

# Ontario Autism Program Clinical Framework

Prepared by the Autism Spectrum Disorder (ASD) Clinical Expert  
Committee for the Ministry of Children and Youth Services

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# The Ontario Autism Program (OAP) Clinical Framework

Prepared by the Autism Spectrum Disorder (ASD) Clinical Expert  
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# Introduction

The Ontario Autism Program (OAP) of the Ministry of Children and Youth Services is fundamentally changing how behavioural supports and services are provided to children and youth with Autism Spectrum Disorder (ASD) and their families. A single continuum of individualized and flexible services will support the learning, wellness and development of these children and youth. This change must also be reflected in how individualized decisions are made about the interventions that children, youth and families receive. This Clinical Framework describes how clinical decision-making will be supported while promoting consistency of practice across the province. It is intended to be used in conjunction with the program guidelines for the new Ontario Autism Program.

Individualized, personalized services recognize the complex profile and learning needs of each child and youth with ASD, and current research supports this personalized approach.<sup>1,2</sup> Getting the right services at the right time starts as a child or youth is referred to the OAP and is welcomed into the OAP entry point within their community. Flexible and responsive service is evident as the family begins to receive a series of interventions, moving along a continuum of evidence-based interventions, starting as early as infancy, continuing throughout their school years and through their transition to adult services and supports. During that time children will grow and learn; strengths, interests and needs will evolve and the continuum of evidence-based services will adjust to meet the changing goals of each individual.

A key aspect of clinical decision-making in the OAP is the principle of child-, youth- and family-centred services. Family-centred care is an approach to planning and delivering care that promotes collaborative partnerships between care providers, children, youth and their families.<sup>3,4,5</sup> All decisions about supports, behavioural interventions and the coordination of services are made in partnership with the family and/or youth, and their priorities are at the heart of those critical conversations. For example, research indicates the need for clinicians to establish a supportive relationship with a child's or youth's caregivers and family as they design services that fit best with an individual family's values and needs (e.g., cultural values, capacity, etc.).<sup>6</sup> Therefore, a collaborative assessment and goal-setting process is a necessary step in family engagement. The OAP plays a critical role in supporting youth and families not only to make key decisions about their child's services, but also to develop children's and youths' self-advocacy and self-actualization skills that they will call upon throughout their lives.

Evidence-based behavioural services and best practices play a fundamental role in the process of a youth's and/or parent's informed decision-making. Information given to parents and youth in clear and understandable ways is required to support an effective decision-making process and optimal outcomes.

Lastly, the OAP is not a program that can exist in isolation within a family's community. The enduring, often lifelong support of extended family, friends, other parents of children with ASD and community members cannot be underestimated. Medical, educational and other services for people with special needs, as well as community programs also play vital roles in the lives of children and youth with ASD. As directed by the family, the coordination of services and collaborative partnerships that fit with the family-centred care approach are an expectation within the OAP Clinical Framework.

This document provides the clinical framework to be used in the OAP. It was developed to assist families across the province of Ontario to understand how needs are assessed, how intervention is planned, how progress is reviewed, and how transition planning is undertaken in the OAP. Within this framework, children and youth with ASD, their families and caregivers will receive supports and behavioural intervention, including education and training, to ensure best outcomes.

The Clinical Expert Committee (CEC) prepared this clinical framework by gathering information regarding how behavioural interventions and other supports could best be delivered. Families, clinicians, educators and behavioural service providers from across the province participated in focus groups to help the committee consider the skills, needs, goals, and hopes of children and youth with ASD and their families as the new OAP is being developed. In addition, parents were invited to provide input via an online survey. Input from clinicians who are currently involved in treatment planning with children with ASD in Ontario was solicited to participate in a clinical decision-making simulation study to identify key information used by clinicians in the clinical-decision making process. All this information was integrated with evidence from relevant literature that could inform the development of this clinical framework. Detailed information about each of the three consultation methods can be found in Appendix A.

The current document is the first phase in the development of a framework that will evolve based on feedback/validation from various OAP stakeholders over time, as well as from the data from evaluations of the first group of children and youth who will enter the OAP in June 2017. Initial evaluation of this framework will take place between September 2017 and January 2018. The evaluation will identify any gaps in knowledge essential to understanding family needs, and the information or further assessments that may be required to understand the most effective intervention for the child or youth. This feedback will be used to gather information regarding any changes required to support a comprehensive intervention planning process, and the framework will be

adjusted as necessary before implementation of the full OAP in Spring 2018. This framework will then continue to evolve over time, based on evaluation over the course of its implementation, allowing for further clarification and refinement of an OAP Clinical Framework that best meets the needs of children and youth with ASD and their families in Ontario.

# Key Terms and Definitions

**Applied Behaviour Analysis (ABA):** An applied science, based on the principles of learning and behaviour, which uses specific methods to change behaviour. ABA is supported by a body of scientific knowledge and research, established standards for evidence-based practice, distinct components for service provision, recognized experience and educational requirements for practice, and identified educational requirements in universities.

**Behaviour Plan:** A detailed description of the recommended behavioural intervention developed by an OAP Behavioural Clinician. Behaviour Plans share common components and can vary considerably depending on the nature of the behaviours being addressed and the intervention modality.

**Autism Spectrum Disorder (ASD):** A neurodevelopmental disorder with qualitative differences and impairments in reciprocal social interaction and social communication, combined with restricted interests and rigid and repetitive behaviours.

**Evidence-Based Practice (EBP):** The integration of clinical expertise, client values, and the best research evidence into the decision-making process for client care.

**Family:** Families can include parents, caregivers, grandparents, siblings and other relatives.

**OAP Behavioural Clinician:** General term used that encompasses any behavioural clinician of the Ontario Autism Program. Further information is provided in the OAP program guidelines.

**OAP Family Support Worker (FSW):** An individual assigned to a family to assist with needed service and program navigation, supports and planning, including the development of the OAP Family Service Plan.

**OAP Family Service Plan (FSP):** An evolving plan that describes the services and supports that a family and their child need and agreed upon next steps. It is developed by the family with an OAP clinician, and Family Team if applicable.

**OAP Family Team:** Coordinates and aligns the broader services a child/youth and their family may be receiving with their OAP behavioural services on an ongoing basis. It also promotes consideration of the whole child/youth. A family team is optional, based on the family's choice, and its membership is determined with the family/youth.

**Family Team Lead:** An individual chosen from a Family Team to support team function, scheduling and communication.

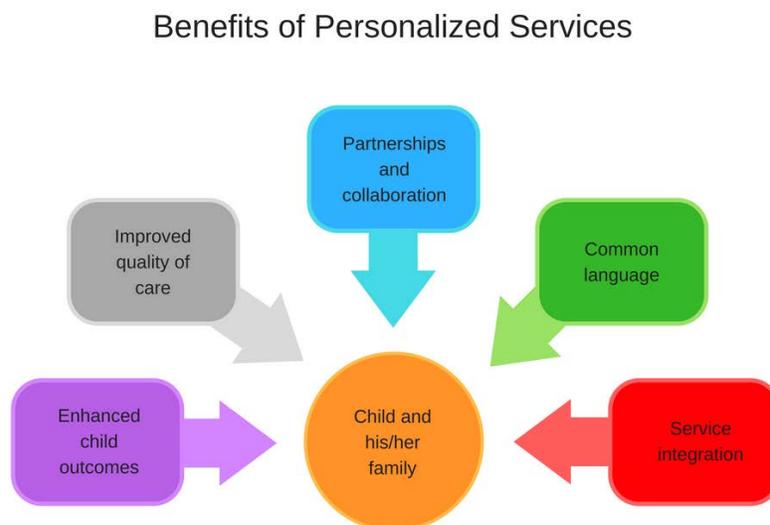
# Acronyms

ABA	Applied Behaviour Analysis
ASD	Autism Spectrum Disorder
BCBA	Board-Certified Behaviour Analyst
CANS	Child and Adolescent Needs and Strengths Measure
CEC	Clinical Expert Committee
DFO	Direct Funding Option
DSO	Direct Service Option
EBP	Evidence-Based Practice
ECE	Early Childhood Educator
FSW	Family Support Worker
FSP	Family Service Plan
IBI	Intensive Behavioural Intervention
MCYS	Ministry of Children and Youth Services
OAP	Ontario Autism Program
ONTABA	Ontario Association for Behaviour Analysis
RAPON	Regional Autism Providers of Ontario

# Guiding Values

- All assessments and interventions should be culturally responsive and respectful.
- Children, youth and their families should have voice and choice regarding participating in any assessments and interventions.
- All interventions should be evidence-based, personalized, respectful and have demonstrable value to the people they serve.
- Collaborative processes, inclusive of children, youth and families, should be used for all decisions at all levels of the system.
- Consensus on the treatment goals and intervention and optimal outcomes are primary results of collaborative processes.
- Information about the people served and their outcomes should always inform decision-making at all levels of the system.

**Figure 1: Benefits of Personalized Services<sup>7</sup>**



# Outcomes and Guiding Principles of the OAP

The Ontario Autism Program's *Guiding Principles* and *Child, Youth and Family and System Outcomes* as developed by the OAP Advisory Committee (Appendix B) have and will continue to provide ongoing guidance for service design and evaluation. These fundamental principles and outcomes are essential to the development and evolution of the clinical framework, therefore are also embedded throughout.

## Engagement and Roles

### Family Engagement

The OAP's emphasis on family-centred care creates a fundamental basis for service delivery. This offers new possibilities in parent and family supports through a range of options, including peer-to-peer (i.e., parent-to-parent) support and connection with relevant community-based family support organizations and access to parent and family education opportunities. This approach values parents and caregivers as experts on their child and as key decision makers in their child's interventions, but it also recognizes their lifelong commitment to their child's learning and wellness. Opportunities to participate in evidence-based parent training interventions will be offered so that families can help their child to learn and use new skills in their everyday lives, and actively participate in their communities.

Families/caregivers and youth want to experience a sense of trust with the clinicians entrusted to work with them. Strong communication practices and transparency in both process and decision-making are necessary components to creating and sustaining a collaborative relationship with the family. This is particularly true during transition planning. It is critical that families/youth have a complete understanding of both current services and what will follow. Knowing why, how and when they could transition to a new phase of behavioural intervention and what each stage will look like for them is important.

**Parents can expect:**

- To be recognized as the experts regarding their child, bringing essential information on the child's strengths and challenges to the process of making clinical decisions;
- To play a central role and be actively involved in assessment, goal-setting, intervention, decision-making and review processes;
- That clinicians will bring to their conversations their expertise and experience about a broad range of individuals with ASD and knowledge of the evidence-based literature;
- That their family's culture will be treated with sensitivity and dignity;
- That conversations will be mutually respectful;
- That clinicians will share their expertise in ways that are understandable, respectful of culture-specific considerations and transparent to the family;
- To receive written summaries at key decision and update points (e.g., treatment goals and assessment and progress results, team meeting minutes);
- To be welcomed to ask questions and update the treatment team on new information;
- To be provided with information about any consents required for services and sharing of their personal health information in a manner they can understand (i.e., either verbally and/or written);
- To share information openly and to work collaboratively with the clinical team; and
- To understand OAP-based interventions, transition processes and their implications.

**In addition, youth can also expect:**

- To have their priorities, strengths and interests incorporated into their intervention plan;
- To be recognized as the experts in their own lives;
- To be active partners in all aspects of the assessment process and treatment planning decisions;
- To have opportunities to learn self-advocacy skills; and
- To have their privacy respected.

# The Role of the Ontario Autism Program (OAP) Behavioural Clinician

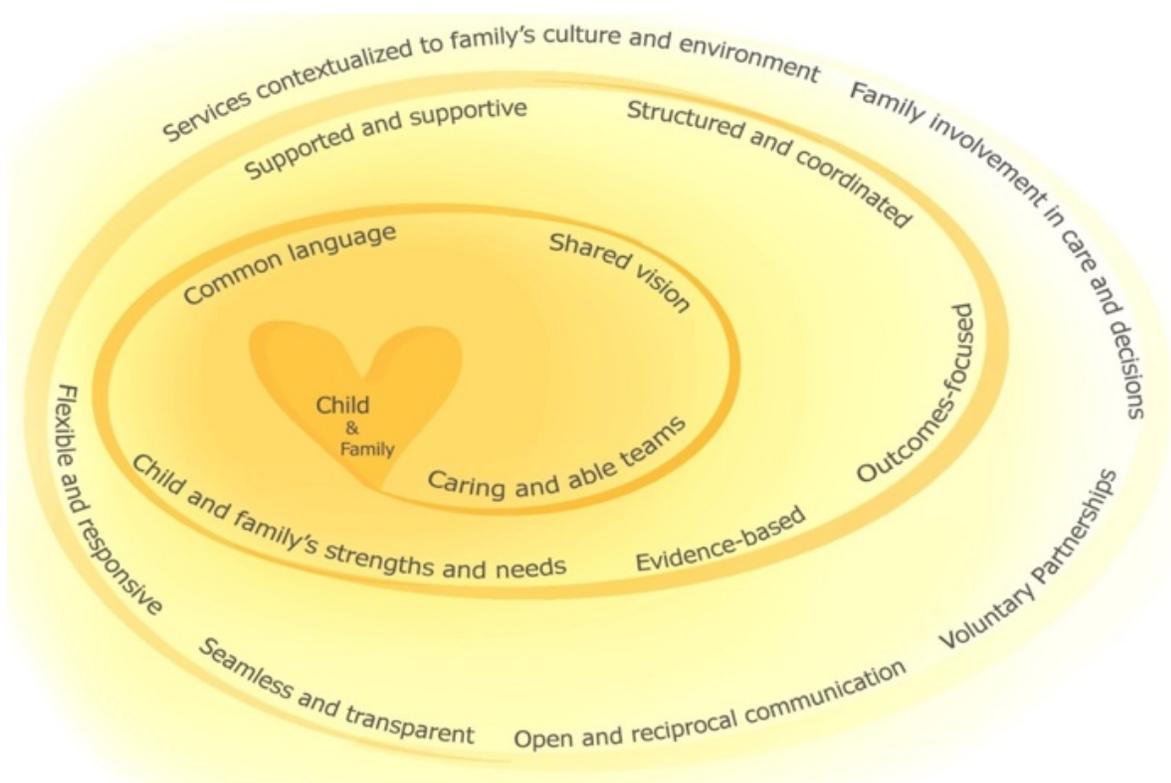
As an expert in assessment and behavioural treatment options, the role of the OAP Behavioural Clinician is to lead these collaborative processes and to assess, apply and recommend relevant and indicated treatments and supports or refer to appropriate resources as outlined in the program guidelines.

## **OAP Behavioural Clinicians can be expected to:**

- Apply their expertise about- and experience with a broad range of individuals with ASD as well as their knowledge of the evidence-based literature and application of that information to ensure optimal intervention;
- Be transparent and collaborative with parents, youth and other community partners, with parent consent, with respect to the treatment planning process;
- Consistently demonstrate inter-professional collaboration and partnership;
- Share their expertise in ways that are understandable to the family;
- Provide families with information about the data being used to determine their child's progress;
- Accurately assess and evaluate the effects of intervention, and to make adjustments as needed;
- Provide written summaries at key decision and update points (e.g., meetings, review of treatment goals and assessment and progress results, team meeting minutes). These are shared with parents and other team members as appropriate. As part of clinical practice, clinicians are required to keep detailed clinical notes of all relevant communication;
- Ensure that conversations are mutually respectful; and
- Ensure that families' cultures are treated with sensitivity and dignity.

NOTE: Adherence to Ontario's legislated consent to treatment requirements is expected throughout OAP service and supports provision. Parents/youth will be provided with information about Ontario's consent to treatment processes and the support they need in order to make an informed decision about consent to treatment and the sharing of their personal health information, as needed.

**Figure 2: Personalized and Family-Centred Care**



The term 'family-centred care' is well aligned with the concept of 'personalized services' in the context of services meant for children and youth with ASD and their families. This term recognizes the child at the heart of service decisions and delivery, while also recognizing the key role of the family within such decisions and service provision.<sup>8</sup>

## Inter-professional Collaboration

Inter-professional partnerships are essential and are embedded in OAP services and supports. Collaboration can take many forms. The scope of practice of each profession involved will be understood and respected.

Reports of physicians, family support providers, other professionals, educators and clinicians can be important sources of assessment information. These clinicians may also serve as consultants during intervention planning and/or delivery. At the same time, OAP clinicians should also share their reports with other involved professionals. At other times, other professionals may provide needed supports and services (i.e., to ensure generalization of acquired skills across the child's environments, to promote successful transitions and to enable joint professional development for key partners).

# The OAP Family Team

Families may benefit from having a point person to help them to navigate both the OAP and the wider service system. An OAP Family Support Worker (FSW) will be identified for the family upon entry into the OAP, and their role will be determined in collaboration with the family. Although the FSW may change over time, families will always be aware of who their key contact person is and how to contact them.

An important aspect of inter-professional collaboration is the development of an OAP Family Service Plan (FSP), with input from the clinicians involved in supporting the child and family. At the initial family meeting following OAP entry, the OAP Family Support Worker and the family will work together to begin a personalized OAP Family Service Plan. The Family Service Plan may include the formation of a Family Team, should the parents wish to do so. This plan will continue to evolve throughout the course of the child/youth's time in the OAP.

The OAP Family Team is formed to coordinate and align the broader services that a child/youth may be receiving with their OAP behavioural services on an ongoing basis, including services that begin before entry into the OAP. It also promotes consideration of the whole child/youth. Its membership is made up of participants chosen by the parent(s)/youth. The child/youth may also be a member of the team. Members may include clinicians who provide parents or their child with regular support, education and/or intervention, other family members, service providers, educators/school representatives, and community-based service providers as determined by the family. The OAP Behavioural Clinician is also a critical member of the team. Special guests may be invited depending on the agenda. Membership is expected to shift over time as the needs of the child/youth and the services they are receiving evolve. As a family receives OAP services and supports, the family and Family Support Worker contribute to the ongoing development of the OAP Family Service Plan, and if requested by the family, the first meeting of the child/youth's Family Team is held.

In some situations, if the child has multiple and/or complex needs, the OAP Family Support Worker may refer the family to Coordinated Service Planning under the Special Needs Strategy. In these situations, the OAP Family Support Worker will remain involved with the family and will participate in Coordinated Service Planning.

Family Team meetings do not occur without the family/youth present and/or their explicit consent/assent. At the first Family Team meeting, the goals of all identified members of the team are reviewed, augmented and added to the OAP Family Service Plan. These goals will be aligned with the goals in the child's OAP Behaviour Plan, which is part of the overall Family Service Plan, as available. Goals will be described in family-friendly language. The Family Team will also discuss and jointly problem-solve any concerns or potential challenges. The date, time and location of the next meeting are also determined at this meeting. Following the meeting, a summary and next steps are provided to all participants.

Although the first Family Team meeting is led by the OAP FSW (or parent, as preferred), responsibility for facilitating future Family Team meetings is determined by the parents with the team members. An OAP Behavioural Clinician must be in

attendance. A Family Team Lead is identified by the team at the first meeting, and is responsible for team communication and planning. S/he may or may not be a family member, an OAP clinician or another team member who provides services outside of but in collaboration with the OAP.

The Family Team will maintain a current OAP Family Service Plan (FSP). This is an evolving living document that identifies the child/youth's complete set of goals and the team member most responsible for each. Members will regularly share new information, review data and progress towards the FSP goals. At subsequent meetings, at least every 6 months, similar updates are provided by all members, including data and any changes in goals and intervention. Communication expectations are developed and regularly modified by the family and their team.

## Elements of Clinical Decision-Making

The following are recommended stages and critical elements of the clinical decision-making process. Good clinical decision-making is informed by multiple perspectives, making this process inherently complex. These stages are not necessarily linear and may occur in various sequences and sometimes simultaneously.

### Understanding and Building the Story

To be able to provide high quality, family-centred personalized services, Rosenbaum and colleagues (1998) identified the following key service provider, behaviour-based components: supporting the family, using active listening skills, believing and trusting parents, promoting and facilitating parent decision-making, encouraging participation of all stakeholders, and ensuring clear and active communication.<sup>9</sup>

## Comprehensive Information Collection

Upon entry to the OAP, the OAP FSW gathers information to develop a comprehensive understanding of the strengths and needs of the child/youth, the family and the environment in which they live. Key information about the whole child or youth is collected, summarized, and initial needs and strengths are identified. Information gathering will be a continuous process as a child/family move through the OAP.

Information should be obtained from a variety of sources as indicated by the experiences, strengths and needs of the individual child/youth. This includes but is not limited to contexts in which a good deal of time is spent (e.g., in childcare, school), other involved therapies being given (e.g. motor speech development, Augmentative and Alternative Communication use), community-based programs and supports, and medical intervention. Other information that may be helpful includes:

- a child's age, diagnosis, profile of strengths and needs;
- cognitive and adaptive profile, medical conditions or history;
- details about their social and communication skills;
- details and context about problem behaviours;
- current family stressors, family's capacity to participate in interventions and/or any barriers;
- information/communication with school staff (e.g., teacher, Educational Assistant, Early Childhood Educator, ASD team);
- information from previous service providers (e.g., reports about specific goals, interventions used, and outcomes); and
- direct observation and/or interaction with the child.

The outputs of this information will be organized systematically, possibly through an administration of the Child and Adolescent Needs and Strengths (CANS) assessment, to establish from onset a method to both collect the same categories of information across the province and to provide a baseline for each child/youth. In some cases, where applicable, the OAP Behavioural Clinician may be involved in the early stages of information gathering.

Prior to the first meeting with the family, the OAP Behavioural Clinician reviews all relevant and available medical, educational and clinical community support documents about the child/youth that have been compiled to help inform their OAP Family Service Plan. This review includes the identification of any gaps in knowledge or relevant documentation. Appropriate means are then taken to fill in identified gaps (e.g., current education IEP), request additional information, and/or make needed referrals for other services.

## **Building the Story and the Family Service Plan**

An initial meeting with the OAP FSW and the family/youth occurs to promote a shared understanding of the child/youth and to discuss OAP services and supports, including possible family supports. A comprehensive description is developed of the parents'/youth's perspective on strengths, needs and areas of concern, and those requiring action. This includes reviewing the story or portrait of the child/youth, and identifying the child's strengths and needs, possibly through the administration of a Child and Adolescent Needs and Strengths (CANS) assessment. The CANS is a tool used to ensure consistent attention is paid to key assessment outputs. It also provides a common practice approach to the assessment process that is applied systematically across all providers, allowing provincial comparisons of child and family characteristics and outcomes.

The OAP Family Service Plan is initiated at this point to begin services as quickly as possible. An OAP Behavioural Clinician will also become involved in this process.

## **Assessment, Goal Setting and Development of the Behaviour Plan**

After initiation of the OAP Family Service Plan, the OAP Behaviour Plan is created. This plan is based on feedback from the family, a clear understanding of the parents'/youth's expectations, capacities and which domains are priority areas to be addressed. Observations of the child and sometimes caregivers are included to better define behavioural intervention goals and strategies, and to establish a baseline for ongoing observations.

The OAP Behavioural Clinician will initiate assessment through informal and formal observations, which may take place in the child's natural environment(s) and/or in a clinical setting. This will involve getting to know the family/youth, the child's strengths, needs and interests, and open discussion of the family's/youth's highest areas of need and contextual/practical factors relevant to the behavioural assessment and intervention (e.g., language and cultural considerations, transportation, scheduling constraints, etc.) The OAP Behavioural Clinician will describe the behavioural service options, assessment process and plan, as developed in collaboration with the family, and answer the family's questions. The OAP Behavioural Clinician will identify behavioural challenges, if any, and conduct formal assessments as needed.

Observations are a necessary component of the assessment phase and can be conducted in natural and/or structured settings. In line with Wong et al. (2014)<sup>10</sup> and input from stakeholders, a review of the range of domains that require support for children/youth with ASD may include: social/interpersonal, communication, cognitive

functions, school readiness skills, motor skills, personal responsibility/adaptive skills, play and leisure, self-regulation, vocational skills, and challenging behaviours.

Standardized tools (e.g., parent/school report, child/youth assessment tests such as the ABLIS curriculum, Social Skills Improvement System, etc.) may be useful to further direct the understanding of the child as they influence treatment decisions across the lifespan. Assessment processes are individualized to the age, abilities and interests of the child/youth. A formal developmental assessment and/or a functional assessment may be needed to further inform key decisions in the planning.

Once observations and formal assessments are completed, the OAP Behavioural Clinician will share the assessment results and discuss them with the family/youth. Together they will develop consensus on a common understanding of the child's/youth's priority goals and the plan for intervention. This may include both short- and long-term goals and priorities.

This consensus-based planning process continues throughout the child's treatment experience.

### **Development of the Behaviour Plan**

Despite the individualized nature of ABA service decision-making and delivery, there are common processes that underlie most ABA case preparation, assessment, and intervention decisions. Below is a list of elements that are generally required for each step of behavioural service planning, depending on the child's needs. (Note that given the diversity of OAP clients, there likely will be reasonable exceptions and/or additions to these elements.)

#### *1. Recommendations regarding the amount and modality of needed behavioural service*

Based on information from all previous elements (above), and the evidence from the literature, the OAP Behavioural Clinician and the family/youth will develop a plan for recommended behavioural service (this is called the Behaviour Plan). The Behaviour Plan will include a description of the proposed intervention and a summary of the discussion between the clinician and family about the proposed intervention, information about the amount, scheduling, and anticipated duration of the intervention. The plan will include details about how progress will be measured and assessed, and how next steps will be determined.

The OAP Behavioural Clinician together with the family/youth will determine involvement of the family and other supports (as available) in the recommended intervention.

#### *2. Development of the Behaviour Plan*

The OAP Behavioural Clinician will write up the Behaviour Plan as developed in collaboration with the family/youth and with the involvement of other professionals, as

needed, and document his/her clinical decision-making process, including the rationale for the recommended intervention.

The OAP Behavioural Clinician will explain the Behaviour Plan to the family/youth, and will document both the plan and parental/youth consent to proceed with plan.

- Written Behaviour Plans will include the following components:
  - a. brief summary of the behavioural observations/assessment and rationale for the Behaviour Plan;
  - b. description of domain(s) to be addressed;
  - c. definitions of skills to be increased;
  - d. definitions of behaviours to be decreased (if needed);
  - e. description of planned intervention approach (e.g., discrete trial, naturalistic, 1:1, small group, parent training, etc.), with recognition that this will need to be flexible based on child's learning;
  - f. measurable, relevant and realistic behavioural goals (i.e., for behaviours defined in c. and d. above), with mastery criteria and approximate time frames (e.g., a family and Behavioural Clinician may agree that reviews at 3, 6, and 12 months would be helpful) to achieve mastery (or meaningful reduction of problem behaviour) for each skill/behaviour identified;
  - g. therapeutic expectations including anticipated risks and benefits;
  - h. description of generalization and maintenance strategies;
  - i. roles and responsibilities of relevant parties;
  - j. outline of a review plan. Note that intervention goals and strategies can be changed, as needed; and
  - k. a summary of the OAP Behavioural Clinician's rationale for the elements of the plan and how they were discussed with the family.

Once the Behaviour Plan has been developed, the Behavioural Clinician will discuss with the family/youth and provide a written follow-up, which will include, but not be limited to:

- The Behaviour Plan and the goal(s) with their measurable targets (these measurable targets should be explicitly linked to the child's comprehensive assessment);
- Modality/type of intervention, expected amount and duration;
- Location of intervention;
- Ongoing communication plan (schedule of parent/provider touch points);
- Plan for measuring and assessing progress;
- Plan for generalization and maintenance of newly learned skills; and
- Rationale for the elements of the plan and how they were discussed with the family.

The OAP Behavioural Clinician must document any necessary parental consent and, as appropriate, child/youth consent, to proceed with the plan.

## Delivery of Behavioural Intervention

Once the Behaviour Plan has been developed and consensus is reached between the family and the OAP Behavioural Clinician, intervention is delivered as discussed with the family/youth.

Behavioural services support children, youth and their families throughout OAP, varying in form and intensity as needed. The OAP provides a continuum of behavioural interventions. Children's needs change over time and as those needs change, children and youth with ASD move between different levels and forms of interventions/treatments. The child/youth may, according to priority goals and needs, receive 1:1, small group or consultation supports. Learning new skills and the generalization and maintenance of skills are integrated components of each child/youth's OAP Behaviour Plan.

To promote the child/youth's learning, including the transfer and retention of new skill(s) to home and community, parents of children receiving intervention should be actively involved in the child's behavioural services. This could include parents receiving consultation support and/or training and coaching in the clinic, at home and/or in other community settings. When a child or youth is receiving behavioural assessments or behavioural intervention for skill development and/or behaviour changes/reduction and their generalization, parents and caregivers will be offered parent/caregiver training and education.

As a child or youth is achieving the goals outlined in the OAP Behaviour Plan, the focus will include consolidating and/or maintaining the skill(s) recently acquired and using it flexibly and in new ways, in new environments and with new people. Goals may also focus on increasing the capacity of the people around the child to maintain and/or extend those skills in the child/youth's natural environments.

### **Family and Family Team Intervention Support**

As a child/youth is achieving the goals outlined in the OAP Behaviour Plan, the parents and the Family Worker and Team, including the OAP Behavioural Clinician, will meet to consider how they can best support the child/youth's learning. This process may involve updating the OAP Behaviour Plan. The family will be involved in any modifications to the Behaviour Plan, including the identification of new goals. The OAP Family Support Worker/Team will also modify the broader OAP Family Service Plan (FSP), identifying a new set of goals related to the real-life generalization and flexible use of the new skill(s).

As described above, individualized goals within an OAP Behaviour Plan are developed with the family/youth, and progress information is shared regularly through informal

updates (i.e., Touch Points) with the family and their Family Team. The OAP Behavioural Clinician is responsible for monitoring, communicating and evaluating the OAP Behaviour Plan. A written progress summary is provided to the family and to the Family Team at meetings as required at least every six months.

Parents/caregivers may receive education, training and/or consultation support. Consultation to the child or youth's school or primary learning environment(s), from OAP clinicians or other Family Team members may also be provided according to needs. As needed, the OAP Behavioural Clinician can provide consultation and support to reinforce and support maintenance of newly learned skills. Generalization and maintenance is coordinated with the Family Team members. This can occur in a variety of places in which the child/youth spends considerable time. For example, early years or school ABA staff could assist staff in helping a child/youth to use their newly achieved self-help skill(s) in childcare, after school care and/or in school. In other situations, a youth may be supported to use new conversation skills with his friends at soccer practice by the Family Team SLP. In another instance, a child may be supported to maintain her toileting skills at home and at her grandparent's home by an Early Interventionist. The OAP Behavioural Clinician may provide consultation to staff of a child and youth community-based mental health provider in managing a youth's challenging behaviour. This collaborative partnership work is coordinated at the Family Team level.

At the next Family Team meeting, individualized goals and data tracking are developed, and the OAP Family Service Plan is updated. The OAP Behavioural Clinician is a member of the Family Team and provides consultation as required. Again, although frequency and type of communication are individually determined, a re-evaluation meeting must be held at least every six months or earlier as needed. Communication expectations are also confirmed, including when and how the family and the Family Team will be updated with Touch Points and/or Progress Review (full team) meetings. Clinicians are responsible for the ongoing monitoring and evaluation of their assigned responsibilities and the Family Team Lead ensures this is reviewed on a regular basis. The parent/youth may decide that next steps be determined either at that meeting or following that meeting with support from the OAP Behavioural Clinician. The next steps are determined based on an individual's needs and can include an updated Behaviour Plan with continued or new goals.

Note: An updated behavioural assessment and/or other required assessments may be required when there is a marked change in needs, priorities and/or intervention goals.

### **Monitoring and Evaluating the Behaviour Plan**

As a child/youth is receiving behavioural intervention, progress information is shared regularly through informal updates (Touch Points) with the family and their Family Team.

Behaviour plans are not static and should be monitored and evaluated on an ongoing basis to ensure a child's/youth's continuous progress. Monitoring and evaluation of the Behaviour Plan is the responsibility of the OAP Behavioural Clinician. The Behavioural Clinician will also examine the effectiveness of programming and treatment fidelity. On

an ongoing basis, the Behavioural Clinician will monitor the child's response to treatment. If a child is not making progress, the Behavioural Clinician will examine what has been done or could be done to refine the Behaviour Plan.

The OAP Behavioural Clinician writes a progress summary every six months or sooner if needed. The progress summary will include the target skills/behaviours, the behavioural goals, a brief description of the intervention, the results to date (based on data), and recommendations for next steps. The OAP Behavioural Clinician reviews the summary with the family/youth and Family Team and provides them with a copy of the summary.

## Progress Reviews and Updates to the Story

Communication between each family and their OAP Behavioural Clinician is individualized and determined with the family/youth as part of the OAP Behaviour Plan. A progress summary will be provided to the family and Family Team at least every six months.

There is an expectation that Touch Points will occur between the OAP Behavioural Clinician and the family/youth and Family Team, on an ongoing basis as needed (i.e., in response to significant changes to goals or strategies). An update of the child's overarching needs and strengths is conducted every six months or sooner as needed.

In addition to the regular progress reviews, there will be a clear, mutual understanding of the Touch Points (e.g., updating conversations, emails, etc.) that will occur in between progress reviews. The Touch Points will be determined collaboratively with the family/youth.

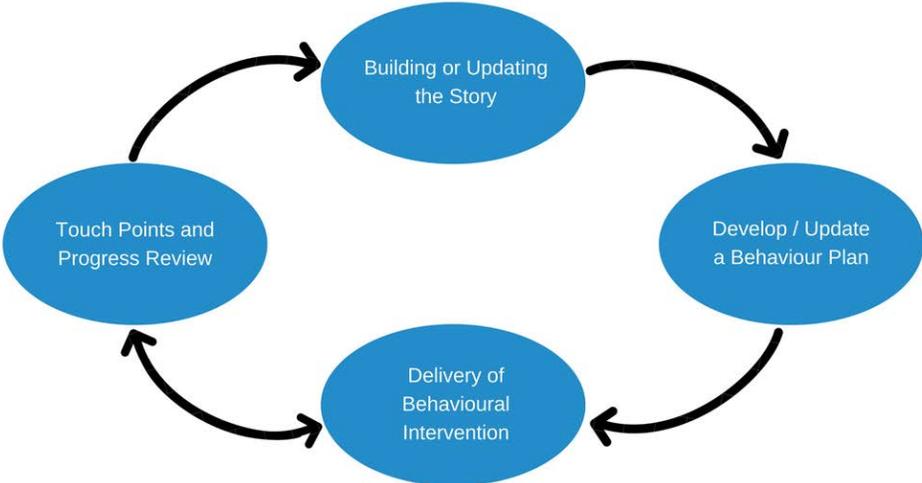
Progress reviews with the Family Team will occur at least every six months. They will "build on the story" developed at intake and involve:

- A complete summary of progress in behavioural goals set at the onset of intervention or at the time of the last review.
- An update of any family or child factors that have significantly changed; new information may require updating parts of the initial CANS, if administered.
- Discussion of additional needs or gaps that have emerged in the understanding of the child's areas of function, and further or updated assessments that may be needed (e.g., cognitive, communication, adaptive skills assessments or investigation of possible medical conditions that could affect behaviour).

If there are changes to the behaviour plan (e.g., significant changes to goals and/or methods) this information is conveyed through an agreed upon form of communication (e.g., written, telephone, meeting) to parents and Family Team members. All verbal communication is documented in written form by the Behavioural Clinician.

As the goals outlined in the OAP Behaviour Plan are met, the OAP Behavioural Clinician initiates a family team meeting, as appropriate, to determine next steps and plan for a transition to the next intervention. Transition decisions are individualized based on the achievement of goals, and are made by the family/youth and the behavioural clinician based on the current profile of strengths and needs of the child/youth and their family.

**Figure 3: Critical Elements of Clinical Decision-Making**



# Other Aspects of the OAP Clinical Framework

## Crisis Situations

Urgent situations in the lives of children and youth with ASD may emerge, despite preventative measures. Regional OAP providers will have policies and procedures to follow with regard to varying degrees of crisis and the appropriate, immediate responses for their staff. Following a crisis, however, there may be times when OAP clinicians could make valuable contributions to future planning and prevention. Crisis situations involve a high risk of significant harm to self-and/or to others. OAP responses could include prioritizing services and supports for the child and family and working with community partners, including schools, in collaborative ways that are family-centered and evidence-based. A specialized expert crisis team that can respond to such situations should be developed in ways that do not affect support and behavioural intervention for other children and youth in the OAP.

## Transitions

Transition planning and associated best practices are important parts of clinical work. Many children and youth with ASD have considerable challenges in making significant changes in their lives. Skilled clinical planning and support services can make an important difference.<sup>11</sup>

### **OAP-Related Transitions**

Any transition in or out of the OAP is also individually planned in partnership with the family and/or youth. It is an expectation that individualized, responsive and best practice transition processes be developed in collaboration with the OAP clinician(s), the family/youth, school, ongoing Family Team and the receiving community organizations.

Once a child/youth enters the OAP, they will remain in the program until age 18, per the OAP program guidelines. There is no “discharge” from the OAP and secondary students are supported with individualized transition planning as they shift from the OAP into adult services, and/or transition to postsecondary education and/or employment.

A family or child/youth may request to withdraw from the OAP either with or without transition support services. The removal of the diagnosis of ASD would also warrant an individualized transition plan out of the OAP. Should circumstances change for a child/youth who has withdrawn but remains within the age limit and catchment area, they are welcome to re-enter the OAP.

If a family in the OAP moves to a new region in Ontario, the intake process may include behaviour assessment and transition planning.

### **Other Transitions**

Other transitions can include personal transitions (e.g., a move of the family home, changes in family makeup), school-related transitions (e.g., into Kindergarten, Middle and/or Secondary School) and the transition to adult services. Depending on need, any of these transitions can require individualized supports and services developed through careful planning between parents, youth, OAP clinicians, and education and community partners. It is important to note that for school-aged children and youth, the OAP recognizes the importance of children learning with their classmates at school, and designs OAP services and supports to accommodate this goal as much as possible.

# Conclusion

The Clinical Framework supports the OAP Outcomes and Guiding Principles (Appendix B) by promoting consistency of approach amongst OAP service providers. It also recognizes the skilled and dedicated practitioners from across sectors and disciplines providing exemplary practices in partnership with children/youth with ASD and their families.

The framework aims to contribute to an ongoing discussion of what it means, in concrete real-life terms, to provide individualized and child-, youth- and family-centred services. It sets the stage for the development of positive, trusting relationships amongst families, support and service providers, educators and community partners. The goal of the OAP is to provide a personalized system of care that offers effective and evidence-based practices/interventions so that each child or youth with ASD in Ontario, within the context of their family and community, can reach their optimal potential.

# ASD Clinical Expert Committee

The ASD CEC was established in 2012 to provide advice to the Ministry of Children and Youth Services on effective intervention, current research, and best clinical practices for working with children and young people with ASD.

An important long-term goal of the CEC is to aid in the development of a model of care that is up-to-date with the state of evidence, and includes a comprehensive continuum of services and supports for children and youth with ASD and their families.

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# Appendices

## Appendix A: Methods

### 1. Parent/Youth, Clinician and Educator Stakeholder Consultations

Stakeholder focus groups took place from November 2016 to March 2017. The purpose of the consultations was to document the advice, experiences, perspectives, and priorities from as many stakeholders across the province as possible. This wide gathering of information was done to ensure recommendations to the Minister about the OAP reflected the advice of children and youth, their families and their support and service providers, and took into consideration not just the individual skills that a child/youth can improve, but also their ability to participate as fully and as independently as possible in all their settings. Importantly, we wanted to ensure that the priorities of children and youth with ASD and their families were well understood.

Each meeting was arranged with the intention of having between 10 and 12 stakeholders present to allow for fulsome participation. Most meetings achieved this target number, with a small number of groups having fewer than 10 participants and others with 15-20. Stakeholders included parents, youths, clinicians (e.g., members of the Regional Autism Providers of Ontario Network, the Ontario Association for Behaviour Analysis, the Independent Review Mechanism, Direct Funding Option providers, occupational therapists, speech language pathologists, physiotherapists, pediatricians), and educators (e.g., early childhood educators, resource teachers, teachers, educational assistants, school-based ASD and ABA specialists, superintendents, principals). Three parent/family and two school board focus groups were also conducted in the north.

Youth focus groups discussed the types of goals they each have achieved, as well as supports that might benefit others. Parents were asked questions about the best ways for interventionists to get to know their children, how to decide what to work on, and optimal communication with the clinical team. Focus groups of clinicians discussed four main areas: information sharing within and outside of the OAP; factors and tools that should be considered when making clinical decisions within the OAP; and ways to create an integrative team that includes caregivers and service providers. Minutes from each meeting were analyzed for common themes.

## **2. Community Stakeholder Consultation and Ontario Parent Survey**

Input from parents was solicited using an online survey. The survey was sent to parents within the networks of stakeholder groups who were invited to participate in our community-stakeholder consultations (e.g., Autism Speaks, Autism Ontario, South Asian Autism Awareness Centre, the Ontario Autism Coalition, and La Société franco-ontarienne de l'autisme). The Société franco-ontarienne was not able to attend but did circulate the survey. The survey consisted of 4 questions that addressed the general strengths and needs of a child/youth with ASD and how clinicians should work with a family to consider these factors.

The survey was open for input between March 6, 2017 and March 17, 2017. A total of 467 individuals from across the province participated in the survey. A clear majority of participants were parents with a few individuals self-identified as well as teachers or clinicians.

## **3. Intervention Planning Framework Study**

The CEC worked closely with RAPON to identify clinicians in all regions across the province, including both Direct Service Option and Direct Funding Option providers, in three professional groups (i.e., psychologists/psychological associates, Board Certified Behaviour Analysts, and speech-language pathologists). Clinicians who self-identified as having dual-credentials (e.g., SLP and BCBA certifications) were coded according to their primary clinical affiliation.

Clinicians (N = 83) from across the province volunteered several hours of their time to complete these surveys. There was a strong representation from different sectors, professions, and treatment setting experiences. The high rates of participation make it clear that clinicians in Ontario value the opportunity to guide system-level change to better support children and youth with ASD and their families.

Clinicians were given nine different case vignettes that included a comprehensive description of the bio-psycho-social status and history, detailed cognitive, developmental, and health information about individuals with ASD (i.e., preschool, school-aged, and youth) and their families/caregivers. Clinicians were then asked to (a) determine the 'level of support needed' for each individual (i.e., support needed vs. substantial support vs. very substantial), and (b) identify the specific domains (e.g., communication, school readiness, etc.) that they saw as relevant to that individual's needs.

Key information identified as particularly important to clinicians in the clinical-decision making study included that there was a robust pattern in how clinicians valued the "whole child and family story/ vignettes" to help in the intervention design process (e.g., CANS and story). Other information that was helpful included a child's age, diagnosis, child's profile of strengths and needs, cognitive and adaptive profile, details about their social and communication skills, details and context about problem behaviour, current

family stressors, family's barriers and capacity to participate in interventions, and information/communication with school staff.

Clinicians as a group consistently assigned children/youth with ASD into three defined levels of support. These results support the feasibility of a standardization component in the OAP.

A range of intervention domains were identified for each child/youth. When asked to endorse the "domains" (e.g., communication, emotion regulation, etc.), clinicians provided response patterns that cut across all three "levels of support needed". In other words, the idea that "more severe" cases require a wider range of supports while "less severe" cases require a more limited range of support was not supported by the data.

# Appendix B:

## Outcomes and Guiding Principles for the Ontario Autism Program Developed by the Ontario Autism Program Advisory Committee

### Ontario Autism Program Outcomes

#### Child, Youth and Family Outcomes

- All children and youth with autism will have timely access to high quality and evidence-based (where evidence exists) interventions that will optimize long term outcomes.
- Families will experience services that are effective, well-coordinated, family-centered and responsive to their child or youth's changing needs in order to maximize their potential and quality of life.
- Children and youth with autism are supported to attain long-term success and meaningful and active participation in society.
- Family members are key partners in determining their child or youth's care, and they will be actively engaged to enable them to acquire skills that support their child's development.

#### Systems Outcomes

The Ontario Autism Program will provide services that are:

- Flexible, relevant and responsive to the needs of individual children and youth with autism.
- Integrated into the larger service system to allow for seamless transitions and collaboration across multiple providers, schools and care settings as well as all relevant provincial ministries, and their respective services and supports.
- Sustainable and obtain maximum benefit and outcomes for resources invested while allocating resources in the most effective way possible.
- High quality, innovative and rooted in evidence-based practice, and delivered by qualified and trained professionals.
- Available to children, youth and their families within a timeframe that provides maximum therapeutic benefits.

## Ontario Autism Program Guiding Principles

***Child, youth and family centered services:*** Children, youth and families are partners and are actively engaged in intervention planning. Evidence-based services are delivered according to a relevant assessment of a child or youth's needs, strengths and interests and the family's concerns and priorities. Families will be supported throughout the decision-making process. Informed choice is a key element.

***Coordinated and collaborative:*** Intervention will be integrated and coordinated with other services that a child, youth or their family may be receiving. Families will experience a high degree of inter-professional partnership with mechanisms in place to support information sharing and collaboration amongst services and the community. Collaboration will take place among provincial ministries to support provision of coordinated services.

***Flexible and responsive:*** Children, youth and their families will receive timely and individualized services in accordance with their needs, strengths and goals. The approach to intervention will be guided by an individualized service plan, developed in partnership with the family. Services will be flexible, proactive and continually responsive to the child, youth and families' needs, recognizing that these needs change over time.

***Available and accessible:*** Children and youth and their families can access the services they need close to home. Services are responsive to cultural, social, geographical and economic diversity and language needs of children, youth and their families. Entry into service will be straightforward and easy to navigate through a single entry point.

***Transparency:*** Decisions regarding access to and provision of service will be transparent to families and other service providers, and information will be shared appropriately.

***Continuous quality improvement:*** Approach to service delivery is outcome oriented and evidence-based. Services are flexible to be responsive to changing evidence and practice, and are accountable through continuous evaluation and monitoring. Capacity-building for families and service providers that incorporates evidence-based strategies and competency-based improvement is an essential component of service delivery.

***Equitable and fair:*** Families with children and youth with autism have an equal opportunity to access equitable services that respond to their individual needs.

***Free from conflict of interest:*** Clinical decisions will be made in the child or youth's best interest.

