

# ABA Services and Supports for Children and Youth (aged 9-18), Central West Region

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## Cycle One Executive Report

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## Executive Summary

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This report summarizes the results of the first evaluation cycle (October 2013-March 2014) for the Applied Behaviour Analysis services for children and youth (aged 9-18) in the Central West Region. The lead partner for this program is Kerry's Place Autism Services (KPAS). KPAS works collaboratively with: Community Living North Halton (CLNH), Peel Behavioural Services (PBS), Reach Out Centre for Kids (ROCK), Sunbeam Residential Development Centre (SRDC), and Canadian Mental Health Association Waterloo Wellington Dufferin (CHMA).

An ABA program logic model was created to explain the continuum of service. The process starts with intake/referral, followed by service planning, ABA service delivery, and discharge and interfacing. A child/youth and their family may go through the process as multiple times before they reach the age of 18. System-level activities are also undertaken with KPAS partnership and external agencies.

Both quantitative and qualitative methods were used for this evaluation. The quantitative methods included the ABA roll-up (including the Goal Attainment Scale (GAS), the Child and Adolescent Needs and Strengths (CANS), the consumer feedback survey, and the Central West Region (CWR) Applied Behavioral Analysis (ABA) Services-Intake Management. Qualitative methods included focus groups with families, focus groups with staff, and key informant interviews.

Evaluation findings were categorized under the following headings: implementation, outcomes, and future directions.

**Implementation:** In general, most children/youth who apply to the program are eligible for services. As such, there are many families within the system. At any point in time, more children/youth are on the waitlist than in services. KPAS (which has centres in all the regions) takes in the highest number of children/youth overall, followed by PBS. The majority of families receiving or waiting for services live in the Peel region. For children aged 9-18, social skills and behavioural/emotional regulation are of most importance. In addition, most families prefer to have individual sessions instead of group sessions.

Overall, the vast majority of parents/caregivers who participated in the ABA program expressed a high satisfaction and appreciation for the service. The accessibility of the program to the wide spectrum of ASD children/youth, and the dedication of ABA consultants to the clients' learning process are considered key strengths of the program. Other program strengths included:

- For intake, parents appreciated the minimal requirements for eligibility. They also appreciated that services are available to children up to the age of 18.
- Parents/guardians appreciated the one goal planning and the flexibility to change the goal when new behaviours arise.

- Parents appreciated the in-home consultations. It allowed the child/youth to learn in a natural setting and provided an opportunity for the parent/guardian to observe and learn techniques.
- Parents/guardians appreciated the social skills groups because they felt that the children/youth were well matched. They also found it to be a safe environment for their child/youth.
- Many of the parents/guardians had positive things to say about the ABA Consultants. When the child/youth and the ABA consultant were matched perfectly, the program was very successful.
- Parents/guardians appreciated that information was presented in a clear and easy to follow format and that staff were available to answer questions.
- The ABA roll-up was seen as an excellent way to track information.
- At a system-level, there was agreement that communication lines between agencies are quite strong and the various committee meetings were considered valuable spaces to share and exchange knowledge.

While high satisfaction was reported with the ABA program, program stakeholders still identified a wide range of challenges with program implementation that curtail long-term outcomes for children/youth and their families. The main challenges identified included:

- There were limited human resources to meet Ministry set service targets.
- Some inconsistency of training and experience of ABA consultants was noted.
- Some parents felt that not enough information was provided during the intake process about the program and the active role of the family within ABA.
- Service coordination needs of many clients were neither identified nor addressed during intake. This left ABA consultants to do this work during sessions.
- If the child/youth and ABA consultant were not properly matched during intake, this led to a less successful session.
- Limiting the age to 18 left many parents/guardians concerned for the welfare of their children especially if they received a late diagnosis.
- The length of time on the waitlist was seen to as being too long, while time in sessions was seen to be too short.
- Forming social groups was sometimes a challenge due to the first-come-first-serve nature of the waitlist. Children/youth could not always be matched properly.
- There were some challenges during the goal setting process between ABA consultants and parents/guardians. Parents/guardians felt that they were not always being heard and ABA consultants felt that parents/guardians were overestimating or underestimating the abilities of the child/youth.
- ABA consultants showed some dissatisfaction with assessment tools including the Functional Assessment Interview (FAI) and the Goal Attainment Scale (GAS). They did not feel that these tools captured enough of the child/youth's abilities and successes.
- The four domain areas were not seen as sufficient enough especially when a child/youth had a dual diagnosis.
- Generalizing social skills learned within sessions to other areas of life was a problem for some parents.

- Cooperation between ABA services and the school boards was inconsistent across the Central West Region.

**Outcomes:** The evaluation found that many of the outcomes anticipated by the program were in fact being realized. This was particularly true for shorter-term outcomes and for outcomes specific to children/youth. There was also evidence for outcomes related to family and the broader system of support. However, the challenges noted above were reported to have limited the extent of program impacts, most notably longer-term outcomes. Many outcomes included:

- Overall clients experienced many positive behavioural changes.
- Goals were often reached and some clients significantly exceeded their goals. This was evident in the GAS scores and the consumer feedback survey results.
- Parents/guardians felt a greater sense of competency and confidence in supporting their child/youth. They felt they were better able to cope and could use the techniques they were taught on their own.
- However, there was some difficulty maintaining goals over the long-term.
- At the system-level, there has been stronger coordination between ASD agencies and external agencies across the Central West Region.
- Schools are increasingly more involved, yet there is inconsistency across school boards.

**Future Directions:** The evaluation data suggested improvements to various components of the program to maximize outcomes for child/youth and their families. There were three main groupings of suggestions related to: 1) children/youth and parents/caregivers, 2) ABA staff, and 3) ABA service partners. These suggestions were shared by key informants, and during ABA consultant, clinical supervisor, and family focus groups. These suggestions were considered by the evaluation steering committee in developing 14 recommendations for improving program implementation:

*Recommendation #1:* Provide a range of additional resources in multiple formats for parents/caregivers on the wait list, prioritizing the following:

- Information and orientation sessions on the ABA program, its family-centered approach, and goal setting process.
- Information and parent training on ABA principles.
- Information on other ASD-related services to help parents/caregivers navigate the system.
- Resources on behavioural management of ASD children/youth.

*Recommendation #2:* As part of the intake process, identify the service coordination needs of clients and make the necessary referrals.

*Recommendation #3:* Adjust the first-come-first-serve policy for clients in the social skill domain so that clients in each group are selected according to similar social capacities and needs.

*Recommendation #4:* Link the Child and Adolescent Needs and Strengths (CANS) to the four current domains of ABA: communication, social skills, daily living, and behavioral/emotional regulation.

*Recommendation #5:* Investigate how to incorporate an assessment tool that tracks secondary outcomes for ABA clients, in order to measure outcomes for the full range of behavioural changes that occur.

*Recommendation #6:* Explore options for including more natural settings in ABA sessions, particularly for clients in the social skill domain to support them in navigating real life situations.

*Recommendation #7:* Improve reporting mechanisms and increase parental involvement in social skill interventions to strengthen long term outcomes for participating children/youth.

*Recommendation #8:* Institute additional options for an in-person booster session one month after program completion between parents/caregivers and ABA consultants. Additional monthly follow-ups via telephone are also recommended to ensure maintenance of goals.

*Recommendation #9:* Explore developing a brief assessment tool to track the extent to which ABA goals are generalized. This quantitative tool could be administered during booster sessions.

*Recommendation #10:* Improve coordination with schools by ensuring that school administrators, staff and ASD itinerants are informed when a student is enrolled in the ABA program, and information is provided on the school's critical role in goal attainment.

*Recommendation #11:* Prepare informational materials on the ABA program to distribute to ASD, mental health and health care services, and schools. These resources should clearly outline what the program is (and is not) and how it differs in treatment from the IBI program.

*Recommendation #12:* Increase program resources to sustainably meet service targets and achieve long term outcomes for the diversity of child/youth clients and their families. Additional ABA consultants should be hired, with greater focus on male recruitment, and interpretative services enhanced in Peel Region.

*Recommendation #13:* Implement standardized staff time tracking logs across the Central West Region for all aspect of program delivery, including areas presently not being effectively tracked (e.g., service planning, booster sessions and other follow-up, travel time, and lengthened cycles for complex clients). Report the entirety of human resource needs for program implementation to the Ministry and determine ABA consultant case loads based on actual staff time required for full program delivery.

*Recommendation #14:* Implement consistent training of ABA consultants across the Central West Region, when first hired and quarterly thereafter (topics to include the application of assessment tools as well as treatment strategies for complex cases).

Based on the cycle one evaluation experience, another nine recommendations were proposed for the cycle two evaluation:

*Recommendation #1:* Revise CWR ABA Intake Management System so that it is easy to extract data on children/youth by age and year along the continuum of service.

*Recommendation #2:* Explore creating an assessment tool on other program outcomes for children/youth, in addition to GAS outcomes (see program improvements recommendation #6)

*Recommendation #3:* Explore creating a brief assessment tool on the generalization of ABA goals related to long term outcomes for children/youth and their families (see program improvements recommendation #11).

*Recommendation #4:* Adapt CANS client data so that data is reportable in relation to the four domain areas (see program improvements recommendation #5)

*Recommendation #5:* During interviews with ABA staff and parent/caregivers, collect further information on i) child/youth outcomes by specific domain area; ii) challenges of applying the ABA treatment approach to the needs of complex clients.

*Recommendation #6:* Increase the sample size of parent/caregivers, ABA staff, and key informants interviewed across the Central West Region, in order to enhance evaluation data and reporting on regional differences with respect to program implementation and outcomes.

*Recommendation #7:* Streamline coordination of family focus groups to foster greater participation by parents/caregivers. Consider holding individual interviews in addition to group interviews.

*Recommendation #8:* Conduct case studies with 3-4 families across the Central West Region to gather more in-depth data on program implementation and individual-level outcomes.

*Recommendation #9:* Assess changes in system-level outcomes based on the system-level recommendations proposed in this report.