Cycle Three Evaluation Report

April 2016

ABA Services and Supports for Children and Youth in the Central West Region
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EXECUTIVE SUMMARY

This report summarizes the results of the third evaluation cycle (April 2015 – March 2016) for the Applied Behaviour Analysis (ABA) program delivered to children and youth (ages 9-18) in the Central West Region of Ontario. The lead partner for this program is Kerry’s Place Autism Services (KPAS), in partnership with other key agencies in the region. KPAS works collaboratively with Community Living North Halton (CLNH), Reach Out Centre for Kids (ROCK), Peel Behavioural Services – Trillium Health Partners (PBS), Developmental Services Resource Centre Waterloo Region (DSRC), and the Canadian Mental Health Association Waterloo Wellington Dufferin (CMHA WWD).

This evaluation involved both quantitative and qualitative methods of data collection. Quantitative methods included the ABA roll-up (including the Goal Attainment Scale), the Consumer Feedback Survey, and the Central West Region ABA Services Intake Management. Qualitative methods included interviews with parents/caregivers (n=7), written responses from parents/caregivers (n=9), focus groups with ABA Consultants/Behaviour Therapists (n=23), a focus group with Clinical Supervisors (n=5), key informant interviews (n=8), and three in-depth case studies (n=9).

Evaluation findings were categorized under three main headings: program implementation, program outcomes, and future directions.

Program Implementation: Overall, as in previous evaluation cycles, participants expressed an appreciation for the ABA program and continue to want and need the service. In most agencies, the largest age bracket of clients served is between 11 to 14 years, followed by those aged 15 to 18 years. Most families who participate in the ABA program go back on the waitlist, in addition to new families signing up, meaning the waitlist continues to grow in all regions, with an average wait of 476 days. KPAS (which has centres in all regions) provides service to the greatest number of children/youth, followed by PBS. As in previous cycles, the majority of families eligible for ABA in the Central West Region (i.e., those in service or on the waitlist) live in Peel. Most clients who participate in ABA receive individual support (as opposed to support in a group setting), though four of the nine participating agencies are now serving over 50% of their clients in groups.

Data from Cycle Three revealed 10 key strengths of program implementation. These included:

1. Program structure (i.e., the flexible, individualized, and goal-directed approach)
2. Consistent client-consultant matching
3. The use of natural environments
4. Great staff
5. Group matching
6. Camps
7. Partnerships with schools
8. Relevant programming for teens
9. Partnerships within and across agencies serving children/youth with ASD
10. Reduced travel times
Despite these strengths, evaluation participants also identified a number of challenges, many of which were highlighted in past evaluation cycles. The 10 most significant challenges that emerged in Cycle Three are as follows:

1. Waitlist length
2. Heavy staff workloads
3. Insufficient training opportunities for staff
4. Family involvement
5. Intake and waitlist process
6. Transitions between partnerships
7. Deferrals
8. Working with complex clients
10. Ageing out of ABA

Program Outcomes: In Cycle Three, a number of outcomes were identified at both the child/youth and parent/caregiver levels, while system-level outcomes were not identified. At the child/youth level, families and staff are seeing positive changes in clients’ behaviours and skills, with almost all children/youth reaching or exceeding their program goals. In many cases, children/youth are becoming more confident and independent as a result of participating in ABA. Children/youth are also forming friendships with their Consultants, and in many cases – especially for clients in groups or dyads – friendships with other children/youth in the program. Maintenance and generalization are also important outcomes of the ABA program; while some families struggle with maintaining and generalizing program goals, others have successfully kept up with their strategies and skills and used them in other settings and with other people. Finally, some participants explained that the ABA program can assist families to experience fewer moments of crisis by teaching strategies to address current and individualized needs.

Parents and caregivers themselves are also experiencing positive outcomes from the ABA program. Firstly, they are learning and using new strategies with their children, and gaining confidence in their abilities to support them. Parents/caregivers are also experiencing decreased anxiety, through setting and achieving realistic goals, and are becoming more aware of additional resources for themselves and their children. Finally, some parents/caregivers explained that they are also experiencing improved family dynamics as a result of the ABA program, including better communication with their children and more time spent together.

Future Directions: Participants provided numerous suggestions to enhance the effectiveness of ABA programming. Below are the key recommendations that emerged from Cycle Three, based on discussions with the evaluation Steering Committee as well as suggestions from evaluation participants.
Recommendation #1. Explore ways to simplify the intake process for the ABA program in order to create a clear path for families to follow, prevent duplication of files, and reduce time spent on incomplete intakes.

Recommendation #2. Explore upgrading the current intake database system to a system that is capable of supporting a large number of client files and related administrative information.

Recommendation #3. Continue to provide families with as many relevant resources as possible (e.g., books, videos) and ensure that resource libraries have client-oriented resources (e.g., toys, activities).

Recommendation #4. Explore the possibility of providing information to families at intake to encourage realistic goal-setting and speed up the service planning process (e.g., provide examples of possible ABA goals or illustrations of how the program works).

Recommendation #5. Continue to strengthen collaboration between ABA Consultants and Service Coordinators to provide more integrated and holistic support for families, where possible. For example, encourage communication between Consultants and Service Coordinators at the beginning and/or end of a round of service.

Recommendation #6. Explore how goals are developed across agencies, and develop a means to ensure consistency in the level of difficulty and the scoring of goal attainment.

Recommendation #7. Explore why parents/caregivers are not always engaged in the ABA program. Moreover, consider adding an educational component for parents/caregivers to the first session of each round of service, in order to increase their engagement and understanding of the ABA program, as well as their ability to – and likelihood of – maintaining and generalizing goals.

Recommendation #8. Continue exploring ways to develop more creative and effective groups, including girls-only groups, dyads, and summer camps. Some ways of developing better matched groups could include cross-agency groups and mock groups (i.e., larger trial groups to determine suitability and compatibility).

Recommendation #9. Continue to explore options for including more natural settings in ABA sessions to support clients in navigating real-life situations. One way to do this could be to use a natural setting for the last session(s) in a round of service to practice what was learned. Consider also implementing groups in new settings, for example community centres or school gyms to increase accessibility for families.

Recommendation #10. Continue to create new and relevant programming for teens.
Recommendation #11. Explore ways to communicate program planning and outcomes (including goals and strategies) to caregivers/parents in a more accessible and user-friendly format.

Recommendation #12. Consistently ensure that transition plans are in place for children moving from the ErinoakKids partnership to the KPAS partnership, including the transfer of relevant program documents (e.g., Behaviour Support Plans, discharge reports).

Recommendation #13. Continue to develop partnerships with key school or school board representatives to increase general understanding of the ABA program and to increase mutual awareness of ways of providing support. Moreover, continue to explore opportunities to implement ABA program goals in school settings.

Recommendation #14. Continue to advocate for transition supports for 18-year-olds and their families.

Recommendation #15. Consider having inter-agency autism work groups in all regions (similar to the Autism Work Group in Peel).

Recommendation #16. Explore how the complexity of challenges related to mental health can be better addressed for children/youth across developmental stages, and for parents/caregivers, within each region.

Recommendation #17. Continue to seek funding to hire additional ABA Consultants and Clinical Supervisors in order to shorten waitlists, increase frequency of service for clients, and potentially decrease evening work for staff.

Recommendation #18. Upon hiring new staff, ensure a clear and realistic understanding of the number of evenings of work required for the position.

Recommendation #19. Continue advocating to the Ministry of Children and Youth Services to revise the funding formula so that ABA Consultants have reduced caseloads and are able to sustainably meet their service targets.

Recommendation #20. Explore ways to provide more flexibility in program structure to better serve the diverse client base. For example, some clients could benefit from shorter, more frequent sessions, whereas other clients could benefit from longer sessions but over a shorter period of time.

Recommendation #21. Create more frequent opportunities for ABA Consultants from different agencies within and across regions to discuss challenges, share new and innovative curriculum and program materials, and build a community of practice.
Recommendation #22. Increase relevant training opportunities for ABA consultants, prioritizing opportunities where all Consultants can learn about and implement the cutting-edge practices in the field of ABA. Also consider arranging/providing training opportunities in the field of mental health.

Recommendation #23. Ensure KPAS has no overlap in job titles. For example, Service Coordinators and ABA Consultants are both titled “Autism Consultants”, which can be confusing for families.

Recommendation #24. Make the Consumer Feedback Survey anonymous by removing identifiers (client name or ID). Instead, consider making the ABA Consultant’s name mandatory.
INTRODUCTION

This report summarizes the Cycle Three evaluation findings of the Applied Behaviour Analysis (ABA) services for children and youth (aged 9 to 18 years) in the Central West Region of Ontario (Waterloo, Wellington, Dufferin, Halton, and Peel). The report covers the evaluation period beginning April 1, 2015 and ending March 31, 2016, and is the third and final evaluation cycle. As lead agency for the Central West Region, Kerry’s Place Autism Services (KPAS) contracted the Centre for Community Based Research (CCBR) to lead the evaluation under the guidance of a cross-stakeholder evaluation Steering Committee.

Background

ABA services in the Central West Region are delivered to children/youth ages 9 to 18 years with Autism Spectrum Disorder (ASD) through a network of service agencies known as the ABA Central West Region. This network includes: KPAS (lead partner), Peel Behavioural Services - Trillium Health Partners (PBS), Community Living North Halton (CLNH), Reach Out Centre for Kids (ROCK), Developmental Services Resource Centre Waterloo Region (DSRC), and the Canadian Mental Health Association Waterloo Wellington Dufferin (CMHA WWD). Another partnership exists for ABA services delivered to children ages 0 to 8 years; this is led by ErinoakKids and includes Dufferin Child and Family Services, KidsAbility, and Woodview mental health and autism services. A joint ABA waitlist for both partnerships is managed by KPAS.

The ABA program is focused on establishing skills and/or addressing key issues to improve the quality of life for children/youth with ASD. These services are oriented around the following four domains:

- Communication
- Behaviour/emotional regulation
- Social skills
- Daily living skills

The partnering agencies also provide support to the parents/caregivers of children with ASD, aiming to improve their quality of life, enhance their behaviour management skills, and instil a sense of competence. To address these goals, a flexible support model is developed collaboratively with participating children or youth and their parents/caregivers, and can include group, individual, family, and parental capacity supports. Training is provided to parents/caregivers while their child is participating in the ABA program.

The ABA Central West Region is committed to the development, delivery, evaluation, and continuous improvement of its ABA-based services and supports. To this end, they requested that an evaluation of the ABA services be conducted to enable the program to make evidence-based decisions for future program delivery. The evaluation was to be grounded in the perspectives of children and youth, their families, and the systems of service in their communities. The scope of the evaluation was to be focused on the service delivery partnership for children ages 9 to 18 years (i.e., the KPAS-led partnership).

Evaluation Purpose

The evaluation was designed to understand how existing ABA programming is being implemented at each of the Central West agencies for children and youth ages 9 to 18 years. In particular, the evaluation
was designed to assess what is working well and what is not working well within the context of ABA programming. The evaluation should therefore clarify what helps and hinders ABA Central West from creating the desired change that they wish to see in children and youth, their families, and the networks of ASD-related services in their communities. In other words, the evaluation seeks to understand the processes of ABA programming, and how these processes link to intended outcomes.

This evaluation was also designed to explore the impact of ABA programming in the Central West Region. Specifically, the evaluation explores the outcomes of ABA on: 1) its clients (children and youth ages 9 to 18 years); 2) the families of its clients; and 3) the networks of ASD-related services. Implementing a multi-cycle evaluation allows the program to consider outcomes over time.

Finally, the evaluation was designed to be forward looking. Data from the evaluation provides concrete recommendations on how the Central West Region can improve their ABA services in the future for children/youth, their families, and within the local networks of ASD-related services.

Overall, the evaluation has three inter-related objectives:

- To assess the implementation processes of ABA programming in the Central West Region
- To assess the outcomes of ABA programming at the child-, family-, and systems-levels
- To identify future directions for improving ABA services in the Central West Region

Main Research Questions

Three main research questions guided the evaluation, consistent with the three objectives mentioned above. These questions (and corresponding sub-questions) are listed below, and form the basis of how this report is organized.

1. *How is the ABA program being implemented at agencies in the Central West Region? (process)*
   a) What is the underlying program theory, including the main activities and expected outcomes?
   b) What are the child and family demographics in ABA Central West Region communities?
   c) What resources (e.g., human, financial, partnership) support the various aspects of program functioning (i.e., inputs)?
   d) What aspects of the program seem to be working well? Not working well?
   e) What is facilitating and what is hindering effective program implementation?
   f) How are the guiding principles evident in service delivery?

2. *How and to what extent has ABA programming impacted participating children/youth and their families? (outcomes)*
   a) What are the main accomplishments and products of the ABA program? (i.e., outputs)
   b) What outcomes has the ABA program had on participating children and youth in the domains of communication, behaviour/emotional regulation, social skills, and daily living skills?
c) What outcomes has the ABA program had for the families of participating children and youth in terms of their quality of life, enhanced behaviour management skills, and sense of competence?

d) What systems-level outcomes has the ABA program achieved?

e) How have outputs and outcomes changed over time?

3. **What recommendations can be made to improve the outcomes of ABA services for children, families, and the networks of ASD-related services in their communities? (future directions)**

   a) What should be done to enhance the effectiveness of the ABA programs for children and youth? For families? For the network of ASD-related services in their communities?

   b) How should future ABA programming be evaluated?

**EVALUATION DESIGN**

**Evaluation Approach**

This evaluation was carried out using an approach consistent with the three hallmarks of community-based research: community-situated, collaborative and action-oriented (Ochocka & Janzen, 2014).

*Community-situated*. Community-situated means that research is of practical relevance to community members and is carried out in community settings, rather than being driven simply by researcher interests. This evaluation therefore seeks to understand the program context across the Central West Region, paying close attention to the program’s guiding principles. It also means that the evaluation draws on information already collected by the program (i.e., secondary data), while involving ABA staff in helping to collect primary data (e.g., helping to organize interviews and focus groups).

*Collaborative*. Collaborative means that community members and researchers share control of the research agenda through reciprocal involvement in the research design, implementation and dissemination. This evaluation therefore makes sure to involve different stakeholders (including children/youth, parent/caregivers, various levels of staff, and community partners) throughout the evaluation process. Concretely, most stakeholders are involved through the evaluation Steering Committee that guides each step of the evaluation. This Committee creates momentum and increases the likelihood that findings will be acted upon. In addition, stakeholders are also involved as research participants.

*Action-oriented*. Action-oriented means that the process and results of research are useful to community members in making positive change. This evaluation is therefore utilization-focused, meaning it is designed to be as useful as possible. Action-oriented also means that there is ongoing feedback of the evaluation findings so that action can be taken following each evaluation cycle. To this end, the evaluation report includes concrete recommendations for future action. Action-oriented also means that the evaluation is open to improvement from one cycle to the next; recommendations to improve Cycle Three of the evaluation are included at the end of this report.
**Cycle Three Methods**

This section outlines the methods of data gathering for Cycle Three of the ABA services evaluation. These methods were determined through a systemic process of building an **evaluation framework**. The evaluation framework process clarified the main research questions, program theory (i.e., program logic model), and corresponding measurement matrix. The **program logic model** (Appendix 2) was developed during Cycle One in collaboration with the evaluation Steering Committee and depicts the main activities and anticipated outcomes of the ABA program. The **measurement matrix** (Appendix 3) demonstrates expected program outcomes (impact measurement) and processes (performance measurement) with indicators and corresponding data collection tools. The matrix also lists questions about future directions (strategy measurement) linking them with corresponding data collection tools.

Based on this measurement matrix, data collection tools were identified and developed. The individual tools include a mix of existing measures used by the ABA Central West Region and those developed by the evaluation team. Many of the methods are the same as those used in Cycles One and Two, although two quantitative methods used in Cycle Two (the time utilization charts and the secondary outcome tool) were dropped in Cycle Three as they provided sufficient data in Cycle Two and were time-consuming for staff to collect. A few additional qualitative methods (youth interviews and parent/caregiver written responses) were added in Cycle Three to address gaps in previous data. Combined, all tools include a mix of quantitative and qualitative measures to provide breadth and depth of insight. Appendix 4 includes primary data collection tools with corresponding consent forms.

Cycle Three methods are listed below, organized into quantitative methods (representing secondary data already gathered by the program) and qualitative methods (representing primary data that was collected specifically for the evaluation).

**Quantitative Methods (Secondary Data)**

**ABA Roll-up.** The ABA Roll-up is an Excel spreadsheet that is regularly updated and maintained by Clinical Supervisors across the Central West Region. Each region independently completes their own spreadsheet, which includes quantitative information about program participants and program delivery. More specifically, the spreadsheet tracks program outputs by client (e.g., number of hours of service delivery, type of service, and region). Included within the ABA Roll-up are client results from the **Goal Attainment Scale (GAS)**.

GAS quantifies the achievement of client goals based on a 5-point rating scale from -2 to +2. If a chosen goal (for example, reduction in aggression) is recorded as -2 in the Roll-up, then the outcome level was much less than expected (e.g., there was a regression in the goal area). If the goal is recorded at +2, then the outcome was much greater than expected (e.g., the child greatly improved and the aggression was significantly reduced). A score of zero means that the expected level of goal attainment was reached but not surpassed (i.e., the child met but did not exceed their goal).
This report includes data collected in the ABA Roll-up for most of Cycle Three, from April 1, 2015 to January 31, 2016. In total, outcomes from 750 clients aged 9 to 18 years (across all agencies) were tracked in the Roll-up during this time, and were included in the analysis.

**Consumer Feedback Survey.** The Consumer Feedback Survey (CFS) is self-administered by parents/caregivers of clients participating in the ABA program. Upon completing a round of service, parents/caregivers are given a hardcopy of the CFS, and are asked to fill it out and return it in an envelope (in-person or by mail) to the program manager at their agency. Central intake staff at the various ASD agencies will then input the individual CFS data into the online version (i.e., on Survey Monkey), where all CFS data from agencies in the ABA Central West Region is stored.

The CFS quantitatively evaluates program outcomes related to behaviour management skills and feelings of competence at the family level. The survey also contributes quantitative insight into program processes (i.e., what is working well and not working well), and provides suggestions for future directions via a qualitative component (i.e., a box for parents/caregivers to provide suggestions and other comments). The CFS was discontinued on November 23, 2015.

In this evaluation cycle, data was retrieved on March 7, 2016, and included 249 parent/caregiver responses dated from February 1, 2015 – November 23, 2015. Approximately 71% of these were from Peel Region, 14% from Halton, and 15% from Waterloo, Wellington, and Dufferin.

**Central West Region (CWR) Applied Behavioural Analysis (ABA) Services- Intake Management.** The CWR ABA Services Intake Management database provides demographic information on all children/youth and their families that are currently enrolled in ABA services within the Central West Region, in addition to information on total number of clients ever served and interventions delivered. The database provides details about how many clients are on the central waitlist vs. in service, and identifies the domain area(s) that families are working on during their sessions.

Aggregate data from the intake database (for the period of April 1, 2015 to December 31, 2016) was analyzed during Cycle Three. ABA staff de-identified and collated all data prior to sending it to the external evaluating team. Data from the Child and Adolescent Needs and Strengths (CANS) tool was analyzed in Cycle One but was not re-visited in Cycles Two or Three.

**Qualitative Methods (Primary Data)**

**Interviews with parents/caregivers.** A total of seven individual interviews were conducted in Cycle Three with parents/caregivers of ABA clients, one of which was done in-person and six were done over the phone. Each interview was originally scheduled as a focus group with four to six participants, but only one parent/caregiver was able to attend each one. Participants were selected and recruited in cooperation with program managers on the evaluation Steering Committee, and according to purposive sampling criteria (i.e., diversity in gender, ethnicity, child’s age and diagnosis, number of children, model of service, geographical location, length of involvement in service). All main research questions were addressed in these interviews.

**Written responses from parents/caregivers.** In order to increase the number of parent/caregiver voices in Cycle Three, additional parents/caregivers were given the option of submitting written responses to
the same interview questions used for the parent/caregiver interviews. Nine such responses were received by the external evaluating team by mail, email, or fax. Participants were selected and recruited in cooperation with program managers on the evaluation Steering Committee, and according to purposive sampling criteria (same as listed above for parent/caregiver interviews).

**Interviews with youth.** A total of four individual telephone interviews were conducted in Cycle Three with ABA Clients aged 11 to 18 years. Participants were selected and recruited in cooperation with program managers on the evaluation Steering Committee, and according to purposive sampling criteria (i.e., diversity in gender, ethnicity, age and diagnosis, model of service, geographical location, length of involvement in service, school involvement). All main research questions were addressed in these interviews, with an emphasis on how service could be improved for older age groups.

**Focus groups with staff.** Four focus groups were held with ABA staff during Cycle Three, including one with clinical supervisors (n=5) and three with ABA Consultants/Behaviour Therapists (n=23). Participants were selected and recruited in cooperation with program managers and according to purposive sampling criteria developed by the evaluation Steering Committee (i.e., representation across Central West Region, diversity in clinical and frontline staff, and diversity in length of involvement with program). All three main research questions were addressed to gain front-line insight on program processes and outcomes for children/youth and parents/caregivers, as well as recommendations for improvement. *In this report, both ABA Consultants and Behaviour Therapists will be referred to as ABA Consultants.*

**Key informant interviews.** Eight key informant interviews were held in Cycle Three via telephone, to gain insight into the three main research questions related to systems-level processes, outcomes, and recommendations for improvements. Participants were selected and recruited in cooperation with the evaluation Steering Committee and according to purposive sampling criteria. Participants were located across the Central West Region and included senior staff at partner agencies (ABA program managers, intake staff, service coordinators, psychological associates, etc.) and school-board representatives.

**Case studies.** Three case studies were completed to provide further insight into some of the common strengths and challenges of the ABA program, while showcasing the diversity in clients, families, and program experiences. Three clients were selected according to purposive sampling criteria (i.e., diversity in geographic representation across the Central West Region, length of involvement in the ABA program, gender and ethnic diversity, range of child/youth ages and diagnoses, and range of models of service). For each case study, three separate telephone interviews were completed, one with the child/youth, one with their parents/caregiver, and one with their ABA Consultant. In total, nine interviews were conducted across the three case studies.
EVALUATION FINDINGS

Evaluation findings are presented below in accordance with the three main research questions related to program implementation, program outcomes, and future directions. Data was analyzed across all research methods with main themes highlighted below.

Program Implementation
Overall, as in previous evaluation cycles, participants expressed an appreciation for the ABA program and described a number of strengths and challenges related to program implementation. This section will begin by exploring the program overall – including the number of clients served, the type of service they received (individual vs. group), etc. – followed by a discussion of the top 10 strengths and challenges as identified in Cycle Three. Similarities and differences across evaluation cycles will be highlighted throughout, as well as similarities and differences across the Central West Region.

Description of ABA Clients
As outlined previously, the ABA program is available to all children/youth from 0 to 18 years who have a confirmed ASD diagnosis (Autism/Autism Disorder, Pervasive Developmental Disorder, or Asperger’s Disorder). Confirmation of diagnosis must come from a certified and qualified professional (i.e., a family physician, pediatrician, psychiatrist, psychologist, or psychological associate) (Autism Ontario, 2015).

Figure 1 shows a snapshot of the total number of clients (aged 8 to 18 years) in service on March 4, 2016, within all areas of the Central West Region. The majority of children who were in service were between the ages of 11 to 14 years, followed in most regions by those aged 15 to 18. This is different from Cycle Two, where – at approximately the same point in the year (March 6, 2015) – children ages 9 to 10 were the second largest age bracket in service. While most clients of the ABA program within the KPAS partnership are at least 9 years of age, there are occasional clients under the age of 9 years. The reasons for serving younger clients are diverse; as one example, parents/caregivers may request an early partnership switch for a younger child if they have another child in service within the KPAS partnership.

Figure 1 also demonstrates that Peel had the greatest number of clients in service at this time (101), accounting for 49% of all clients who were in service across the Region. KPAS Peel served approximately 24% of all eligible clients in 2015, and PBS served another 24%. Peel has a higher population than the other regions, and is thus allocated more of the funding and resources.
**Figure 1**: Number of clients in service by age group and region (N=205)

Source: CWR ABA Service-Intake Management (Snapshot of those in service on March 4, 2016)

Figure 2 shows the total number and percentage of eligible clients who had either been served or remained on the waitlist between April 1 and December 31, 2015. In this report, ‘eligible’ is defined as all children/youth who are either on the waitlist or in service. Most agencies served just under half of their eligible clients, with PBS and DSRC serving nearly 50% of eligible clients, while CLNH only served 25%. The mid-year funding increase (which meant both an increase in staff and an increase in targets) may account for some of this variance.

**Figure 2**: Total number of eligible clients served vs. on waitlist by service provider (N=2134)

Source: CWR ABA Service-Intake Management (Cumulative for April 1, 2015 to December 31, 2015)
Description of ABA Programming

Children/youth in the ABA program can work on one goal per session related to one of four domains: communication, social skills, daily living skills, and behaviour/emotional regulation skills. Figure 3 depicts the percentage of clients within each domain who were in service on March 4, 2016. As demonstrated, the majority of clients focused on either social skills (39%) or behavioural/emotional regulation skills (27%), with slightly fewer working on daily living skills (20%) and communication skills (14%).

Figure 3: Skill domains of ABA clients in service across the Central West Region (N=260)

Source: CWR ABA Service-Intake Management (Snapshot of those in service on March 4, 2016)

ABA is offered as an individual, one-on-one program or as a group program with two or more children/youth of a similar age, level of functioning, and specified goal area. Figure 4 reveals the total number of clients in each service agency who participated in each type of service during Cycle Three. Clearly, most agencies served a greater number of clients through one-on-one sessions, with the exceptions of PBS, KPAS Waterloo, and DSRC who served more clients through their group sessions.

While PBS and DSRC also served a greater number of clients through group sessions in Cycle Two, KPAS Waterloo had served only about 37% of clients in groups in Cycle Two, compared to 66% this cycle. In fact, most agencies served a greater percentage of clients by groups in Cycle Three compared to Cycle Two, with the exception of KPAS Peel and CLNH. Also, when comparing this data with average waitlist times (Figure 8), it can be noted that the four agencies with the longest waitlists (e.g., KPAS Waterloo, CMHA WWD, PBS, and DSRC) also served a greater percentage of clients in groups.
Figure 4: Form of service delivery (individual vs. group) by service provider for clients (N=750)

![Graph showing percentage of served clients]

**Source:** ABA Roll-up (April 1, 2015 – January 31, 2016)

Figure 5 shows the total number of hours spent on client intervention (i.e., directly with the child/youth) versus parent/caregiver training from April 1, 2015 to January 31, 2016. Definitions of client intervention hours and parent training hours are provided in Appendix 5. All agencies with the exception of CLNH spent more time working directly with clients vs. parent/caregiver training. The average amount of time that consultants spent with each child/youth was between 13 to 19 hours per round. The average amount of time that consultants spent training parents was between four to 19 hours per round. As was found in Cycle Two, CLNH spent the most amount of time, on average, training parents/caregivers (approximately 17 hours/round). CLNH spent an almost equivalent amount of time on both client intervention and parent/caregiver training, as compared to most other agencies who spent almost double the amount of time on client intervention.

When comparing data from Figure 4 with data from Figure 5, it can be noted that in many cases, agencies who spend comparatively more time on client intervention vs. parent/caregiver training (e.g., PBS, KPAS Waterloo, DSRC) also serve a greater percentage of clients in groups. This makes sense as parents/caregivers are often not as involved in group sessions as they are in one-on-one sessions, and occasionally – in some agencies such as PBS – were not always able to observe groups in the past. The age, diagnosis, and preference of the client may also play a role in the ratio of client intervention vs. parent/caregiver training hours; a high-functioning 17-year-old, for example, may not want (or need) their parent(s)/caregiver(s) to be as involved.
**Figure 5:** Average amount of time spent per client on intervention vs. parent/caregiver training by service provider (N=750)

![Bar chart showing average amount of time spent per client on intervention vs. parent/caregiver training by service provider (N=750)]

*Source: ABA Roll-up (April 1, 2015 – January 31, 2016)*

**Strengths and Improvements of Program Implementation**

Commensurate with previous evaluation findings, participants in Cycle Three explained that the ABA program is “very much wanted, needed, and desired”. According to several key informants, the ABA program has filled a gap in the community by providing clinical support to any child on the spectrum, many of whom do not qualify for other services. Parents/caregivers are generally happy with the program and have commented on how “helpful” and “effective” it can be. On the Consumer Feedback Survey, 98% of parents/caregivers agreed that they “found the service helpful”, and 98% agreed that they would “recommend this service to other families”. Moreover, evaluation participants appreciated that the program is free and available across Ontario. According to one key informant, this means that families are “free to move and live their life” without losing their spot on the waitlist.

> “Families are quite happy with the program, they want to come back into services, they are asking for re-referrals continuously.” (Clinical Supervisor)

> “It was [a] great experience for us.” (Parent/Caregiver)

Participants highlighted 10 key strengths and/or improvements of the ABA program, many of which were also featured in reports from previous cycles. However, a few of the strengths identified this year were previously talked about as challenges, but have since been addressed or at least improved upon. The strengths and improvements are listed below, in order of strength.
Strength #1: Program structure

Participants explained that the structure of the ABA program is working well. For example, parents/caregivers appreciate the fact that the program is **flexible**, and can occur in different settings (i.e., at home or in the community) and in different ways (i.e., one-on-one or in a group). The goals chosen within ABA are “client-specific”, meaning the program **caters to the individual**, even within a group setting. Moreover, some participants explained that if a goal and/or setting is not working for the client, the Consultant will try to alter the plan, to create a more successful program.

“I find it really supportive for families in that they’re able to have the sessions in a centre or in a home or individual or, you know, in groups, just depending on the goal that the family or the individual needs to work on.” (Key Informant)

“They will put something together for the area of need that the family feels we really need to get this under control now. Having that option is good. Everyone’s needs are very specific. Every child is very different. So to have the option of saying hey this is really a struggle right now, and then putting a plan together to work on that specific need is amazing.” (Parent/Caregiver)

Most participants agreed that the **goal-directed approach** of ABA works well, as it makes the program manageable for both families and ABA Consultants within the typical 10 to 12 week session. As one key informant explained, “Families love the opportunity to have one thing addressed and done quickly”. Participants also explained how important it is for a Consultant to work with the family to create a goal and get their input into the plan or strategy. Figure 6 demonstrates that most parents/caregivers and/or their children felt involved in this planning process.

**Figure 6:** “I, and/or my son/daughter, had input into the plan or strategy that was developed” (n=244)

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**Source:** Consumer Feedback Survey (February 2, 2015 – March 7, 2016)
Nevertheless, as in previous evaluation cycles, ABA Consultants discussed the difficulties in choosing specific goals with parents, who may either: (1) be overwhelmed with goals to choose from; (2) have no goal in mind, or (3) do not understand (or wish to address) the prerequisite skills needed to achieve a goal. As various participants explained, focusing on one specific goal is especially difficult with complex clients. These clients may not benefit from such a narrow focus, or may not be able to achieve a goal given other confounding factors (e.g., anxiety).

**Strength #2: Consistent client-consultant matching**

Another strength across all three evaluation cycles is the matching of clients with their past Consultants. While this matching cannot always occur (for example, if a client or Consultant has moved locations, or if the Consultant has a full caseload), it is often the intent and has many benefits. As participants explained, Consultants have built rapport and trust with their past clients, and understand their strengths, challenges, and behaviours, making it easier to develop strategies and work towards a goal.

Parents/caregivers also explained that consistency is important for their children, and that many of their children look forward to working with their Consultant again.

“We have good rapport with the therapist. And mind you we’ve had the same therapist come back to us... She worked really well with my boy... I requested her to come back again, I think we had her three times in a row... The program is flexible enough in this way that we can request the same therapist.” (Parent/Caregiver)

“There didn’t need to be those first few sessions that were kind of like get-to-know-you sessions. They could just get right off onto working and following through with what they had done, which meant that they had more workable time.” (Parent/Caregiver)

**Strength #3: The use of natural environments**

The third strength identified in Cycle Three was the use of natural environments within the ABA program. Implementing sessions either at home or in the community (depending on where the behaviour normally – or ideally – occurs) helps the client to maintain and generalize the learned skill, so they can use it in everyday life. Some participants explained that providing service in a natural environment is fairly unique to ABA, compared to other services for children/youth on the spectrum.

“I think one of the things is because we are teaching in that natural environment, not a lot of other service providers and agencies will provide that support.” (ABA Consultant)

Participants from Halton explained that their use of natural environments has remained about the same from Cycle One to Cycle Three, and that they use them quite often. Participants from Peel, however,
noted that throughout Cycle Three, the use of natural environments within their ABA program has increased, likely because they ran more Summer camps. In fact, across all regions, agencies tend to use natural environments more in the Summer, when children are available during the day as opposed to solely in the evenings. Consultants explained that children/youth tend to like working in natural environments, though some high-functioning youth would rather stay at home to avoid being seen in public with a “therapist” and/or be labelled by others as “autistic”.

“This year we also tried to go out a little more into the natural setting... where students are in camps. During the school year that’s not always possible because it’s an after the school day program, I think during Summer we were definitely able to do some groups, dyads, or even individuals in some other settings.” (Clinical Supervisor)

“We had a group and we took them out to the mall one time and we just said like ‘go socialize, this is typical for you guys’. So like they all had lunch together, and then they all went around, it was like those are the goals that those kids really benefit from and [like].” (ABA Consultant)

**Strength #4: Great staff**

As in other cycles, parents/caregivers, key informants, and Clinical Supervisors noted that the ABA Consultants are wonderful to work with, and were described as “great”, “calm”, “respectful”, and “helpful”. As one key informant explained: “The quality of the staff... is amazing. They all know their stuff, they all know what they’re doing”. Within the Consumer Feedback Survey, a number of parents/caregivers commented on how easy it was to work with their Consultant, and how the information presented was always clear and easy to understand, as demonstrated in Figure 7.

**Figure 7:** The information presented by the therapist was presented in a clear, easy to understand manner (n=247)

Parents/caregivers also commented that their Consultants exceeded their personal expectations, for example by providing them with additional resources or offering to speak with the client’s school.
“Many of my friends that have the same experiences are really happy with the therapists. The program has some really good people on it.” (Parent/Caregiver)

“I’ve always felt that the ABA consultants or therapists are a lot more accommodating and a lot more helpful as far as the child’s entire world and not just the 1-2 hour allotment they have a week with them. They kind of see the big picture – they’ve always been great.” (Parent/Caregiver)

Throughout all cycles of this evaluation, Consultants have also expressed gratitude for their Clinical Supervisors. As one key informant explained, “The staff in general I think seem pretty happy with what’s been happening, you know, they appreciate the supervision that they get from them [their Clinical Supervisors].”

Strength #5: Group matching

Participants explained that most group programming in Cycle Three has worked well, largely because clients have been well-matched. While a few types of groups have been more difficult to find matches for (e.g., girls-only groups), most parents/caregivers have been appreciative of the group matches and the opportunities for their children to learn with – and from – similar others.

“We’ve had some really nice group compositions that have been working quite well for us... It’s been going really quite smooth and we’ve been able to make some really nice matches with the children that we have seen.” (Clinical Supervisor)

Several factors may help to explain why clients are becoming better matched in groups. Firstly, over the past two cycles, staff have been able to pull further down the waitlist, in order to group children with similar behaviours, goals, interests, and/or demographics (e.g., all-boys groups). Staff from Halton explained that during Cycle Three, there was “more of an opportunity to pull forward clients that make sense if there was some sort of group opportunity”. Moreover, as children complete a block of service and are placed back on the waitlist, they tend to come off the waitlist at the same time, making it easy to group them together once more.

Some regions have taken additional steps in Cycle Three to ensure good quality matches. In Peel and Halton, for example, pre-interviews and online surveys have been implemented with parents/caregivers to understand whether their child/youth is a good fit. In Waterloo, mock groups have also been piloted wherein Consultants can: (1) assess group dynamics to decide who would work best together; (2) collect baseline data from clients; and (3) complete consent forms and other paperwork with parents. Children in mock groups have a chance to meet and play, and Consultants can collect enough information to have some of the BSPs complete by their first day of group.

“For us now we’re starting to do mock groups before any of our groups... So I find that that’s working a lot better. For the first time we’ve actually had a couple groups that all the kids worked well together.” (ABA Consultant)
Another new strategy developed in Cycle Three was a joint group with DSRC and KidsAbility in Waterloo. This group was specifically for children aged 8 to 9 years transitioning from KidsAbility to the Kerry’s Place partnership. The group allowed children and their parents/caregivers to meet new ABA Consultants, and ABA Consultants to get to know upcoming clients. An ABA Consultant described this group as “going really well”, and is one strategy being used to address Challenge #6 (transitions between partnerships).

Strength #6: Camps
Summer and march-break camps were described by participants as working well. In Cycle Three, Summer camps occurred in all regions except Halton, where Consultants continued to run groups throughout the Summer but not in a condensed, one to two week format.

According to participants, one advantage of running Summer camps is that Consultants can reach their targets quickly by serving many children at once. According to ABA Consultants, parents/caregivers also seem to like the intensity of the program, where children/youth receive help for several hours a day as opposed to once or twice a week.

“We were able to serve quite a lot of kids in a fairly short period of time.” (Clinical Supervisor)

“I got a lot of comments from my families that they liked the everyday, straight for a week, that intensity that they seem to lack in the regular program for a lot of them. Especially the older kids, they like getting it done, you know.” (ABA Consultant)

Within the Summer camps, children focus on a particular goal (e.g., resume building) within a broader theme (e.g., job skills). Thus, while they work every day towards their own goal, they will also benefit from learning other skills or strategies (e.g., interview skills, job search techniques, etc.).

“They each have an individual goal but they’re learning all the different skills, so they’re getting a lot more out of camp than they would in individual service where they only work on one thing.” (ABA Consultant)

Participants also explained that parents/caregivers appreciate the respite they get from Summer camps, as well as the opportunity for their child to get that “camp experience” that some cannot otherwise have. Nevertheless, Clinical Supervisors, key informants and ABA Consultants all commented that Summer camps are a lot of work for staff and require significant planning ahead of time.

“There’s a lot of planning that goes into it, they’ve got to make games... So you know, there’s a whole bunch of other work involved. So I’m not sure if they’re saving time.” (Key Informant)

Strength #7: Partnerships with schools
Participants agreed that the best way to serve children/youth with ASD is through an integrated and holistic approach, which includes partnerships with other services (primary care, mental health, etc.) as well as partnerships with schools. Partnerships with schools are especially important for many children/youth in the ABA program, when a behaviour or goal could be best addressed (or additionally
addressed) within the school setting. Working with schools can help children/youth to achieve, maintain, and generalize their goals, and can also help to address staff workloads. Nevertheless, there are other situations where school goals are not appropriate, as one key informant explained below.

“Because ABA is such a short-term service, there isn’t always time for the ABA consultant to meet with the school in their service planning. Also, teachers might not hear about the strategies while the kid is in service, might not be able to really help out. Also, the goal isn’t always related to school, so it’s not always important that the school is involved.” (Key Informant)

Throughout this evaluation – ever since Cycle One – partnerships with schools have been both a strength and a challenge. The extent of these partnerships has varied significantly across the Central West Region. In Peel, for example, partnerships between PBS and the school boards have been working well, while partnerships between KPAS Peel and the school boards have not been working well. With a few exceptions, ABA Consultants at PBS have been able to attend school meetings, consult with school staff, observe the child in their natural setting, and sometimes ask school staff to take data. However, staff in Peel have not been able to implement ABA within the school setting, and some participants (Service Coordinators, ABA Consultants) were unsure as to how much the teachers were using the ABA strategies once the Consultant had left.

“Schools haven’t opened up their doors completely for us. They have been willing to listen to and take what we say has worked and hasn’t worked and all that stuff, now will they actually implement? Not sure about that.” (Clinical Supervisor)

Unlike at PBS, staff in Halton have noticed some major changes in relation to school partnerships over the course of Cycle Three. According to the Clinical Supervisor, “all of my staff have worked with at least one [public] school... in addition to private schools and at both the elementary and high-school levels”. Some ABA Consultants have worked directly with school teachers and EAs to train them in ABA techniques and to implement goals within the classroom. Others have simply attended case conferences, discussed the strategies in ABA, and/or observed their client within the school settings.

“At the end of the first group session I actually asked the therapist to come into the school to explain the report... what kinds of things they need to continue working on... the school is awesome in that they understood the strategies... they just reinforced what was learned in ABA.” (Parent/Caregiver)

Wellington and Dufferin have not seen many changes in their partnerships with schools over the course of Cycle Three. Partnerships in Wellington were reported to be working fairly well – with some ABA Consultants implementing service directly in the school setting – while partnerships in Dufferin were described by participants as less consistent, sometimes working well and other times not. ABA Consultants explained that one reason for this inconsistency in Dufferin is because of the large number of school boards there.

“I think our partnership with [a school board in Wellington] is still pretty good. The problem is again Dufferin, because Dufferin is a region with three different school boards.” (ABA Consultant)
Finally, partnerships with schools in Waterloo do not seem to be working well, with no major changes in Cycle Three. While some Consultants have been invited to case conferences in schools to explain their programming, this is often the extent of their involvement. Most Consultants cannot implement service in schools, train teachers/EAs, or even observe their clients.

“We’re not allowed to go into the schools to implement anything, the only thing we can do in the schools is show them what we’ve done, share information, that’s all we’re allowed to do. So we’re not allowed to go in, give any opinions on anything, nothing.” (ABA Consultant)

“We dealing with elementary schools in particular [in Waterloo] can be very time consuming, draining, and an unpleasant experience to say the least.” (Parent/Caregiver)

**Strength #8: Relevant programming for teens**

One of the recommendations that emerged from Cycle Two was to explore more relevant programming options for youth aged 13 to 18 years. In this cycle, much more than in any other, evaluation participants from all groups (staff, parents/caregivers, youth, etc.) described a number of creative and relevant programs that were implemented for this older age group. As one Clinical Supervisor explained, “We’ve gotten better [at] being creative with our programming options”. Below are some examples of creative programming that were discussed in the interviews and focus groups.

- Job skills and career planning (interviewing, resumes, cover letters)
- Budgeting skills
- Riding public transit
- Getting a driver’s license
- Healthy sexuality and healthy relationships
- Transitioning to college or university life
- Living independently

As Clinical Supervisors and ABA Consultants explained, one reason why creative programming may be more prevalent now is because children who started in ABA when it first began are simply growing up. They are experiencing new challenges that they had not encountered previously (entering high school, puberty, etc.) and have acquired the prerequisite skills necessary to address these goals.

“We may have addressed some previous behavioural skills in previous rounds that would’ve maybe made those goals more difficult to work on, but now because the behaviour is under control we can work on those goals.” (Clinical Supervisor)

Another important point to mention is that ABA Consultants still struggle to get buy-in from teenagers. By working on relevant skills that these youth have an interest in, they may be more likely to enjoy the process, experience success, and use what they have learned.

“Sometimes we have trouble getting buy-in from those clients, they don’t want to do ABA again, but when we frame it as getting ready to move out on your own, being able to budget, that’s important, then they get on board a little more.” (Clinical Supervisor)
Strength #9: Partnerships within and across agencies serving children/youth with ASD
Several key informants explained that there is good collaboration among service providers supporting children/youth with ASD in the Central West Region. Firstly, there are a number of opportunities for service providers within the ABA program to meet, such as the Clinical Supervisors meeting where Clinical Supervisors from all five regions can meet to problem-solve and share ideas and resources.

“I do think that every effort is made to ensure that the ABA providers across all of Central West Region are working in partnership with the agencies that serve our mutual clients.” (Key Informant)

“The clinical supervisors also meet every month. We problem-solve [clinical] situations, resource sharing regularly, program materials, could be journal articles, so I think we’re also sharing capacity that way.” (Clinical Supervisor)

Although some ABA Consultants have the opportunity to connect with Service Coordinators, this is an area that could be enhanced. As one key informant explained, these conversations and connections may help to better serve families, both before and after a round of service. For example, in many cases, Service Coordinators have known families for years, and may have important insight into what goals a client could or should work towards, especially a complex client.

Secondly, there are opportunities for ABA providers to meet with other agencies or sectors providing other services to children/youth with ASD. One example is the Autism Work Group in Peel, where ABA representatives as well as representatives from other services and programs can work together.

“The Autism Work Group in Peel... is another table that has broad representation from the school boards, with mental health, with preschool programs, all sorts of different kinds of providers sit at that table, and so that’s another opportunity to you know market the [ABA] program but also discuss any issues if any are arising.” (Key Informant)

Participants explained that partnerships with mental health agencies can work well in some cases, and not so well in others. For example, participants from Wellington, Waterloo, and Halton explained that referrals to mental health services can work fairly well as there are many options available, some even within the same agency (e.g., CMHA WWD, ROCK). In Dufferin, however, connections to mental health agencies were described as not working as well. As one Consultant explained, this is sometimes because “the mental health agency likes to say that they [the referred clients] have autism, so [they] don’t qualify for services here”.

Strength #10: Reduced travel times
During Cycle Three, a few changes were made that helped to reduce travel times for some staff and provide more service to families. An additional staff was hired in Halton, for example, which helped to decrease travel time for staff and serve more families at the same time. An additional staff was also hired in Wellington/Dufferin, which meant that separate staff could serve the two areas, rather than one staff being stretched across the two. This division meant less travel per staff and more flexibility in
terms of what is offered in each Region. For example, while service was not regularly offered in Dufferin during the Winter months, Dufferin now has an ABA Consultant serving families year-round.

### Summary: Strengths & Improvements in Cycle Three

1. Program structure  
2. Consistent client-consultant matching  
3. The use of natural environments  
4. Great staff  
5. Group matching  
6. Camps  
7. Partnerships with schools  
8. Relevant programming for teens  
9. Partnerships within and across agencies serving children/youth with ASD  
10. Reduced travel times

### Challenges of Program Implementation

Despite the many strengths associated with ABA program implementation, evaluation participants also identified a number of challenges, many of which have been highlighted in Cycles One and Two. This section will outline the top 10 challenges identified in Cycle Three, in order of strength.

**Challenge #1: Waitlist length**

As in other cycles, the length of the waitlist was the most common challenge cited by evaluation participants. In the Consumer Feedback Survey, when asked “Is there anything about our service we need to improve or change?”, 22% of respondents (n=31) said that they would appreciate a reduced waitlist and more frequent service. As demonstrated in Figure 8, most families wait at least one year between rounds, with families at KPAS Waterloo currently waiting the most amount of time (average of 609 days), and families at ROCK waiting the least amount of time (average of 411 days). Moreover, as evaluation participants explained, waitlists continue to grow in all regions as awareness of ABA climbs.

**Figure 8: Average wait time in days by service provider**

Source: CWR ABA Service-Intake Management (Data retrieved on March 4, 2016)
According to Clinical Supervisors, ABA Consultants, and some key informants, the length of the waitlist is slowing down the progress of clients, as it is difficult to build upon skills that were learned so long before. Oftentimes, ABA Consultants must review the skills that were learned in a previous round of service – or even repeat the same goal - rather than moving forward to new skills. One to two years of waiting is simply too long for most families to maintain and generalize the skills on their own, especially when they have so many other behaviours and issues to deal with, with often little professional support.

“The longer the waitlist gets, the harder it is for us to build on previous rounds of service and I’ve absolutely found that the maintenance piece of a lot of the goals, mostly the behaviours goals, is much more challenging for families now that the wait is getting longer and longer. It’s kind of like two steps forward, one step back.” (Clinical Supervisor)

“The waiting list continues to grow. ABA is so needed but the value decreases when the waiting period is 24 months.” (Parent/Caregiver)

Finally, some participants (Clinical Supervisors, ABA Consultants, and key informants) agreed that the additional funding in 2015 will help to reduce the wait times, given the hiring of additional staff (e.g., two permanent staff were hired in Wellington). Nevertheless, some participants were hesitant to make such a call.

“I think I’m hopeful that more clients will be served on the wait list in a much shorter [time]... but I don’t know, that hasn’t happened yet” (ABA Consultant)

Challenge #2: Heavy staff workloads
Another recurring theme within Cycle Three is that ABA Consultants continue to be overworked. Most agreed that their targets are too high; serving eight clients at the same time can be challenging and overwhelming, depending on the complexity of cases, the number of clients in groups, etc.

“I think the workload is still pretty high. Staff are still struggling to maintain numbers.” (Key Informant)

Largely due to the age of their clients – and that most are in school during the day – ABA Consultants must work many evenings, often running sessions past seven or eight o’clock. Consultants find these evenings hard on themselves and their families; when discussing the concept of work-life balance, one consultant explained “It’s not really a good balance” while another commented “You literally never see your own family”. As Clinical Supervisors and key informants explained, such high targets and long evenings are contributing to significant staff burn-out.

“[It is] more than so clear that we are stretching our staff, stretching our staff, stretching our staff to the point of snapping.” (Clinical Supervisor)
In Halton, one small change was made in Cycle Three wherein staff can use the week between baseline data collection and BSP implementation to write their BSPs. As one Consultant explained, “Taking that week... to write plans, that is amazing” and helps to ease a bit of their stress.

Finally, it is important to note that several key informants and ABA Consultants recognized that their Clinical Supervisors are also stretched thin, especially given the additional hiring of ABA Consultants this year. Additionally, Service Coordinators were described as having very large and often unmanageable caseloads, with Service Coordinators in Peel not accepting new clients. This presents issues for the service coordinators themselves (who are stressed and sometimes overwhelmed), for ABA Consultants (who must sometimes take on a Service Coordination role for families), and for parents/caregivers (who need guidance in navigating the various resources and supports).

“That’s challenging [for ABA Consultants] because you don’t really want to spend clinical hours doing service coordination, [but] on the other hand, a parent is sitting in front of you, asking you for information about things that they would normally get from a Service Coordinator if they had one.” (Key Informant)

Challenge #3: Insufficient training opportunities for staff

ABA Consultants are hungry for additional training opportunities, even though their caseloads are large and they cannot often find extra time. ABA Consultants, Clinical Supervisors, and key informants named a few different training opportunities that are available for Consultants; some have attended conferences, for example, while others have attended short workshops or lectures. Nevertheless, these opportunities are not always accessible (due to time constraints, etc.) and are often not relevant to what the Consultants are practicing or wanting to learn.

“[We are in] a research-based program where we keep learning and keep our, you know, our research up-to-date, and there’s not a lot of opportunities, and funding and time to do it, for that professional development, and yet it’s integral for our role.” (ABA Consultant)

“Kerry’s Place will constantly offer us training, but it’s in things that aren’t new, right? Or like they might be new to other staff that don’t have an ABA background.” (ABA Consultant)

“I think all of that, in the end, helps better serve our families, right? Like if there is that work-life balance, if there is that education, that professional development, we can take that and we can better serve our families. So in the end, they win, right?” (ABA Consultant)

Challenge #4: Family involvement

As found in previous cycles, parent/caregiver involvement in the ABA program continues to be a challenge. The willingness and/or ability of parents/caregivers to participate varies from family to family; while some parents/caregivers are very much engaged, others appreciate the respite that ABA provides, are burnt-out or too busy to participate, or feel that their participation in the program may hinder their child’s progress. Nevertheless, as participants explained, parent/caregiver involvement is fundamental to the success of the program and the client’s ability to maintain and generalize their goals.
“Parents want someone to fix their kid, right? And not really realizing that they need to play an actual role in that. It’s like gosh, another thing to do right? They work all day, they go home, cook supper, clean, and now they have to come to group and work on this with their kids, and the kids are all needing homework done. It’s like, really?” (Key Informant)

 Occasionally, the ABA program can work well without family involvement, if Consultants are aware of this from the beginning and can plan strategies that do not rely on parents/caregivers. Moreover, as participants explained, goals related to independence and daily living can sometimes be best addressed without family involvement.

 “Some of the best families I work with don’t have parent involvement, because parents are honest and say I do not have the patience to do that... Knowing that up front changes how we write or plan for that maintenance and generalization type of thing.” (ABA Consultant)

 Recent efforts have been made to encourage family involvement, including additional training for parents/caregivers (in the form of workshops for those on the waitlist or sessions built into the child’s round of service) as well as homework for parents/caregivers (to help children maintain and generalize their skills). Moreover, while parent/caregiver involvement is not a Ministry requirement, all agencies strongly encourage families to be engaged.

 Despite efforts to involve families and create ways for them to observe programming, some parents/caregivers continue to comment that they have limited opportunities to observe groups. This has come up in each cycle of the evaluation, and it is unclear whether these opportunities truly exist (and parents/caregivers are simply unaware of them), or if, in some cases, it is not easy for families to participate and/or watch. According to staff, opportunities for observation have been consistently available across most agencies and regions (e.g., in Halton). In Peel, however, bureaucratic challenges have prevented some agencies in the past from allowing parents/caregivers to observe groups. As of the end of Cycle Three, all agencies involved in this evaluation are able to provide opportunities for observation of the ABA program.

 “Parents would be benefitted if allowed to observe the service.” (Parent/Caregiver)

 Challenge #5: Intake and waitlist process

 Key informants, parents/caregivers, and a few ABA Consultants explained that the intake process, as well as the process of re-applying to the ABA waitlist, is disjointed and confusing for families. While families can apply for ABA through any agency offering the service, all intakes end up at KPAS, the central hub. KPAS must then follow up with families if there are any mistakes or missing documents, which, according to key informants, happens quite often.

 “The intake process happens in a million different ways... It’s a very simple easy two-step process in a perfect world, but with so many cooks being in the kitchen, you know, the intake never really follows that one two three four step.” (Key Informant)
We do see lots of errors from, you know, other intakes that are being done out of our hands that do come to us. It certainly does become a very disjointed process... We definitely do a lot of, you know, damage control and chasing down errors.” (Key Informant)

As participants explained, intake becomes especially confusing for families when multiple agencies become involved. For example, if a family completed intake at DSRC but their documents are missing information, KPAS central intake would follow up. Then, when parents are assigned a service agency to receive ABA, it may or may not be KPAS or DSRC – it could be a third agency such as CMHA WWD. Thus, as participants explained, families become confused about whose waitlist they are on (especially when transitioning between partnerships at age 8), who they should call for assistance, and/or why they must often repeat their story. This confusion is compounded by the fact that most services have separate intakes (e.g., KPAS general services vs. ABA), that families have to reapply for the ABA waitlist each time they complete service, and that similar to KPAS for ABA, ErinoakKids in the central intake for IBI, so families often communicate with them as well.

“I speak to families daily who have no clue which intakes they’ve done, where they’ve sent documents to, which intake is complete, which intake is still pending. It’s incredibly confusing for families to actually access all of these services.” (Key Informant)

“All you hear is, do you want to go back on the waiting list? If you do, you just wait and wait and wait, you don’t know which agency you’re waiting for.” (Parent/Caregiver)

According to a key informant, one improvement during Cycle Three was the implementation of a one-time consent form which does not expire after one year (as the previous forms did). This eliminated the time-consuming task of contacting families to re-sign consent.

“Previously, families were signing a new consent form yearly, so now we have a one-time consent form so that has really streamlined the process and as well has been able to streamline our files and documents. So that’s great.” (Key Informant)

Challenge #6: Transitions between partnerships

Transitioning between the ErinoakKids and KPAS partnerships at the age of 8 to 9 years has been a challenge in all cycles of this evaluation. First of all, as was explained in Challenge #1 about intakes/waitlists, the process of switching partnerships is confusing for families as they are not always aware of whose waitlist they are on, or which agency will be providing their service. Secondly, other than in Halton (where paperwork is being received from Woodview), there is still little to no paperwork being passed between agencies serving the different age groups. This means that when families make the transition, parents/caregivers are asked to repeat their story and to remember details about their child’s past experience with ABA. Sharing paperwork would help Consultants to better understand their clients, such as which goals a child has worked on and what strategies have worked well. Thirdly, prior to
calling a new client’s parents, not all ABA Consultants are even aware if the child has done ABA before. Such insight would be helpful prior to such conversations.

“If you’re doing really good clinical work with a family or a child, there may be some really good features that you’re providing that could be generalized to the next provider so that you’re much more efficient when you’re working with that family.” (Key Informant)

“[We do not know] if they [our clients] are transfers over from KidsAbility. Because sometimes I don’t find that out until like the first meeting. Or yeah if they’ve had ABA through another agency and then switched over, that information is good to have on your first phone call, but it’s not really written out anywhere.” (ABA Consultant)

According to participants, some efforts have been made in Cycle Three to improve transitions for children aged 8 to 9 years, particularly in the Waterloo Region. For example, joint groups have been created between KidsAbility and DSRC, and occasional meetings have transpired between Clinical Supervisors of the different partnerships to discuss specific clients.

“So that [transitions between partnerships] has come quite a long way. So if we have a client that we think is through KidsAbility, we can tell our Clinical [Supervisor] and she will talk to the other Clinical [Supervisor] and then they can talk, okay this is a good fit, is this a behavioural kid or is it a social?” (ABA Consultant)

Challenge #7: Deferrals

Many participants discussed the challenge of deferrals this cycle, especially in the Waterloo, Wellington and Dufferin regions. Families are allowed to defer service twice before being placed on the bottom of the waitlist, a change from the three deferral rule of previous years. As participants explained, many families tend to linger near the top of the list in order to receive ABA at a more convenient or appropriate time, such as when they do not have other agencies or therapists involved with their children. Deferrals, however, can put staff behind, as it takes a lot of time to follow up with families.

“You spend a month calling and chatting back and forth a bit and then they say ‘we’re going to defer.” (ABA Consultant)

According to participants, some families prefer to receive service in the Summer, when their children have more free time and can receive ABA support during the daytime. Other parents prefer to defer service until the Fall, as some are on vacation during the Summer and/or they want their children to work on school-related goals such as homework or setting routines. By having the option to defer service, families can have more “say” into the timing of ABA, which some parents/caregivers described as a challenge in and of itself.

“I think some parents feel we have this never-ending list and we go through the cycle – your name comes up, you get service, your name goes back on the list; your name comes up, you get service, your name goes back on the list, instead of actually using services when it’s most beneficial for your
child... We’re servicing children strictly based on a list versus when it would be most useful and most beneficial and have the most impact on them.” (Parent/Caregiver)

Challenge #8: Working with complex clients

Clinical Supervisors, key informants, and ABA Consultants explained that clients with mental health conditions or whose parents/caregivers have mental health conditions can be particularly challenging to serve. Firstly, many of these clients require more frequent – sometimes daily – interactions with ABA Consultants, as well as a program that extends beyond the rigid six-month limitation. Secondly, many of these clients – such as those with anxiety - require additional services before or during ABA, in order for the program to be successful. However, because of wait times and other systematic issues, this is not always possible. Families are sometimes given the impression by other services that ABA will solve their problems, when in reality they are in need of much more help.

“I think that’s where it’s really tough, the timeline in our model doesn’t fit those complex cases.” (ABA Consultant)

“There are many clients that I’m starting to see that really it’s a stretch to make ABA work for what their needs are, or their needs are beyond what our program should be doing and beyond what certified behaviour analysts should be [doing] within their scope of practice.” (Clinical Supervisor)

Participants also commented that working with low-income families can be a challenge for a number of reasons. First, parents/caregivers of low-income families are sometimes more stressed and less able to participate in ABA. Second, Consultants need to be more creative in coming up with cost-free reinforcers and bringing their clients into cost-free natural settings. Third, Consultants cannot always recommend additional services that would benefit the child as they are not financially feasible.

“[It is] a little bit more difficult to implement things if you’re worried about what’s going on the table for dinner. Telling your kids no and being able to deal with that at that time, they don’t have the energy to be able to do that.” (ABA Consultant)

“It’s nice to have community involvement [within the context of ABA] and going out and doing recreational activities and shopping or whatever, but you’ve got to have the money for it.” (Key Informant)

“[Sometimes] you know that the success of the child would include other services, but financially they can’t afford to have these services. Maybe have one or two, but it’s not enough for their child. And we know that the only other way to serve this child is to involve other services that aren’t available.” (ABA Consultant)

Nevertheless, some ABA Consultants explained that parents/caregivers with lower socioeconomic status are sometimes much more involved in the program, as they cannot afford other services and want to make the most of ABA.

“I find sometimes they [parents with lower SES] are the ones that are more eager to help and learn skills just because they don’t have any other outlets.” (ABA Consultant)
Challenge #9: Behaviour Support Plans and related paperwork

The Behaviour Support Plan (BSP) and other reports were identified as a challenge, not because they are not useful to ABA staff, but because: (1) the discharge reports are difficult to get signed once ABA is complete; and (2) the BSPs and the discharge reports are difficult to read for families and schools. While the final discharge report is sometimes signed within the last session, this is not always possible if the last session is missed or if the final report is not yet complete (due to a lack of time, such as in Summer camps). As Consultants explained, they often spend significant time calling families in order to close their file and – in some cases - to get them back on the waitlist. This was described as a significant challenge for most agencies in the Central West Region, including KPAS Peel and CMHA WWD, though agencies in Halton rarely experience this challenge.

“The other part that I think didn’t work well was I have a number of people who didn’t get back to me to sign the final report after camp. So I have a number of people who are like discharged and not put back on the waitlist until we get that report back.” (ABA Consultant)

Some parents/caregivers as well as ABA Consultants agreed that in many agencies such as KPAS Peel, the BSPs can be overly detailed and difficult to read for families and schools. Several Consultants explained that their reports contain “jargon” which many families and teachers do not understand, especially if they have limited training in ABA, or if English is not their first language. However, staff from some Peel and Halton-based agencies explained that their BSPs are shorter, easier to read, and more “geared to the parents”.

“Sometimes I have to read it [the report] four to five times before I really understand what the point of their conversation is... Specifically for a parent that doesn’t have training in ABA or a parent that has English as a second language, I don’t think they would understand most of that report.” (Parent/Caregiver)

Finally, while most participants did not discuss the CANS this year – perhaps because it continues to be mandated by the Ministry – some ABA Consultants explained that the CANS is not helpful.

Challenge #10: Ageing out of ABA

When clients turn 18, they are no longer eligible for ABA programming and are often left without resources or supports. As one Clinical Supervisor explained, “this is a… crisis. Maybe they’re not screaming [or] shouting, but having no supports whatsoever is another form of crisis too”. All groups of participants expressed their concern for clients at this age, many explaining that they wish ABA could continue for them, or that there was some sort of transition plan available for families.

“If you ask me they should be able to access the program life-long, because you never know the skills

Mitchell’s Case Study

Joanne (Mitchell’s mother) appreciates all of the skills that Mitchell has gained through the ABA program, but is worried about what the future will bring once Mitchell turns 18. Joanne sees this lack of service as a major gap for youth like her son, who are experiencing – or about to experience – many life transitions.

> to read Mitchell’s full case study, see Appendix 1
they’ll need.” (Parent/Caregiver)

“It would be great if your organization can extend services to young people up to 21 years of age since they are familiar with the routines set out by your institution and the adjustment in their lives at this age is too overwhelming (graduation from high school, searching for universities, applications after applications, job searching, etc.). They need more supports at this stage in life!” (Parent/Caregiver)

“When children do, you know, age out of the ABA program at 18, it would be nice if there was some type of a transition into something else. You know, with the ABA program, essentially the child hits 18 and they’re discharged from the program, and it’s a pat on the back and a see you later.” (Key Informant)

One way that ABA Consultants are supporting their older clients is through preparing families for the Developmental Services Ontario (DSO) process. When a client is reaching the end of their service, Consultants explain what the DSO is, and encourage parents to apply for the DSO even if their child is likely ineligible. Unfortunately, while ABA is available to all children/youth with ASD, no matter where they fall on the spectrum, this is very rare for developmental services and almost unheard of for adults.

“Adolescents who are diagnosed with Asperger’s, who are certainly appropriate referrals to the ABA program, will not... they typically don’t qualify for the DSO, so they typically require more supports [and] must go through a mental health service or supports or they’re just out of luck. So that’s a big challenge, at age 18 right?” (Key Informant)

**Summary: Challenges in Cycle Three**

1. Waitlist length
2. Heavy staff workloads
3. Insufficient training opportunities for staff
4. Family involvement
5. Intake and waitlist process
6. Transitions between partnerships
7. Deferrals
8. Working with complex clients
10. Ageing out of ABA
Program Outcomes
As found in previous evaluation cycles, many of the anticipated outcomes that are outlined in the program logic model (Appendix 2) were in fact achieved. Clients and their families continue to be impacted positively by the program, with most clients achieving their goals and learning new skills, and most parents/caregivers feeling supported by their Consultant and learning new strategies and techniques. Unlike in previous cycles, however, there were no system-level outcomes in Cycle Three. This section will explore outcomes for both clients and their parents/caregivers.

Client Outcomes
Evaluation data revealed that children/youth continue to achieve a number of short- and long-term outcomes through participation in the ABA program. These outcomes are listed below, in order of strength. It is important to note that while many outcomes were identified by parents/caregivers, a few of them explained that it is difficult to attribute these outcomes solely to ABA. As one parent explained, “It’s hard to say it’s ‘just the program’ because they do other things as well”.

Consistently meeting goals
Consistent with data from past evaluation cycles, it is very rare for a child/youth to not meet their ABA goal. In fact, the majority of children across the Central West Region either meet or exceed their goal, according to the five levels of outcomes of the Goal Attainment Scale (GAS). Figure 9 shows the percentage of clients across all service providers in the Central West Region that attained each of the five levels of outcomes from the GAS. The two most common GAS outcomes were +2 (outcome much more than expected; 46%) and +1 (outcome more than expected; 29%). This can be compared to data from Cycle Two (Figure 10), where 37% of clients achieved a GAS score of +2, and 37% of clients achieved +1. In total, 96% of all clients who completed the program in Cycle Three (between April 1, 2015 to January 31, 2016) reached or exceeded their expected outcome.
Figure 9: 2015 Goal Attainment Scale (GAS) scores for clients in the Central West Region (N=733)

Source: ABA Roll-up (April 1, 2015 – January 31, 2016)

Figure 10: 2014 Goal Attainment Scale (GAS) scores for clients in the Central West Region (N=619)

Source: ABA Roll-up (April 1, 2014 – December 31, 2014)

Figure 11 shows GAS scores by service provider. All regions had higher numbers of clients meeting or exceeding goals than clients with unsatisfactory results. The most common GAS score in all regions except Halton was +2 (six out of nine agencies). At KPAS Halton and CLNH, the most common score was 0, while at ROCK (also in Halton), the most common score was +1. One evaluation participant explained that following last year’s report, where average scores were +1 (e.g., at KPAS Halton & ROCK) or +2 (e.g., at CLNH), Consultants in Halton were encouraged to set more ambitious goals so that +1 and +2 were more difficult to achieve.

“After last year’s report came out I did notice that the majority of clients had exceeded their goal. That sounds great, but at the same time was concerning to me because if the majority of clients are exceeding their goal perhaps we are not setting ambitious enough goals. The intent is to set a goal they could meet, not a goal they could exceed. I know that is something we’ve made an effort to look at carefully in Halton.” (Clinical Supervisor)
Most evaluation participants agreed that children/youth are meeting their goals, and are gaining skills related to the chosen skill domain. This was reported to be consistent across domain areas and most diagnoses.

“The clinical role is data-driven and shows that they [the clients] are at plus ones and plus twos, there are very few who do not meet their goals.” (Clinical Supervisor)

“Parents are happy that the kids are meeting their goals, it’s extremely rare for a goal not to be met, and that’s usually if parents are not following through or cancel a number of appointments. Like it’s extremely rare.” (Key Informant)

“I think the social skills, the last one was really good for him in terms of just learning more about how to interact with others. That whole social skills is very difficult for him, so that was a good experience for him, and he had really improved.” (Parent/Caregiver)
Figure 12 provides additional insight into parents’ and caregivers’ perspectives on client outcomes, as reported in the Consumer Feedback Survey. As shown in this figure, the majority of parents/caregivers (85%) agreed that their child had met their intended goal.

Figure 12: “In my opinion, my son/daughter reached his/her goal as outlined in the Behaviour Support Plan” (n=238)

Interestingly, 10% of parents/caregivers who completed the Consumer Feedback Survey did not feel that their child had reached his/her intended goal. This can be compared to another question on the Consumer Feedback Survey completed by the administrator (Figure 13), that asked if the goal was met as per the clients’ final discharge report. According to this figure, only 1% of clients did not meet their goal. Clearly, as was identified in Cycle Two, this discrepancy demonstrates that GAS scores do not always reflect parent/caregivers’ perceptions of “success”.

Figure 13: “Admin: Was the goal met as per final discharge indicated on the client system?” (n=240)
Figure 14 provides additional information on parent/caregiver perspectives. According to this chart, 82% of parents/caregivers agreed or strongly agreed that there was a positive change in the skills/behaviour addressed in the ABA program. This is similar to the 85% who agreed that the goal had been achieved in Figure 12.

**Figure 14:** “There has been a positive change in the skills/behaviour in the goal we addressed” (n=243)

![Bar chart showing the percentage of respondents' agreement](chart.png)

*Source: Consumer Feedback Survey (February 2, 2015 – March 7, 2016)*

**Increased confidence, self-esteem, and independence**

As was reported in Cycle Two, several evaluation participants reported heightened levels of self-confidence, self-esteem, and independence in clients following ABA. A number of parents/caregivers reported that their children/youth were proud of themselves for accomplishing their goal and felt more confident in their skills and abilities.

“There was no way my daughter could miss a session because she really looked forward to it and I really think it helped her self-esteem.” (Parent/Caregiver)

“[She’s] feeling pretty good about herself, like I can do anything.” (Parent/Caregiver)

“The most promising aspect is that she’s been really proud of herself for the goals that she achieved during ABA.” (Parent/Caregiver)

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**Paul’s Case Study**

The skills that Paul was able to practice with Tara (his ABA Consultant) and the others in the social skills group increased his confidence in being able to connect with his peers in a wide variety of situations. Paul explained that it is now easier for him to make friends – or at least “acquaintances” – wherever he goes.

> to read Paul’s full case study, see Appendix 1
A few parents/caregivers also reported that because of their child’s involvement in ABA, they are now more confident to discuss the challenges that they face and to ask for help when they need it.

“She’s not even ashamed to tell somebody [that she is in ABA]. I think that is so empowering to say ‘You know what, I’m not embarrassed to say I need this… I’m a great kid, and I have lots of great qualities and that there’s just a few things that I’ve got to work on’.” (Parent/Caregiver)

Building friendships with consultants and other clients

Several evaluation participants in Cycle Three discussed the development of friendships between clients and their Consultants. Parents/caregivers explained that their children look forward to working with their Consultant, especially when there has been consistent matching across the years. As one Consultant explained:

“I’ve been here for five years now so having that rapport with the children, like I’ve known these kids for almost four years now, right? So it’s that watching them grow and I think that is a positive for both myself and for the families.” (ABA Consultant)

According to evaluation participants, some children have also built friendships with other ABA clients in their groups or dyads. Children/youth are able to interact with others of similar ages and abilities within the ABA program, and sometimes re-connect with these individuals outside of ABA. In comparison to other evaluation cycles, very few parents/caregivers discussed this outcome, but this may be due to the limited number of parents/caregivers involved this cycle.

“In successful social skills groups or dyads, I’ve had many relationships formed and then maintained.” (ABA Consultant)

Maintaining and generalizing skills

Participants explained that both maintenance (the continuation of a goal) and generalization (the application of a goal to other people and settings) occurs most often when parents/caregivers are involved with the ABA program and have learned the required strategies and reinforcements. Thus, this outcome is intricately linked to one of the parent/caregiver outcomes explored later called ‘learning and using new strategies’.

Within Cycle Three, a number of parents/caregivers commented on how well their child/youth had maintained and generalized their goal, with some explaining that following ABA, they began to see their child’s new skills being applied in other settings (e.g., at school, in the community) and with other people (e.g., teachers, neighbours). Some parents/caregivers commented that their children have used the strategies learned in ABA to create — and follow through with — new goals on their own.

“I’ve seen some of those skills transferred playing with neighbours and friends.” (Parent/Caregiver)

“Now that she knows that she can be successful with goals that we’ve set together and she kind of sees how you go about to achieve them, she has been coming up with ideas to set her own goals. For
example she came up with a goal to brush her teeth a little bit more, not just in the morning.” (Parent/Caregiver)

Nevertheless, some parents/caregivers reported that maintenance can be difficult if the strategy takes a significant amount of time, and/or if the family must continue with rewards or other reinforcements.

“Continuing was great, but sometimes actually doing all the implementation where he had a system of rewards, and he got extra minutes if he asked for help, we drifted off from doing that after the session was over, but we still maintained doing the list of jobs and the reward at the end of it. So we partly kept them on, but I didn’t have time to do all of it.” (Parent/Caregiver)

Experiencing fewer moments of crisis
Finally, some evaluation participants – mostly key informants – explained that the ABA program helps to ensure that fewer families are experiencing moments of crises related to their child’s ASD. As they explained, Consultants can focus on a family’s immediate needs and address behaviours before they become overwhelming or too severe. Nevertheless, it must be noted that the first-come-first-serve nature of the waitlist, the extremely long wait times, as well as the fact that ABA is not a mental health service, means that ABA cannot always help families when a crisis is on their hands.

“[ABA is] alleviating some of the families that were going into crisis because the behaviours were out of control and the Consultant was able to get connected, was able to find out what are the triggers or what are the goals that they can work on.” (Key Informant)

“I find that a service such as this prevents a family [from] going into crisis... It’s a preventative measure, and I think that was the intent of it when it was developed.” (Key Informant)

Summary: Client Outcomes in Cycle Three
1. Consistently meeting goals
2. Increased confidence, self-esteem, and independence
3. Building friendships with consultants and other clients
4. Maintaining and generalizing skills
5. Experiencing fewer moments of crisis

Parent/Caregiver Outcomes
According to participants, parents/caregivers are also experiencing some important outcomes as a result of – or at least in part due to – their child’s involvement in ABA. These outcomes are explored below in order of strength.

Learning and using new strategies
A number of evaluation participants commented on the various strategies and techniques that parents/caregivers gain from ABA, especially those who observe and participate. There was some acknowledgement among evaluation participants that parents tend to learn more strategies when their
child receives one-on-one versus group support, possibly because they can have more individual interactions with the Consultant, and the Consultant is focused solely on their child. Once ABA is over, parents/caregivers can continue to implement the strategies that they have learned, in order to help their child maintain their goal.

“I was given the tools to achieve the goals set in place and tools to continue so that my child progresses even after sessions were complete.” (Parent/Caregiver)

“For families, I think there’s an incredible opportunity to provide more education, to help families learn to generalize skills. I mean if we do our job properly, they should be able to generalize to the next behaviour, and that’s challenging them, so I think that part’s excellent.” (Key Informant)

Figure 15 demonstrates that 89% of parents/caregivers who completed the Consumer Feedback Survey said that they can use the strategies and techniques from ABA to address their child’s goal on their own.

**Figure 15:** “I am able to use the strategies/techniques to address the goal on my own” (n=240)

![Figure 15: I am able to use the strategies/techniques to address the goal on my own (n=240)](image)

Source: Consumer Feedback Survey (February 2, 2015 – March 7, 2016)

Some parents/caregivers also explained that they can use the strategies gained in ABA to work in other settings and on other goals, thus helping their child to generalize what they have learned. In fact, 79% of parents/caregivers who completed the Consumer Feedback Survey agreed that “I have been able to use the strategies/techniques in other settings”, and 77% agreed that “I have been able to use the knowledge I learned to address other behaviours and/or teach other skills”. Moreover, some parents/caregivers explained that they have been able to use their new ABA strategies with other children in the family.

“I have been implementing the same system with his twin brother, been trying to do that as well. We get a lot more out of him than we used to. So it’s very transferable in that way.” (Parent/Caregiver)

Finally, just over half (59%) of parents/caregivers who completed the Consumer Feedback Survey agreed that other people have been able to use the strategies/techniques from ABA with their child, while 16%
disagreed and 25% responded ‘not applicable’. However, it is unclear who these other people are, as parents/caregivers were not given a chance to comment. They may be referring to family members, teachers, sports coaches, or others.

**Greater confidence in abilities**

Parents/caregivers, as well as ABA Consultants, explained that through the ABA program, parents/caregivers become more confident in their ability to support their child, and more reassured that they are doing the “right thing”. According to participants, this feeling of reassurance stems from working closely with a professional in the field – the ABA Consultant – who can provide tips and strategies, check in with parents/caregivers, and help them to see how their child is improving.

“It really made me feel like for once right now anyways, I’m doing the right thing.” (Parent/Caregiver)

“The accountability of somebody checking in on them, to make sure that, with the behaviour programs especially, that they’re sort of doing what they’re supposed to, building their capacity, and then telling them that they’re doing a good job, goes a long way.” (ABA Consultant)

**Decreased anxiety**

According to a few parents/caregivers, the ABA program helps to relieve some feelings of anxiety and stress because they are able to set and achieve relevant and meaningful goals. ABA is one of the only supports that many of these parents/caregivers receive, and they are thus thankful to receive some support with the behaviours and challenges they face every day.

“It does help... Psychologically as a parent, at least something has been done for him. Otherwise we have that anxiety ourselves in terms of what is he going to be? Where is he going to learn these basic life skills?” (Parent/Caregiver)

“No more diapers, no more fighting on this issue. One less big issue to manage.” (Parent/Caregiver)

**Increased access to resources**

Through the ABA program, and by talking with Consultants, Service Coordinators, Intake Managers, and other families accessing the program, parents/caregivers are able learn about other relevant resources in their community. Several parents/caregivers explained that these various individuals – especially the ABA Consultants – had provided them with books, videos, and referrals when necessary, which helped to answer their questions and make them feel more supported.

“I really took advantage of the therapist and I asked a lot of questions outside of the goals that we were working on, and she was really great about sharing her resources and she left me with a few books... She left us with a video that we watched together and I returned. That was really helpful.” (Parent/Caregiver)
Improved family dynamics

Lastly, a number of parents/caregivers mentioned that their family dynamics improved as a result of participating in the ABA program, though what exactly this was varied from family to family. For some families, they experienced better communication as a result of ABA, between the parents and their children, or between children and their siblings. For others, ABA provided a better understanding of ASD, thus helping family members to better understand – and interact with - the person(s) with it. And still for others, ABA helped family members to spend more time together, after diminishing behaviours that may have kept them apart (e.g., swearing, being aggressive, not communicating properly, etc.). Overall, as one parent put it, ABA has created “a little bit less stressful environment for everybody”.

“I think she [my daughter] is maybe not as embarrassed as she once was [of her sibling with ASD]... Sometimes she just didn’t even want her friends to be around my other daughter, but now that seems to be okay.” (Parent/Caregiver)

“[Following ABA], we can spend time with [each] other and our life quality improved.” (Parent/Caregiver)

Summary: Parent/Caregiver Outcomes in Cycle Three

1. Learning and using new strategies
2. Greater confidence in abilities
3. Decreased anxiety
4. Increased access to resources
5. Improved family dynamics
**Future Directions**

This section provides 21 recommendations that emerged through discussion with the evaluation Steering Committee as well as suggestions from evaluation participants in Cycle Three. It is divided into sections according to the main components of the ABA program, as outlined in the program logic model. While there were many suggestions provided by evaluation participants, the recommendations below are seen to be the most feasible and impactful. Note that in light of the differences in ABA program implementation across the Central West Region, certain recommendations are more relevant to some of the regions than others. Also note that some recommendations are very similar to recommendations from Cycle Two (marked by an asterix).

**Intake and Wait List**

1. Explore ways to simplify the intake process for the ABA program in order to create a clear path for families to follow, prevent duplication of files, and reduce time spent on incomplete intakes.

2. Explore upgrading the current intake database system to a system that is capable of supporting a large number of client files and related administrative information.

3. Continue to provide families with as many relevant resources as possible (e.g., books, videos) and ensure that resource libraries have client-oriented resources (e.g., toys, activities).*

4. Explore the possibility of providing information to families at intake to encourage realistic goal-setting and speed up the service planning process (e.g., provide examples of possible ABA goals or illustrations of how the program works).*

**Service Planning**

5. Continue to strengthen collaboration between ABA Consultants and Service Coordinators to provide more integrated and holistic support for families, where possible. For example, encourage communication between Consultants and Service Coordinators at the beginning and/or end of a round of service.

6. Explore how goals are developed across agencies, and develop a means to ensure consistency in the level of difficulty and the scoring of goal attainment.

7. Explore why parents/caregivers are not always engaged in the ABA program. Moreover, consider adding an educational component for parents/caregivers to the first session of each round of service, in order to increase their engagement and understanding of the ABA program, as well as their ability to – and likelihood of – maintaining and generalizing goals.

8. Continue exploring ways to develop more creative and effective groups, including girls-only groups, dyads, and summer camps. Some ways of developing better matched groups could include cross-agency groups and mock groups (i.e., larger trial groups to determine suitability and compatibility).
**Service Delivery**

9. Continue to explore options for including more natural settings in ABA sessions to support clients in navigating real-life situations. One way to do this could be to use a natural setting for the last session(s) in a round of service to practice what was learned. Consider also implementing groups in new settings, for example community centres or school gyms to increase accessibility for families.*

10. Continue to create new and relevant programming for teens.*

11. Explore ways to communicate program planning and outcomes (including goals and strategies) to caregivers/parents in a more accessible and user-friendly format.

**System-Level**

12. Consistently ensure that transition plans are in place for children moving from the ErinoakKids partnership to the KPAS partnership, including the transfer of relevant program documents (e.g., Behaviour Support Plans, discharge reports).*

13. Continue to develop partnerships with key school or school board representatives to increase general understanding of the ABA program and to increase mutual awareness of ways of providing support. Moreover, continue to explore opportunities to implement ABA program goals in school settings.*

14. Continue to advocate for transition supports for 18-year-olds and their families.

15. Consider having inter-agency autism work groups in all regions (similar to the Autism Work Group in Peel).

16. Explore how the complexity of challenges related to mental health can be better addressed for children/youth across developmental stages, and for parents/caregivers, within each region.

**Overall**

17. Continue to seek funding to hire additional ABA Consultants and Clinical Supervisors in order to shorten waitlists, increase frequency of service for clients, and potentially decrease evening work for staff.*

18. Upon hiring new staff, ensure a clear and realistic understanding of the number of evenings of work required for the position.

19. Continue advocating to the Ministry of Children and Youth Services to revise the funding formula so that ABA Consultants have reduced caseloads and are able to sustainably meet their service targets.*
20. Explore ways to provide more flexibility in program structure to better serve the diverse client base. For example, some clients could benefit from shorter, more frequent sessions, whereas other clients could benefit from longer sessions but over a shorter period of time.

21. Create more frequent opportunities for ABA Consultants from different agencies within and across regions to discuss challenges, share new and innovative curriculum and program materials, and build a community of practice.

22. Increase relevant training opportunities for ABA consultants, prioritizing opportunities where all Consultants can learn about and implement the cutting-edge practices in the field of ABA. Also consider arranging/providing training opportunities in the field of mental health.

23. Ensure KPAS has no overlap in job titles. For example, Service Coordinators and ABA Consultants are both titled “Autism Consultants”, which can be confusing for families.

24. Make the Consumer Feedback Survey anonymous by removing identifiers (client name or ID). Instead, consider making the ABA Consultant’s name mandatory.*
REFERENCES


APPENDICES

Appendix 1: Case Studies

Amelia’s Case Study

Amelia* is a 15-year old girl who is in grade 10. She is highly engaged in academics; last year, she made the Honour Roll and received the Science Award for her school. Amelia loves playing games, and has recently started her own YouTube channel, where she posts videos of herself playing video games.

Amelia and her older brother Jacob currently live with their mother, Margaret, and their step-father, Phil. Jacob was diagnosed with ASD at an early age, and so Amelia’s development was closely monitored from birth. At the age of six, Amelia was diagnosed with Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS).

Following Amelia’s diagnosis, and after witnessing Jacob’s success in IBI therapy, Margaret signed her daughter up for IBI. However, according to Margaret, it quickly became clear that IBI would “not work at all for her [Amelia]”. Although Margaret is very resourceful in finding avenues of support for her children, she described being at her “wits end” trying to figure out how to best support Amelia. When Margaret heard about the ABA program, she said that she was therefore “the first person to sign up”. To date, Amelia has completed two rounds of ABA, the first in a group setting and the second at home. Amelia is scheduled to participate in her third round this Spring.

A Challenging Beginning

Amelia’s first experience with ABA involved working on social skills in a group setting. Amelia was resistant to participating in any form of therapy, so Margaret thought that the group setting might mitigate some of that resistance. Unfortunately, however, Amelia did not thrive in the group environment, and fought participation every week of the program. Nevertheless, Margaret explained that “something stuck” from her participation in the first round of ABA, and Amelia managed to connect with one of the other children in her social skills group.

After that experience, Amelia was placed back on the waitlist for a second round of ABA. When her name came up again, Margaret decided that another group session would not be the most beneficial, so she requested a one-on-one session in their own home.

Developing Trust

Margaret had requested that Amelia’s second round of ABA be focused on emotional regulation, with the goal of being more empathetic, using appropriate language, and setting boundaries. According to Amelia’s ABA Consultant – Jane – Amelia knew that her recent outbursts were negatively impacting her family, though she “wasn’t fully involved in saying ‘I want to change my behaviour’”. Thus, although Amelia knew that her behaviour was a concern for her family, she did not completely “buy-in” to the program, and was still not interested in participating in ABA. In fact, she was so resistant to therapy that she was initially told that Jane was actually in their house for Jacob, as they had worked together previously. Eventually, Jane gained Amelia’s trust and their relationship grew. Amelia explained that she

*All names in all case studies have been changed
appreciated having someone outside of her own family to confide in. According to Margaret, taking the time to build this rapport was especially important for Amelia’s success in ABA, since Amelia has always had difficulty trusting adults.

A Greater Understanding

One of the positive impacts of Amelia’s participation in the ABA program was the insight it provided to Margaret and the rest of her family regarding Amelia’s day-to-day experiences. For example, Margaret explained that she was always confused by Amelia’s strong reactions. However, throughout the ABA program, as Amelia opened up to Jane, she was able to describe in detail the reasons for her strong reactions. Eventually Jane helped Amelia to share these reasons with Margaret and the rest of the family. This understanding has allowed Margaret to be more sensitive to Amelia’s triggers, which in turn have reduced Amelia’s strong reactions.

A More Cohesive Family

The changes that Amelia has made through ABA have positively impacted her relationships with her family members. Margaret noted that instead of immediately retorting with a mean comment, Amelia is now “processing” before she speaks. Margaret said that Amelia is “stopping and looking at the whole picture” of what is going on, which in turn moderates some of her strong emotional reactions. Jane agreed that by the end of Amelia’s second round of ABA, she was “thinking about what she was saying before she said it so it wasn’t a hurtful comment”. In speaking with Margaret and Jane, it was clear that this small change made a substantial impact on the family and home environment.

Amelia’s participation in ABA has also improved her relationship with her brother Jacob. During the ABA session, Jane helped the two siblings to negotiate appropriate boundaries. For example, one of the strategies they used was to put stop signs on each of their bedroom doors. When the stop sign was up, it indicated that it was not okay to enter the room. Although at first this was difficult, Margaret explained that the signs remain on both Amelia and Jacob’s doors and are now quite effective in ensuring that boundaries are maintained. Recently, Margaret has also enjoyed watching her two children voluntarily converse about mutual interests, which she said was surprising given their ASD diagnoses. The conversations have mostly been focused on the YouTube channel that Amelia is building, given Jacob’s experience designing YouTube channels as well.

Ongoing Development

After completing her second round of ABA, Amelia participated in a program through Autism Ontario called the PEERS Social Skills Intervention. This program was also a very positive experience for both Amelia and her family, in part due to the groundwork already laid during their time in ABA. According to Margaret, Amelia would not have been ready to participate in an intensive social skills program had she not worked with Jane through ABA.

Amelia continues to have increasingly positive interactions with family members and friends. When her family attended a Christmas party last December, for example, Amelia – for the first time – was the
person who wanted to stay the latest, despite the noisy and stimulating environment which she normally does not like.

For her next round of ABA, Jane hopes that Amelia can be directly involved in determining her goal. Amelia explained that she is interested in participating in ABA again, but hopes that future sessions can involve more programming outside of her house, such as at a mall or a movie theatre.

As for Margaret, her biggest concern moving forward is what will happen when Amelia turns 18. Since emotional regulation continues to be difficult for Amelia, Margaret anticipates that being cut off from existing supports will be a struggle, especially since she has developed such a positive, trusting relationship with Jane. Margaret plans to find all of the supports available to Amelia and Jacob prior to their 18th birthdays, and is continuously advocating through Autism Ontario for continued support past the age of 18. Overall, Margaret is thankful for all of the support she has received from Jane and the ABA program. As she explained, “[Amelia] is definitely where she is because of the ABA [program].”
Paul’s Case Study

Paul is a grade seven student who recently turned 13. He lives with his younger sister, Adeline, and his mother, Dorothy, and spends a lot of time with his father, Michael. Paul is interested in collectable toys, such as transformers, and likes to play video games.

About three years ago, Paul’s parents took him to the doctor as they were concerned that he had an anxiety disorder. The doctor confirmed that Paul has generalized anxiety as well as Asperger’s Syndrome. He recommended several books and programs for the family, including ABA. Paul was quickly signed up for the ABA program and received his first round in the Winter of 2015.

Creating a Unique ABA Experience

Paul’s first round of ABA focused on social skills, with the goal of eliciting conversations with other people and asking them questions about their own interests. His ABA program coincided with another social skills group, the goal of which was to assist boys aged 9 to 12 years to develop the foundational skills necessary to make friends. Since the social skills group was so closely aligned with the agreed-upon ABA goal, it was decided that the ABA program would be implemented within the social skills group. Paul explained that he was interested in this idea, and that despite some negative experiences with similar programming in the past, ABA and the social skills group “made it work!”

According to Paul’s ABA Consultant, Tara, one aspect that made the program really successful for Paul was getting his buy-in at the beginning. Tara took the time to consult with both Paul and his family, who all agreed that conversation skills were a relevant and meaningful goal. The ABA program that Tara then constructed was well suited to achieve this goal, while ensuring that Paul still benefitted from – and enjoyed – what the social skills group had to offer.

Because Paul did not want to be singled out within the social skills group, it was agreed that Tara would act as a group facilitator and not let anyone know that she was there for Paul. She would watch Paul interact with his peers, and provide subtle indications to encourage his conversations and questions, or to praise him for doing well. After each group session was over, Tara, Paul, and Dorothy would meet to review his progress and practice skills. Missed opportunities were also role-played, to assist Paul in using the skills in the following group.

Building Relationships with Others

According to Paul’s mother, Dorothy, one of the important aspects of the program was the “safe place” that the social skills group facilitators and Tara established. Dorothy explained that this was foundational to Paul’s success in the program. Because the social skills group encouraged relationship-building amongst all of the boys, Paul felt comfortable trying out the conversation strategies suggested by Tara. Paul was able to step outside of his comfort zone because he did not feel as though he was criticized or judged by any of his peers, or the program facilitators. After all, all of the boys in the social skills group were working on similar skills.
The ABA program was also an opportunity for Paul to interact with a Consultant, Tara, who has worked with many other children and youth similar to Paul. Paul was thus able to ask questions, not only about his goal but about his diagnosis in general and how other children cope. Since his diagnosis was still relatively new when Paul entered the ABA program, Tara felt that he was trying to come to terms with the ramifications of his diagnosis. She found that especially near the start of ABA, Paul was asking questions like, “What does that mean about me?” As she explained, Paul’s diagnosis was partially a relief for Paul, since it explained why he had struggled to make friends in his younger years, but also difficult to process, as it inevitably came with many questions and unknowns.

Paul appreciated the conversations that he was able to have with Tara. He saw these conversations as great opportunities to build the skills he needed to interact with his peers, but also appreciated the feedback that Tara gave him. He felt as though Tara was very clear on “what I’m supposed to be learning, where I should improve, where I’m pretty strong,” and this helped reinforce his success in the program. In addition to these more concrete interactions, he especially appreciated the time that Tara took to talk about other broader topics, such as his future.

Transferring Skills to Other Environments

Paul explained that his conversation skills have vastly improved through his participation in the ABA program. Tara agreed with Paul, explaining how she has seen a positive shift in his interactions with others. According to Dorothy, Paul’s teachers have even noticed substantial improvements, even though they had no knowledge of Paul’s involvement in ABA.

“All about a month into the program, we had a number of teachers that we met, and every teacher that his father and I spoke to noticed an improvement in the classroom. [They] noticed that he was contributing more orally, he was trying to be more engaged with the other students, especially in group activities. So it was nice to hear that... It’s nice to hear at the school setting the [the] teachers noticed a difference.” (Dorothy)

Paul said that his experience with the ABA program was really the “seed for the tree”, and now he is able to flourish in many different environments. Moreover, in the social skills group, he became closely connected with one boy in particular and said that he was comfortable “at first speech”, which was not something that he had experienced previously. Paul was able to converse with this boy about mutual interests, such as transformers:

“Well, there is this one kid... who was the closest to my age... For me and him, we love the transformers. Mainly he knew a lot about the modern cartoon series, which was cool because I didn’t know that about transformers. Where[as] I told him about the classic stuff and where it all began... He was one guy that I actually really connected with.” (Paul)

The skills that Paul was able to practice with Tara and the others in the social skills group increased his confidence in being able to connect with his peers in a wide variety of situations. Paul explained that it is now easier for him to make friends – or at least “acquaintances” – wherever he goes. Paul said that his experience with ABA “really made me more confident engaging in conversations in school ground
activities.” Dorothy agreed with Paul, explaining that before ABA, he had a lot of difficulty making friends at school, but is now able to more positively interact with his peers at recess.

Dealing with the Inherent Challenges of ABA

According to Tara, one of the biggest challenges of implementing ABA within the social skills group was the timing of the sessions. Although the two programs undoubtedly reinforced each other and enhanced a variety of outcomes, Tara felt as though Paul could have benefitted even more if she had additional time to spend with Paul at his home, to ensure the generalization of skills elsewhere. However, due to the limited intensity of the ABA program, this was not possible.

While Dorothy enjoyed Paul’s experience with ABA, and believed the programming had certainly met his needs, she is concerned about the long wait until Paul’s next round of service. Although Paul will participate in other groups at school, Dorothy explained that they are not catered to Paul’s specific goals and needs, and are thus not as beneficial as ABA. Tara agreed that the long waiting period is not ideal for Paul, since she “really feels like we’re just getting started”. Nevertheless, Dorothy explained that she will continue practicing the strategies she learned to help Paul maintain and generalize his skills.

Looking Into the Future

In addition to his improved conversation skills and ability to make friends, Paul is now more comfortable with his ASD diagnosis. Tara explained that by the end of his ABA program, Paul had better come to terms with what it means to have ASD.

“And then the other part is just with him coming to terms with his diagnosis and what this means for him. I think part of the way we worked with him on this goal is helping him with that idea, because it’s helping him to kind of see that there’s areas that he can improve on, but it doesn’t mean he has to change who he is.” (Tara)

While Paul had a very positive experience with the ABA program, he explained that he still has a lot to learn in order to improve his interactions and conversations with peers. For example, Paul said that he would be better prepared for the future if he could understand body language and learn how to handle conversations involving “expressions” or “body movement”. Paul also explained that since he was one of the oldest boys in the social skills group, and he gained skills so rapidly, he would like to return to the social skills group as an “instructor’s assistant”, to help others succeed in the group.
Mitchell’s Case Study

Mitchell is a 17-year old boy with one younger brother, Jared. He enjoys going on the computer and playing games, as well as Japanese animation and theatre. In fact, he was recently cast as the lead police officer in a school play. Mitchell also holds a volunteer position, gardening with a local organization.

Approximately ten years ago, Mitchell was diagnosed with ASD. Since then, he has also been diagnosed with generalized anxiety, which further impacts his interactions with those around him. Mitchell’s brother, Jared, also has ASD.

Throughout the years, Mitchell has been involved in a variety of therapies, including occupational therapy, speech language therapy, and cognitive behavioural therapy. However, according to Mitchell’s mother, Joanne, none of these therapies address an important aspect of Mitchell’s life – his difficulty coping with everyday situations and learning everyday skills. This is where ABA enters the scene; according to Joanne, the ABA program helps children and youth like Mitchell to improve their quality of life by teaching “life skills” and boosting their confidence and independence.

Trying Something New

Although Joanne immediately saw the fit of ABA for Mitchell, Mitchell was not as convinced. He was still struggling to come to terms with his diagnosis, and did not want to be identified as having ASD. Being surrounded by others with a similar diagnosis was therefore not something he welcomed. Nevertheless, his mother insisted that a group therapy would be most beneficial, and Mitchell agreed to participate in ABA once he found out that it would be similar to a Summer camp.

Pauline – Mitchell’s ABA Consultant – worked with Mitchell during his week at camp. As she explained, the camp had an ABA-based curriculum and was run from Monday to Friday, five hours each day. The camp had a total of six teenage boys and was focused on developing independent living skills. It was different than many other ABA groups in that although each participant had a primary goal, they all worked on skills within five different areas: finance and budgeting, cooking safety, public transportation, resume building, and interviewing skills.

Joanne was truly appreciative of how well Pauline and the other ABA Consultants did at matching the youth in the camp. She noted that all of the boys were on the same level, and that Pauline in particular did a great job to make the camp a positive experience for all those involved.

“She [Pauline] made it fun and she really changed it up for them. She’s really sweet and she just has a way around, just kind of reaching the kids individually, and then kind of pulling them in as a group to finish what her goals for the day were... She was just really great with the kids. And you know, she was one of the reasons why he [Mitchell] wanted to keep going.” (Joanne)

Mitchell agreed that Pauline was wonderful to work with. As he explained, Pauline was “so nice to all of us, even if we were kind of a pain. She was very calm, and she never got mad at us at all.”
Dealing with a Challenging Timeline

One of the biggest challenges of the ABA camp, acknowledged by Joanne, Mitchell, and Pauline, was the short length of the program. Mitchell felt that the camp experience was too short, and that by the end of the fifth and final day, he was “just getting started to like it”. The fact that it was over so soon was especially disappointing for Mitchell, given the fact that he had waited several years for ABA. Nevertheless, while Joanne agreed that the camp experience felt “rushed”, she acknowledged that Pauline did well to cover a lot of information in such a short period of time.

Building Confidence in his Abilities

One of the greatest impacts for Mitchell was his increased confidence in interacting with other peers who also had a diagnosis of ASD. Joanne explained that before the ABA camp, Mitchell did not typically like to interact with his peers as it either increased his anxiety and/or made him feel “different”. However, during ABA, Joanne remembers Mitchell telling her, “I fit in. I’m not weird there... When I go to those things [at camp], I’m normal.” Joanne felt as though this was a really important outcome for Mitchell and that ABA had helped to “reinforce me telling him that he’s not strange, he’s just a little different and that’s okay.”

“That confidence and the fact that he’s so receptive to actually trying and trying again, and that you know he wants to actually put himself out there. That was good for me. Because then he actually wanted to participate in something in a group format, he was very out of his comfort zone, [that] was very good.” (Joanne)

Through ABA, Mitchell also became more confident in his skills. During one camp module in particular – the interviewing module – Mitchell was able to videotape himself to evaluate his own skills. Pauline saw this as a turning point for Mitchell as he was able to “very candidly” identify the aspects of his interviewing skills that he could work on, such as body language. Mitchell found it gratifying to be able to see the tangible improvements in his own skills and scores, even over the short five-day period.

“I think this maybe in terms of secondary outcomes is just confidence in [his] own abilities. You know he kind of gets down on himself pretty quickly. So being able to show him like hey you were actually very successful starting to change the way [you interacted]... And starting to change the way that he thinks about things.” (Pauline)

Transitioning Beyond ABA

It is likely that Mitchell only has one more round of ABA before he turns 18. For his last round of service, Mitchell hopes to focus on social skills again. While his confidence in a wide variety of skills has increased greatly because of ABA, he hopes to gain more social skills. In particular, he would like to learn how to better interpret body language.

“Well if you’re autistic like me and you can’t really read people socially, like if... they’re telling you to leave them alone, but they don’t tell you directly. Like maybe learning how to read the
hints, or read the hints if someone likes you I guess. Because the one thing I’ve been struggling with - is that person joking, or are they being serious?” (Mitchell)

Joanne appreciates all of the skills that Mitchell has gained through the ABA program, but is worried about what the future will bring once Mitchell turns 18. Joanne sees this lack of service as a major gap for youth like her son, who are experiencing – or about to experience – many life transitions.

“That’s why I wish we had more, because I think he’s going to need some help transitioning out of high school you know? The world’s going to get a lot bigger, and I wish I had some extra help with that. With helping them plan a bit more with what the next step is.” (Joanne)
### Appendix 3: 2014 Measurement Matrix

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<th>Research Question</th>
<th>Sub-Question</th>
<th>Indicators</th>
<th>Stakeholder Perspective</th>
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<td><strong>Processes</strong></td>
<td>What is the underlying program theory, including the main activities and expected outcomes?</td>
<td>Evaluator observation and informal conversation</td>
<td>Staff/Management</td>
<td>Site visit(s) Document review Staff/management informal interviews Staff focus groups</td>
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<td>On-the-ground reports</td>
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<td>What are the child and family demographics in ABA Central West Region communities?</td>
<td>Recorded participant demographics</td>
<td>Staff/Management/Management/Third parties</td>
<td>ABA Roll-up Intake Management Database CANS reports</td>
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<td>What resources (e.g., human, financial, partnership) support the various aspects of program functioning (i.e. inputs)?</td>
<td>Recorded program inputs</td>
<td>Staff/Management</td>
<td>ABA Roll-up Key informant interviews Staff focus groups</td>
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### What aspects of the program seem to be working well? Not working well?

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### What is facilitating and what is hindering effective program implementation?

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### How are the guiding principles evident in service delivery?

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### Outcomes

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| ABA Roll-up | Staff tracking logs | Staff focus groups |

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**Centre for Community-Based Research**
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<th>Recorded participant outcomes</th>
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<td>What outcomes has the ABA program had for participating children and youth in the domains of communication, behaviour/emotional regulation, social skills, and daily living skills?</td>
<td>On-the-ground reports</td>
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<td>What outcomes has the ABA program had for the families of participating children and youth in terms of their quality of life, enhanced behaviour management skills, and sense of competence?</td>
<td>On-the-ground reports</td>
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<td>How have outputs and outcomes changed over time?</td>
<td>On-the-ground reports</td>
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<td>What systems level outcomes has ABA programming achieved?</td>
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### Recommendations

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<td>What should be done to enhance the effectiveness of the ABA programs for children and youth? For families? For the networks of ASD-related services in their communities?</td>
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<td>How should future ABA programming be evaluated?</td>
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Appendix 4: Cycle Three Tools

Evaluation of ABA Services (Cycle 3)
Focus Group Guide – Parents/Caregivers

Thank you for agreeing to participate in this focus group. Focus groups have been organized with parents/caregivers of 9 to 18 year-olds that have participated in ABA program in the five regions that make up the Central West Region: Halton, Peel, Wellington/Dufferin, and Waterloo. The focus groups will give us insight into three main questions:

- How is the ABA program being implemented at agencies in the Central West Region?
- How and to what extent has ABA programming impacted participating children/youth and their families?
- What recommendations can be made to improve the ABA program for children, families, and the networks of ASD-related services in their communities?

There are four main sections in this focus group. We’ll start with an introduction, then talk about your experiences with the ABA program including program implementation and outcomes, and end with your thoughts on future directions for the ABA program. Do you have any questions before we begin?

INTRODUCTION

We will start with some introductions.

1) What is your child/youth’s connection to the ABA program?
   a. How old was your child/youth when they entered the program?
   b. How many times has your child/youth participated in the ABA program?
   c. What ABA domain area(s) was your child/youth working on?
   d. What is their ASD diagnosis?
   e. What other ASD-related services and/or treatments has your child/youth received?

PROGRAM IMPLEMENTATION

With the next few questions, we would like to gain an understanding of how the ABA program functions, from start to finish.

2) Based on your experience in the ABA program, what aspects of the program seem to be working well or not working well?
   Probe in the following areas:
   a. Intake and waitlist process before the child/youth is admitted
   b. Development of ABA service plan – domain areas, goal setting, assessment tools
   c. Implementation of the ABA plan – including child and parental involvement
   d. Discharge activities – booster sessions, re-referrals to ABA, referrals to other programs
   e. Maintenance and generalization of ABA goals
   f. Across the program cycles - ABA consultant, interpretation services, scheduling, etc.
3) Please describe the involvement of your child/youth’s school in the ABA program.
   a. Was the school aware that your child/youth was in the ABA program? If yes, in what ways did they support your child/youth?
   b. Was your child/youth’s Special Education teacher (e.g. ASD itinerant/ASD resource teacher/Life Skills_ISSP) involved in their ABA program cycle? In what ways did he/she support your child/youth’s goal attainment?
   c. Overall, how did the school’s involvement facilitate or hinder ABA program implementation?

4) What kinds of continued support have you received from other ASD-related services?
   a. How satisfied do you feel with the level of support you have received?
   b. How successfully was your child/youth able to transition from the ABA program to other ASD-related services?

PROGRAM IMPACTS

*Now, we would like to learn about the impacts of the ABA program on participating children/youth and their families.*

5) What have been the most promising aspects of the program for your child/youth?
   a. How has the program improved upon your child/youth’s behaviours and skills?
   b. Did you witness changes in your child/youth in addition to the primary ABA goal?
   c. How have your child/youth’s new skills generalized to other settings (e.g. school)?
   d. What have been the longer-term impacts on your child/youth’s well-being?
   e. What makes this experience distinct from other ASD-related services?

6) What have been the most promising aspects of the ABA program for you and your family?
   a. What change have you experienced in your ability to manage your child/youth’s behaviour and to teach them new skills?
   b. How has the ABA program affected your level of confidence and feelings of competency when delivering the program goals?
   c. What steps have you taken to maintain your child/youth’s new skill(s)?

FUTURE DIRECTIONS

*To end, we would like you to consider future directions for the ABA program.*

7) What should be done to improve the ABA program for you and your child?
   a. How could the program meet the needs of your child/youth better?
   b. How could other ASD-related services support you better:
      i. While your child/youth is admitted to the ABA program?
      ii. Before and after your child/youth participates in the ABA program?
Evaluation of ABA Services (Cycle 3)
Parent/Caregiver Focus Group - Sampling/Recruitment Plan

Number: 10 focus groups, 4-5 participants per group (including the option of conference calls with 2+ families, and parents who want to submit written answers instead)

Sampling:
Parents/caregivers will be invited to participate in focus groups (in-person or over-the-phone) to discuss the program processes, outcomes, and recommendations for improvements. Two focus groups (one in-person and one teleconference) will be organized in each of the five regions in the Central West: Halton, Peel, Wellington, Dufferin, and Waterloo. Participants will be selected in cooperation with the Evaluation Advisory Committee according to purposive sampling criteria below. Methods will be implemented with ethical considerations, including fully informed consent.

Criteria:
- Sampling criteria for parent/caregiver participants will include:
  - Representation from across the Central West Region
  - Range of length of involvement (one cycle families and more)
    - Use tracked number of parent training hours
  - Both father and mother representation
  - Ethnic diversity
  - Range of child/youth’s ages
  - Range of child/youth diagnoses
  - Range of number of children involved in program
  - Range of models of services

Recruitment:
The Evaluation Advisory Committee will develop and finalize names based on agreed upon selection criteria. Potential participants will receive an email/phone invitation to participate by ABA staff on the Advisory Committee, and if interested, participants will receive project information, the focus group guide, and the consent form. ABA staff on the Advisory Committee will take leadership in organizing the focus groups with the support of CCBR researchers. ABA staff will also provide interpreters when needed.

ABA staff will pass on contact information to CCBR researchers for families who are interested in participating in the evaluation, but are unable to attend focus groups. CCBR researchers will then take leadership in coordinating the collection of written responses from these families.
Evaluation of ABA Services (Cycle 3)
Parent/Caregiver Focus Group Consent Form

I understand that I am being asked to participate in the evaluation of the Applied Behaviour Analysis (ABA) program in the Central West Region: Halton, Peel, Wellington/Dufferin, and Waterloo. This study is being conducted by the Centre for Community Based Research on behalf of Kerry’s Place Autism Services (KPAS). The purpose of this study is: (1) to assess the implementation processes of ABA programming in the Central West Region; (2) to assess the outcomes of ABA programming at the child-, family-, and systems-levels; and (3) to identify future directions for improving on the ABA programming provided by the Central West Region agencies.

I understand that I have been selected as a focus group participant who may have some insights to share about the processes, outcomes, and future directions of the ABA program.

I understand that the focus group interview will take approximately 90 minutes. I understand that all notes from this interview will be stored in a locked location to protect my confidentiality, and that my name will not be associated with any quotes found in any written summaries.

I understand that this interview is voluntary and that I may withdraw my participation at any time without penalty. I am also aware that I may decline to answer any question or speak to any issue that I wish not to discuss.

I understand that if I have any questions, I can contact Rich Janzen (519-885-1460 ext. 25293), rich@communitybasedresearch.ca at the Centre for Community Based Research.

I understand the purpose of this focus group and I agree to participate.

☐ Agree  ☐ Disagree

Name of child (please print):___________________________

Name of parent/guardian (please print):___________________________

Signature: ___________________________

Date: ___________________________
Evaluation of ABA Services (Cycle 3)
Parent/Caregiver Written Responses

INTRODUCTION

1) What is your child/youth’s connection to the ABA program?
   a. How old was your child/youth when they entered the program?
   b. How many times has your child/youth participated in the ABA program?
   c. What ABA domain area(s) was your child/youth working on?
   d. What is their ASD diagnosis?
   e. What other ASD-related services and/or treatments has your child/youth received?

PROGRAM IMPLEMENTATION

2) Based on your experience in the ABA program, what aspects of the program seem to be working well?

3) Based on your experience in the ABA program, what aspects of the program seem to be not working well?

4) Please describe the involvement of your child/youth’s school in the ABA program.

5) What kinds of continued support have you received from other ASD-related services?
   a. How satisfied do you feel with the level of support you have received?
   b. How successfully was your child/youth able to transition from the ABA program to other ASD-related services?

PROGRAM IMPACTS

6) What has been the greatest impact of the ABA program on your child/youth?

7) What has been the greatest impact of the ABA program on you and your family?

FUTURE DIRECTIONS

8) What should be done to improve the ABA program for you and your child?
   a. How could the program meet the needs of your child/youth better?
   b. How could other ASD-related services support you better:
      i. While your child/youth is admitted to the ABA program?
      ii. Before and after your child/youth participates in the ABA program?
Evaluation of ABA Services (Cycle 3)
Parent/Caregiver Consent Form

I understand that I am being asked to participate in the evaluation of the Applied Behaviour Analysis (ABA) program in the Central West Region: Halton, Peel, Wellington/Dufferin, and Waterloo. This study is being conducted by the Centre for Community Based Research on behalf of Kerry’s Place Autism Services (KPAS). The purpose of this study is: (1) to assess the implementation processes of ABA programming in the Central West Region; (2) to assess the outcomes of ABA programming at the child-, family-, and systems-levels; and (3) to identify future directions for improving on the ABA programming provided by the Central West Region agencies.

I understand that I have been selected as a participant who may have some insights to share about the processes, outcomes, and future directions of the ABA program. I understand that all written responses will be stored in a locked location to protect my confidentiality, and that my name will not be associated with any quotes found in any written summaries.

I understand that participating in this evaluation is voluntary and that I may withdraw my participation at any time without penalty. I am also aware that I may decline to answer any question or speak to any issue that I wish not to discuss.

I understand that if I have any questions, I can contact Rich Janzen (519-885-1460 ext. 25293), rich@communitybasedresearch.ca at the Centre for Community Based Research.

I understand the purpose of this evaluation and I agree to participate.

☐ Agree ☐ Disagree

Name of parent/guardian (please print):___________________________

Signature: _______________________

Date: _______________________


Evaluation of ABA Services (Cycle 3)
Youth Interview Guide

Thank you for agreeing to participate in this interview regarding your experience in the ABA program. By exploring case studies of ABA clients across the Central West Region, we would like to understand how the program is working, what impacts it has had on children/youth and their families, and how the program can be improved.

There are four main sections in this interview. We’ll start with an introduction, then talk about the ABA program implementation and impacts, and end with your thoughts on future directions. Do you have any questions before we begin?

INTRODUCTION

We will start with some introductions.

1) Please tell us about how you began with the ABA program.
   a. How old were you when you entered the program?
   b. What was your life like when you first started ABA?
   c. What were your goals?
   d. Did you have individual or group sessions?

PROGRAM IMPLEMENTATION

With the next few questions, we would like to gain an understanding of the strengths and challenges of the program.

2) What did you like best about the ABA program? What did you not like?
   Probe in the following areas:
   a. Intake and waitlist process
   b. Development of ABA service plan – domain areas, goal setting, assessment tools
   c. Implementation of the ABA plan – ABA sessions, parental involvement
   d. Discharge activities – follow up sessions, re-referrals to ABA, referrals to other programs
   e. Across the program cycles - ABA consultant, interpretation services, resources

3) What topics have you covered in ABA? What topics would you like to cover?
   a. How could the topics be better suited to someone your age?

4) How was your school involved while you were in the ABA program?
   a. Did your school know that you were in the ABA program? If yes, in what ways did they support you?
   b. Did you have a Special Education teacher (e.g. ASD Itinerant, Life Skills, ISSP)? If so, in what ways did they help you to achieve your goals?

5) What kinds of other programs or activities have you been involved in?
a. In what ways did these other programs or activities help you to reach your ABA goals?

PROGRAM IMPACTS

Now, we would like to learn about the impacts of the ABA program on you and your family.

6) What did you learn through the ABA program?
   a. What has the program helped you to achieve? Do you continue to use these new skills?
   b. Where (and with whom) have you used your new skills?
   c. What have been the longer-term impacts of ABA on your life?
   d. What makes this experience unique from other programs you have participated in?

7) What prevented you from meeting your ABA goals and expectations?

8) What has been the best part of the program for your family?
   a. What changes have you seen in your parents/caregivers as a result of the program?
   b. How has your family helped you to accomplish your ABA goals and learn new skills?

FUTURE DIRECTIONS

To end, we would like you to consider future directions for the ABA program.

9) What should be done to make the ABA program better for you and your family?
   a. Is there anything that (staff person) could have done to make your time together better?
   b. If you were in charge of the program, what would you add or take away?
Evaluation of ABA Services (Cycle 3)
Youth Interviews - Sampling/Recruitment Plan

Number: Five interviews

Sampling:
Interviews will be held in-person or over-the-phone with approximately five youth across the Central West Region, who are participating (or have participated) in the ABA program. Participants will be selected in cooperation with the Evaluation Advisory Committee according to purposive sampling criteria (below). The interviews will be implemented with ethical considerations, including fully informed consent.

- Range of ages (13-14, 15-18)
- Representation across Central West Region
- Length of involvement with the program
- Models of service
- Representation across ABA domains
- Gender diversity
- Ethnic diversity
- Clients with success stories as well as clients who faced challenges during ABA program
- School Involvement

Recruitment:
The Evaluation Advisory Committee will develop and finalize names based on agreed upon selection criteria. Potential participants will receive an email/phone invitation to participate by ABA staff on the Advisory Committee, and if interested, ABA staff will pass on contact information to CCBR researchers who will send participants project information, the interview guide, and the consent form. CCBR researchers will take leadership in coordinating the date/time of the interview.
Evaluation of ABA Services (Cycle 3)
Youth Interview Consent Form

I understand that I am being asked to participate in the evaluation of the Applied Behaviour Analysis (ABA) program in the Central West Region: Halton, Peel, Wellington/Dufferin, and Waterloo. This study is being conducted by the Centre for Community Based Research on behalf of Kerry’s Place Autism Services (KPAS). The purpose of this study is: (1) to assess the implementation processes of ABA programming in the Central West Region; (2) to assess the outcomes of ABA programming at the child-, family-, and systems-levels; and (3) to identify future directions for improving on the programming provided by the Central West Region agencies.

I understand that I have been selected as an interview participant who may have some insights to share about the processes, outcomes, and future directions of the ABA program.

I understand that the interview will take approximately 45 minutes. I understand that all notes from this interview will be stored in a locked location to protect my confidentiality, and that my name will not be associated with any quotes found in any written summaries.

I understand that this interview is voluntary and that I may withdraw my participation at any time without penalty. I am also aware that I may decline to answer any question or speak to any issue that I wish not to discuss.

I understand that if I have any questions, I can contact Rich Janzen (519-885-1460 ext. 25293), rich@communitybasedresearch.ca at the Centre for Community Based Research.

I understand the purpose of this interview and I agree to participate.

☐ Agree  ☐ Disagree

Name: ____________________  Signature:____________________

Date:____________________

Name of guardian (if applicable):_____________________  Signature of guardian:____________________

Date:_____________________
Evaluation of ABA Services (Cycle 3)
Focus Group Guide – Staff

Thank you for agreeing to participate in this focus group. Focus groups have been organized with ABA program staff (working with 9 to 18 year-olds) across the Central West Region, in order to gain insight into three main questions:

- How is the ABA program being implemented at agencies in the Central West Region?
- How and to what extent has ABA programming impacted participating children/youth and their families?
- What recommendations can be made to improve the outcomes of ABA services for children, families, and the networks of ASD-related services in their communities?

There are four main sections for this focus group. We’ll start with an introduction, then talk about the ABA program implementation and impacts, and end with your thoughts on future directions. Do you have any questions before we begin?

INTRODUCTION
We will start with some introductions.

1. What has been your involvement with the ABA program and other ASD-related services?
   a. What agency do you work with?
   b. What is your current role? Has your role changed over time?
   c. How long have you been involved in the ABA program?
   d. What did you think of last year’s evaluation report? Do you feel that your perspectives were reflected?

PROGRAM IMPLEMENTATION
With the next set of questions, we would like to determine how successfully the ABA program has been implemented.

2. What aspects of the program seem to be working well or not working well? Please consider the spectrum of clients served (e.g. low to high functioning, dual diagnosis) and the four domain areas.
   Probe in terms of:
   a. Intake/Referrals and Waitlist Resources
   b. Service Planning – professional referral, assessment tools, observation, setting goals and service plan development
   c. Service Delivery – collection of baseline data, service plan implementation, parent training/coaching, using natural settings
   d. Discharge/Interfacing – outcome assessment, booster sessions, referrals, referrals to ABA
   e. Processes and activities across the program cycle – parental involvement, client-consultant matching, consultant-supervisor communications

3. Have you noticed any trends in the types of clients that you have served over time?
   Prompts: age range, ethno-cultural, socio-economic, client diagnosis.
4. What impact do you feel that the increase in resources this fiscal year will have on: (i) your organization? (ii) you, as a staff person?
   a. How do you feel about your workload in general?

5. What region-wide, cross-agency systems and processes are facilitating or hindering implementation of ABA programs?
   a. How developed are partnerships with schools?
      i. How is ABA understood to fit with other supports in schools?
   b. How developed are partnerships with mental health agencies?
   c. How developed are age transitions across agency partnerships?
      
      Prompts: At age 9, when transitioning from middle school to high school, when aging out of the system.

PROGRAM IMPACT

Now, we would like to gain insight into the program’s impact on children/youth and their families.

6. Based on your experience, what are the main accomplishments of the ABA program?
   a. What have been the most promising outcomes for children?
      • To what extent has the program contributed to improvements in the 4 behavioural domains? To secondary outcomes? In children’s overall well-being?
   b. What changes have you perceived in parents/caregivers?
      • To what extent has the program contributed to their behavioural management skills and ability to teach new skills?
      • What kinds of changes have you perceived in their level of confidence, competence, and quality of life?
   c. How successfully are goals being maintained and generalized?

7. What are the greatest barriers being faced in achieving the intended outcomes for children/youth and their families?
   a. Is there discrepancy in client outcomes based on any of the following factors?
      • Ethno-cultural factors
      • Socio-economic status
      • English language proficiency
      • Age
      • Gender
      • Complexity of diagnosis
      • Domain area

FUTURE DIRECTIONS

To end, we would like to capture your recommendations for the future directions of the ABA program.

8. How could the ABA program be improved...
   a. to better serve ABA clients?
   b. to better serve families?
   c. to better support you in your role?
Evaluation of ABA Services (Cycle 3)
Staff Focus Group - Sampling/Recruitment Plan

**Number:** 2 focus groups, 8-12 participants in each group

**Sampling:**

Focus groups will be held with staff across the Central West Region. These group interviews will give insight into ABA programming processes, outcomes, and recommendations for improvements. Methods will be implemented with ethical considerations, including fully informed consent.

**Recruitment:**

The Evaluation Advisory Committee will develop and finalize names based on agreed upon selection criteria. Potential participants will receive an email/phone invitation to participate by ABA staff on the Advisory Committee. If interested, potential participants will be provided with project information, a focus group guide, and a consent form. ABA staff on the Advisory Committee will take leadership in organizing the focus groups, with the support of CCBR researchers.
Evaluation of ABA Services (Cycle 3)
Staff Focus Group Consent Form

I understand that I am being asked to participate in the evaluation of Applied Behaviour Analysis (ABA) program in the Central West Region: Halton, Peel, Wellington/Dufferin, and Waterloo. This study is being conducted by the Centre for Community Based Research on behalf of Kerry’s Place Autism Services. The purpose of this study is to: (1) to assess the implementation processes of ABA programming in the Central West Region; (2) to assess the outcomes of ABA programming at the child-, family-, and systems-levels; and (3) to identify future directions for improving the ABA program provided by the Central West Region agencies.

I understand that I have been selected as an ABA staff person who may have some insights to share about the processes, outcomes, and future directions of the ABA program.

I understand that the focus group interview will take approximately 90 minutes. I understand that all notes from this interview will be stored in a locked location to protect my confidentiality, and that my name will not be associated with any quotes found in any written summaries.

I understand that this interview is voluntary and that I may withdraw my participation at any time without penalty. I am also aware that I may decline to answer any question or speak to any issue that I wish not to discuss.

I understand that if I have any questions, I can contact Rich Janzen (519-885-1460 ext. 25293), rich@communitybasedresearch.ca at the Centre for Community Based Research.

I understand the purpose of this focus group and I agree to participate.

☐ Agree  ☐ Disagree

Name (please print):___________________________

Signature: ____________________________

Date: ________________
Evaluation of ABA Services (Cycle 3)
Focus Group Guide – Clinical Supervisors

Thank you for agreeing to participate in this focus group. Focus groups have been organized with ABA program staff (working with 9 to 18 year-olds) across the Central West Region, in order to gain insight into three main questions:

- How is the ABA program being implemented at agencies in the Central West Region?
- How and to what extent has ABA programming impacted participating children/youth and their families?
- What recommendations can be made to improve the outcomes of ABA services for children, families, and the networks of ASD-related services in their communities?

There are four main sections for this focus group. We’ll start with an introduction, then talk about the ABA program implementation and impacts, and end with your thoughts on future directions. Do you have any questions before we begin?

INTRODUCTION

*We will start with some introductions.*

1. What has been your involvement with the ABA program and other ASD-related services?
   a. What agency do you work with?
   b. What is your current role? Has your role changed over time?
   c. How long have you been involved in the ABA program?

PROGRAM IMPLEMENTATION

*With the next set of questions, we would like to determine how successfully the ABA program has been implemented.*

2. What clinical aspects of the program seem to be working well or not working well? Please consider the spectrum of clients served (low to high functioning, dual diagnosis, age, etc.) and the four domain areas.
   *Probe in terms of:*
   f. Service Planning – professional referrals, assessment tools, observation, setting goals and service plan development
   g. Service Delivery – collection of baseline data, service plan implementation, parent training/coaching
   h. Discharge/Interfacing – Booster sessions, clinical referrals, re-referrals to ABA
   i. Processes across the program cycle – staff-supervisor relationships, client-consultant matching, reporting

3. How are the cross-regional processes of the ABA program functioning?
   a. Are you seeing consistencies in service delivery across regions?
   b. Are you seeing tensions in service delivery across regions?

4. How are broader ASD-related clinical services and agencies contributing to program outcomes?
d. How developed are partnerships with schools?
   i. How is ABA understood to fit with other supports in schools?

e. How developed are partnerships with mental health agencies?

f. How developed are age transitions across agency partnerships?
   Prompts: At age 9, when transitioning from middle school to high school, when aging out of the system.

5. What impact do you feel that the increase in resources this fiscal year will have on: (i) your organization? (ii) you, as a staff person?
   a. How do you feel about your workload in general?

PROGRAM IMPACT

Now, we would like to gain insight into the program’s impact on children/youth and their families.

6. Based on your experience, what have been the most promising outcomes of the ABA program?
   a. To what extent has the program contributed to children/youth’s improvements in the 4 behavioural domains? To secondary outcomes? To their overall well-being?
   b. How has the program contributed to parents’ behavioural management skills acquisition and ability to teach new skills?
   c. How successfully are goals being maintained and generalized?

7. Overall, what types of clients and/or families generally have the most success in the program, and what types of clients/families face the greatest challenges? (Consider diagnosis, domain area, socio-economic status, gender, language barriers, etc.).

FUTURE DIRECTIONS

To end, we would like to capture your recommendations for the future direction of the program.

8. How can the ABA program be improved...
   a. To better serve children/families?
   b. To better support ABA staff in their role?
Evaluation of ABA Services (Cycle 3)
Clinical Supervisor Focus Group - Sampling/Recruitment Plan

**Number:** 1 Focus Group, 5-8 participants

**Sampling:**
A focus group will be held with Clinical Supervisors across the Central West Region. This focus group will give insight into ABA programming outcomes for children and youth, programming processes, and recommendations for improvements. The focus group will be over the phone. Methods will be implemented with ethical considerations, including fully informed consent.

**Recruitment:**
The Evaluation Advisory Committee will develop and finalize names based on agreed-upon selection criteria. Potential participants will receive email/phone invitation to participate by ABA staff on the Advisory Committee. If interested, potential participants will be provided with project information, focus group guide, and consent form. ABA staff on the Advisory Committee will take leadership in organizing the focus groups, with the support of CCBR researchers.
Evaluation of ABA Services (Cycle 3)
Clinical Supervisor Consent Form

I understand that I am being asked to participate in the evaluation of the Applied Behaviour Analysis (ABA) program in the Central West Region: Halton, Peel, Wellington/Dufferin, and Waterloo. This study is being conducted by the Centre for Community Based Research on behalf of Kerry’s Place Autism Services. The purpose of this study is to: (1) to assess the implementation processes of ABA programming in the Central West Region; (2) to assess the outcomes of ABA programming at the child-, family-, and systems-levels; and (3) to identify future directions for improving the ABA program provided by the Central West Region agencies.

I understand that I have been selected as an ABA staff person who may have some insights to share about the outcomes, processes and future directions of ABA programming.

I understand that the focus group will take approximately 90 minutes. I understand that all notes from this focus group will be stored in a locked location to protect my confidentiality, and that my name will not be associated with any quotes found in any written summaries.

I understand that this focus group is voluntary and that I may withdraw my participation at any time without penalty. I am also aware that I may decline to answer any question or speak to any issue that I wish not to discuss.

I understand that if I have any questions, I can contact Rich Janzen (519-885-1460 ext. 25293), rich@communitybasedresearch.ca at the Centre for Community Based Research.

I understand the purpose of this focus group and I agree to participate.

☐ Agree  ☐ Disagree

Name (please print):___________________________

Signature: ___________________________

Date: ___________________
Evaluation of ABA Services (Cycle 3)
Key Informant Interview Guide

Thank you for agreeing to participate in this focus group. Focus groups have been organized with ABA program staff (working with 9 to 18 year-olds) across the Central West Region, in order to gain insight into three main questions:

- How is the ABA program being implemented at agencies in the Central West Region?
- How and to what extent has ABA programming impacted participating children/youth and their families?
- What recommendations can be made to improve the outcomes of ABA services for children, families, and the networks of ASD-related services in their communities?

There are four main sections in this interview. We’ll start with an introduction, move to questions about program implementation and program outcomes, and end with a discussion on future directions for the ABA program.

INTRODUCTION

To begin, I would like to learn about your particular contribution to ABA programming.

2) What is the history of your involvement with ABA services and/or ASD-related services?
   a. What is your current role?
   b. What is your familiarity with the various agencies involved in delivering ABA services in the Central West Region?

PROGRAM IMPLEMENTATION

The next set of questions asks about the successes and challenges of program implementation. We are interested in better understanding how the program is functioning as a whole, with a focus on the role of system-level coordination and processes.

3) What aspects of the program seem to be working well? Not working well?
   a. How does implementation seem to differ across the Central West Region?

4) To what extent are existing program resources adequate to sustainably meet service targets and long term goals?
   a. Do existing staff (frontline, clinical, ASD itinerants) meet the needs of the program in terms of quantity and capacity?
   b. Are existing ABA program sites sufficient to meet client needs?
   c. Are financial resources sufficient for effective service delivery?

5) How is the coordination between ASD services and supports connected to program implementation?
   a. Are you aware of the complexity of organizations serving and supporting children/youth with ASD? How do ABA service providers connect with the range of
other institutions, agencies, and healthcare practitioners that serve and support children/youth with ASD?

b. How and to what extent do these organizations collaborate? What does this look like? How have partnerships/synergies between agencies changed? Are all the right people at the table to maximize ABA program outcomes?

c. Are complex clients being connected to the right agencies for support?

d. What aspects of this coordination is facilitating and/or hindering implementation?

6) What region-wide, cross-agency systems and processes are facilitating or hindering implementation of the ABA program?

a. How developed are partnerships with schools?
   i. How is ABA understood to fit with other supports in schools?

b. How developed are partnerships with mental health agencies?

c. How developed are age transitions across agency partnerships?

PROGRAM IMPACT

In the next set of questions, we would like to gain insight into the program’s impact on children/youth and their families. We are primarily interested in learning about the connection between system-level activities and program outcomes.

7) What has been the greatest positive outcome of the ABA program?

a. For children/youth
b. For families
c. How do outcomes differ for more complex clients? (E.g., dual diagnosis)

8) What are the greatest barriers being faced in achieving the intended outcomes for children/youth and their families?

9) In what ways have other relevant agencies and institutions been impacted by the ABA program?

a. Has the program relieved resource strains on other ASD services?

b. Has the program helped school representatives with behavioural management of ASD students?

FUTURE DIRECTIONS

The final question considers future directions for ABA programming.

10) What should be done from a systems-level approach to enhance the effectiveness of ABA program delivery in the Central West Region?
Evaluation of ABA Services (Cycle 3)
Key Informant Interviews – Sampling and Recruitment Plan

Number: 8-12 interviews

Sampling:

Key informant interviews will be held via telephone to gain insight into systems-level processes and outcomes for ABA service delivery, as well as recommendations for improvements. Participants will be selected using purposive sampling considering the following criteria:

- Location: At least one third of participants in the Peel region and the remainder across the Central West regions
- Senior staff of ABA delivery agencies across the Central West Region
- Senior staff of other related support agencies
- Other community leaders actively working with children with ASD
- Senior school representatives and/or Special Education teachers (ASD Itinerant, ASD Resource teacher, ISSP, etc.)
- ABA funders

Recruitment:

The Evaluation Advisory Committee will develop and finalize names based on agreed upon selection criteria. Potential participants will receive an email/phone invitation to participate by an Advisory Committee member. If they agree to participate, CCBR researchers will follow-up by telephone to gauge interest in participation and to set up an interview time (providing project information, interview guide, and consent form in advance).
Evaluation of ABA Services (Cycle 3)
Key Informant Consent Form

I understand that I am being asked to participate in the evaluation of the Applied Behaviour Analysis (ABA) program in the Central West Region: Halton, Peel, Wellington/Dufferin, and Waterloo. This study is being conducted by the Centre for Community Based Research on behalf of Kerry’s Place Autism Services. The purpose of this study is to: (1) to assess the implementation processes of ABA programming in the Central West Region; (2) to assess the outcomes of ABA programming at the child-, family-, and systems-levels; and (3) to identify future directions for improving on the programming provided by the Central West Region agencies.

I understand that I have been selected as a key informant who may have some insights to share about the processes, outcomes, and future directions of the ABA program.

I understand that this interview will take approximately 45 minutes. I understand that all notes from this interview will be stored in a locked location to protect my confidentiality, and that my name will not be associated with any quotes found in any written summaries.

I understand that this interview is voluntary and that I may withdraw my participation at any time without penalty. I am also aware that I may decline to answer any question or speak to any issue that I wish not to discuss.

I understand that if I have any questions, I can contact Rich Janzen (519-885-1460 ext. 25293), rich@communitybasedresearch.ca at the Centre for Community Based Research.

I understand the purpose of this interview and I agree to participate.

☐ Agree
☐ Disagree

I agree to have my name included in the final report and shared with the Advisory Committee members:

☐ Agree
☐ Disagree

Name (please print):___________________________
Signature: ___________________________
Date: _______________
Evaluation of ABA Services (Cycle 3)
Case Study Interview Guide – Support Person(s)

Thank you for agreeing to participate in this interview regarding your former client, ________________.
By exploring case studies of ABA clients across the Central West Region, we will gain insight into three main questions:

- How is the ABA program being implemented at agencies in the Central West Region?
- How and to what extent has ABA programming impacted participating children/youth and their families?
- What recommendations can be made to improve the outcomes of ABA services for children, families, and the networks of ASD-related services in their communities?

There are four main sections for this interview. We’ll start with an introduction, then talk about the ABA program implementation and impacts for this client, and end with your thoughts on future directions. Do you have any questions before we begin?

INTRODUCTION

*We will start with some introductions.*

1. What has been your involvement with the ABA program and other ASD-related services?
   a. What agency do you work with?
   b. What is your current role? Has your role changed over time?
   c. How long have you been involved in the ABA program?

2. What is your connection to this client?
   a. When did the client undertake the ABA program?
   b. How would you describe his/her diagnosis?
   c. What ABA domain was he/she working on?
   d. Describe the specific behavioural challenges that were addressed.

PROGRAM IMPLEMENTATION

*With the next set of questions, we would like to determine how successfully the ABA program has been implemented for this client.*

3. To what extent do you think the ABA program was able to meet the needs of this client and his/her family?
   a. Was the program design suitable to address his/her behavioural and skill-based challenges?
   b. Was the program design suitable to engage his/her family?

4. What aspects of the program seemed to work best for this client and his/her family? What aspects were the most challenging for this client?
   Probes: service planning, service delivery, goal attainment, goal maintenance, parental involvement, client-consultant matching
5. To what extent were the program resources adequate to meet the expectations of this client and his/her family?
   a. Did you feel that you had the level of competency needed to support their behavioural development?
   b. Were existing supplies sufficient to carry out the intervention?

6. Please describe the level of school involvement in the ABA program (if applicable).
   a. Was the client’s school made aware when he/she was participating in the ABA program? If yes, in what ways did the school support the client?
   b. Was the client’s Special Education teacher (e.g., ASD itinerant, ASD Resource teacher, Life Skills, In School Support Program (ISSP)) involved during the ABA program cycle? In what ways did they support the client in their goal attainment?
   c. When and how were school consultations incorporated into the client’s program cycle?
   d. Overall, how did the school’s involvement facilitate or hinder program implementation?

PROGRAM IMPACT

Now, we would like to gain insight into the program’s impact on this client and their family.

7. What have been the most promising outcomes for this client?
   a. Please describe the improvements you observed in the client, including primary and secondary outcomes.
   b. What changes did you observe in the client’s overall well-being?
   c. How successfully was the ABA goal maintained and/or generalized?

8. What changes have you perceived in the client’s parents/caregivers?
   a. To what extent has the program contributed to their behavioural management skills and their ability to teach new skills?
   b. What kinds of changes have you perceived in their level of confidence, competence, and quality of life?

FUTURE DIRECTIONS

To end, we would like to capture your recommendations for the future directions of the program.

9. How could the ABA program have been improved...
   a. to serve this client better?
   b. to serve his/her family better?
   c. to support you in your role better?
Evaluation of ABA Services (Cycle 3)  
Case Study Interview Guide – Parents/Caregivers

Thank you for agreeing to participate in this interview regarding your child, _________________. By exploring case studies of ABA clients across the Central West Region, we will gain insight into three main questions:

- How is the ABA program being implemented at agencies in the Central West Region?
- How and to what extent has ABA programming impacted participating children/youth and their families?
- What recommendations can be made to improve the outcomes of ABA services for children, families, and the networks of ASD-related services in their communities?

There are four main sections for this interview. We’ll start with an introduction, then talk about the ABA program implementation and impacts for your child, and end with your thoughts on future directions. Do you have any questions before we begin?

**INTRODUCTION**

1) Please tell us what your life and your child's life was like before ABA.
   a. What were the main struggles that your child was experiencing?
   b. What types of formal and/or informal supports did you receive?
   c. How did the diagnosis impact you and your family?

2) How did you first hear about the ABA program?
   a. How did you first become involved?
   b. How old was your child when they entered the program?
   c. How many times has your child participated in the ABA program?
   d. What ABA domain area(s) has your child worked on?
   e. What other ASD-related services and/or treatments has your child received?

3) What is your involvement today in the ABA program?
   a. What domain area is your child working on?
   b. What goal is your child working on?

**PROGRAM IMPLEMENTATION**

*With the next few questions, we would like to gain an understanding of the strengths and challenges of program implementation.*

4) Based on you and your child's experience in the ABA program, what aspects of the program seem to be working well or not working well?
   Probe around the following areas:
   a. Intake and waitlist process before child is admitted
   b. Development of the ABA service plan – domain areas, goal setting, assessment tools
c. Implementation of the ABA plan – including child and parental involvement

d. Discharge activities – booster sessions, re-referrals to ABA, referrals to other programs

e. Maintenance and generalization of ABA goals

f. Across the program cycles - ABA consultant, interpretation services, scheduling

5) Please describe the involvement of your child’s school in the ABA program.
   a. Was the school aware that your child was in the ABA program? If yes, in what ways did they support your child?
   b. Was your child’s Special Education teacher (e.g., ASD itinerant/ASD resource teacher/Life Skills/ISSP) involved in their ABA program cycle? In what ways did they support your child’s goal attainment?
   c. Overall, how did the school’s involvement facilitate or hinder ABA program implementation?

6) What kinds of continued support have you received from other ASD-related services?
   a. How satisfied do you feel with the level of support you have received?
   b. How successfully was your child able to transition from the ABA program to other ASD-related services?

PROGRAM IMPACTS

Now, we would like to learn about the impacts of the ABA program on your child and your family.

7) What have been the most promising aspects of the program for your child?
   a. How has the program improved upon your child's behaviour(s)?
   b. Did you witness changes in your child in addition to the primary ABA goal?
   c. How have your child’s new skills generalized to other settings?
   d. What have been the longer term impacts on your child’s well-being?
   e. What makes this experience distinct from other ASD-related services?

8) What have been the most promising aspects of the ABA program for you and your family?
   a. What change have you experienced in your ability to manage your child’s behaviour?
   b. What change have you experienced in your ability to teach your child new skills?
   c. How has the ABA program affected your level of confidence and feelings of competency when delivering the program goals?
   d. What steps have you taken to maintain your child’s new skill(s)?

FUTURE DIRECTIONS

To end, we would like you to consider future directions for the ABA program.
9) What could be done to improve the ABA program for you and your child?
   a. How could the program meet the needs of your child better?
   b. How could other ASD-related services support you better:
      i. While your child is participating in the ABA program?
      ii. Before and after your child participates in the ABA program?
Thank you for agreeing to participate in this interview regarding your experience in the ABA program. By exploring case studies of ABA clients across the Central West Region, we would like to understand how the program is working, what impact it’s had on children/youth and their families, and how the program can be improved.

There are four main sections for this interview. We’ll start with an introduction, then talk about the ABA program implementation and impacts, and end with your thoughts on future directions. Do you have any questions before we begin?

INTRODUCTION

We will start with some introductions.

10) Please tell us about how you began working with (staff person)?
   a. How old were you when you started working with (staff person)?
   b. How many times have you worked with (staff person)?
   c. What did you and (staff person) do together?
   d. Did you have individual or group sessions?

PROGRAM IMPLEMENTATION

With the next few questions, we would like to gain an understanding of the strengths and challenges of the program.

11) What did you like best about working with (staff person)? What did you like least?
    Probe in the following areas:
    a. Development of the ABA service plan – domain areas, goal setting, assessment tools
    b. Implementation of the ABA plan – ABA sessions, parental involvement
    c. Discharge activities – follow up sessions, re-referrals to ABA, referrals to other programs
    d. Across the program cycles - ABA consultant, interpretation services, resources, etc.

12) How was your school involved while you were in the ABA program?
    a. Did your school know that you were in the ABA program?
    b. In what ways did your school help you to reach your ABA goals?
    c. Do you have a Special Education teacher (e.g., ASD Itinerant, Life Skills, ISSP) at school?
    d. In what ways did your Special Education teacher help you to achieve your ABA goals?

13) What kinds of other programs or activities have you been involved in?
    a. In what ways did these other programs or activities help you to reach your ABA goals?

PROGRAM IMPACTS

Now, we would like to learn about the impacts of the ABA program on you and your family.
14) What did you learn from working with [staff person]?
   a. What has the program helped you achieve? Do you continue to use these new skills?
   b. Where have you used your new skills? Home? School? Other places? With other people?
   c. What have been the longer term impacts of ABA on your life?
   d. What makes this experience unique from other programs you have participated in?

15) What has been the best part of the program for your family?
   a. What changes have you seen in your parents/caregivers as a result of the program?
   b. How has your family helped you accomplish your ABA goals and learn new skills?

FUTURE DIRECTIONS

To end, we would like you to consider future directions for the ABA program.

16) What should be done to make the ABA program better for you and your family?
   a. Is there anything that [staff person] could have done to make your time together better?
   b. If you were in charge of the program, what would you add or take away?
Evaluation of ABA Services (Cycle 3)
Case Studies - Sampling/Recruitment Plan

Description:

Case studies of three or four ABA clients across the Central West Region will give greater insight into program implementation, client and family outcomes, and areas for program improvement. Participants will be selected in cooperation with the Evaluation Advisory Committee according to purposive sampling criteria below. Methods will be implemented with ethical considerations, including fully informed consent.

Data collection for each case study will include:

- Client profile (*client database*)
- GAS outcomes (*ABA roll up*)
- Interview with the client's parent/caregiver (*parent/caregiver interview guide*)
- Interview with the client's ABA consultant who worked with client (*support person interview guide*)
- If applicable, interview with the client (*child/youth guide*)
- If applicable, interview with client’s ASD itinerant or other support person familiar with the client’s program outcomes (*support person interview guide*)

Sampling for case study clients:

- Range of diagnoses
- Representation across Central West Region
- Length of involvement with the program
- Models of service
- Representation across ABA domains
- Gender diversity
- Ethnic diversity
- Age (9 to 18 years old)
- Clients with success stories as well as clients who faced challenges during ABA program
- Diversity in school involvement

Recruitment:

The Evaluation Advisory Committee will develop and finalize names based on agreed-upon selection criteria. Potential participants will receive an email/phone invitation to participate by ABA staff on the Evaluation Advisory Committee, and if interested, ABA staff will pass on contact information to CCBR researchers who will send participants project information, interview guide(s), and consent form(s). CCBR researchers will then take leadership in coordinating the interviews with the families and support persons.
Evaluation of ABA Services
Case Study Interview Consent Form

I understand that I am being asked to participate in the evaluation of the Applied Behaviour Analysis (ABA) program in the Central West Region: Halton, Peel, Wellington/Dufferin, and Waterloo. This study is being conducted by the Centre for Community Based Research on behalf of Kerry’s Place Autism Services (KPAS). The purpose of this study is: (1) to assess the implementation processes of ABA programming in the Central West Region; (2) to assess the outcomes of ABA programming at the child-, family-, and systems-levels; and (3) to identify future directions for improving the ABA programming provided by the Central West Region agencies.

I understand that I have been selected as an interview participant who may have some insights to share about the outcomes, processes and future directions of ABA programming.

I understand that the interview will take approximately 45 minutes. I understand that all notes from this interview will be stored in a locked location to protect my confidentiality, and that my name will not be associated with any quotes found in any written summaries.

I understand that this interview is voluntary and that I may withdraw my participation at any time without penalty. I am also aware that I may decline to answer any question or speak to any issue that I wish not to discuss.

I understand that if I have any questions, I can contact Rich Janzen (519-885-1460 ext. 25293), rich@communitybasedresearch.ca at the Centre for Community Based Research.

I understand the purpose of this interview and I agree to participate.

☐ Agree

☐ Disagree

Name: ____________________

Signature:__________________

Date:____________________

Name of guardian (if applicable):______________

Signature of guardian:_______________________

Date:____________________

Appendix 5: Definitions of Client Intervention Hours and Parent Training Hours

Revised-Oct 1, 2014

Monthly Stats

Recording: Parent Only hrs.

- child may or may not be present
- training/coaching does not relate to the child’s specific goals
- For example e.g. discussing general aba principles unrelated to child’s goal, discussing aba service options with parents/other professionals


- The number of hours for both parent & child as well as child only should match as long as the work was related to the treatment goal
- Exception is when a client is in group then the hours go under child only hours (unless you also met with the parent)

Roll-Up

Total Client intervention hrs = Child only hrs + Parent/child hrs

Total Parent training hrs = Parent only hrs + parent/child hrs