategies*
2. Open preschool autism training sessions to parents of children diagnosed at school-age, or create sessions specifically for them.
3. Expand Autism Outreach Program to accommodate (at a minimum) short-term consults to school-age children and families.
4. Supports should be strength-based; even if a consultation is meant to work on deficits, there should be a focus on recognizing and strengthening a child's abilities.

Appendix

<http://jerobison.blogspot.ca/2014/05/rethinking-education-can-autistic.html>

Starting Early, Starting Strong: Manitoba's Early Child Development Framework

<http://www.gov.mb.ca/cyo/sess.html> (Also consider video highlighting the importance of equipping adult caregivers.)

Rosenbaun P, King S, Law M, King G, Evans J, (1998) Family Centred Service: A Conceptual Framework and Research Review, The Haworth Press Inc.