

Recommendations for a New Needs-Based
Ontario Autism Program

THE ONTARIO AUTISM PROGRAM ADVISORY PANEL REPORT

OCTOBER 2019

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A Message from the Co-Chairs

We believe Ontarians stand with the families of children and youth on the autism spectrum and their right to receive the highest quality care and treatment.

In the spring of 2019, the Ontario government engaged in a province-wide public consultation process and appointed a new 20-member Ontario Autism Program (OAP) Advisory Panel.

This Panel was comprised of parents with lived experience, autistic adults and experts from a range of disciplines like psychology, behaviour analysis, rehabilitation services, education, developmental pediatrics and research. The Panel met for 18 full days over the summer months.

Our Panel was tasked with providing recommendations to the government on the design of a needs-based, sustainable OAP that serves as many children and youth as possible within the increased \$600 million funding envelope.

There has been a tremendous amount of work completed by the Panel to date. Our meeting summaries only scratch the surface when it comes to the depth and length of our conversations and deliberations over the past many months.

Thank you to the community, including Northern Ontario providers, political representatives, families and other experts for submitting reports and recommendations for the consideration of the Panel. Our efforts were informed by the views of children, youth and families with lived experience, service providers, clinicians and experts. Countless hours were spent reviewing and discussing your material, and our recommendations reflect this.

The Panel also examined results from the online survey, telephone town halls, MPP roundtables and written submissions and considered relevant evidence, science and data. Utilizing our experience and in-depth knowledge, the Panel developed recommendations that we believe could, if adopted, position Ontario as a leader in supporting children and youth on the autism spectrum and their families.

It has been our honour and privilege to lead the work of the Ontario Autism Program Advisory Panel. We applaud the government for inviting diverse members of the community to be avid participants in the redesign.

Given the generous scope of our work within a defined budget, the Panel has had to make some hard choices to achieve the recommendations included in this report. Families told us, and the Panel agreed, not to sacrifice the provision of evidence-based, clinically appropriate care at the expense of addressing the waitlist more quickly.

Recommendations for a New Needs-Based Ontario Autism Program

At the same time, to ensure as many children and youth as possible are served and also the long-term sustainability of the OAP, annual caps on the amount of individual service received will be unavoidable into the foreseeable future.

To support implementation of a new program, the Panel is recommending that an implementation committee be established consisting of parents, autism self-advocates, clinical and system experts, researchers and community partners. It is also recommended that detailed, family-friendly transition plans be developed to help families understand what the changes to the program will mean for them.

The Panel believes its recommendations for a new OAP should be cause for hope for children and youth on the autism spectrum and their families.

Needs-based, sustainable within an annual budget of \$600 million, serving as many children, youth and families as possible and aligned and coordinated with the school and health systems, the recommendations offer the chance for a reset and a fresh start. We urge the Government of Ontario to seriously consider our recommendations as it works towards this redesign. Our children, youth and families deserve a future of hope and possibility.

Your Co-Chairs,

Margaret Spoelstra and Marie Bountrogianni

1. About the Ontario Autism Program Advisory Panel

1.1 Members of the Ontario Autism Program Advisory Panel

The province's 20-member Ontario Autism Program Advisory Panel (the Panel) includes parents of children and youth on the autism spectrum, clinicians, researchers, autistic adults, service providers, former public servants and others who have professional and personal experience with individuals on the autism spectrum. The following section provides a brief summary of the experience and expertise of each member of the Panel.

Co-Chairs

Dr. Marie Bountrogianni (co-chair) is the former dean of the Chang School of Continuing Education at Ryerson University and former chief psychologist of the Hamilton Wentworth District School Board.

Margaret Spoelstra (co-chair) has been the executive director of Autism Ontario, the province's leading source of information on autism, since 2001. Prior to joining Autism Ontario, Marg worked in clinical and resources services for the Geneva Centre for Autism. She has worked for almost four decades with individuals with a variety of learning needs, particularly individuals on the autism spectrum. Marg was appointed as a Member of the Order of Canada in 2011.

Panel Members

Christie Brenchley is executive director of the Ontario Society of Occupational Therapists (OSOT). In her role over the past 25 years, Christie has worked with government and other stakeholders on issues that cross the healthcare continuum, the broad determinants of health and a variety of ministries with a solutions-focused approach to assure access to services of occupational therapists for Ontarians who need them. Herself an occupational therapist, Christie has worked with children, youth and adults with special needs.

Jeanne-Marie “Gina” Brennan is a self-employed Applied Behaviour Analysis (ABA) therapist since 2011. She works under the ongoing supervision of a Board-Certified Behaviour Analyst (BCBA) and a clinical psychologist as she transitions to a senior therapist role. Gina recently fulfilled the requirements for completion of the Masters

program in Applied Disability Studies (ABA emphasis) at Brock University and is studying to take the board certification exam for behaviour analysts.

Dr. Jessica Brian is a psychologist and clinician-investigator at Holland Bloorview Kids Rehabilitation Hospital and assistant professor at the University of Toronto in the Department of Paediatrics. She co-directs the Autism Research Centre at the Bloorview Research Institute.

Dr. Robert Cushman is currently the acting medical officer of health in Renfrew County. He has previously served as the director general of the Biologics and Genetic Therapies Directorate, in the Health Products and Food Branch at Health Canada and has served as CEO of the Champlain Local Health Integration Network. Dr. Cushman has also been the medical officer of health for the City of Ottawa and has worked as a primary care physician in a variety of health care settings, including the emergency room of the Children's Hospital of Eastern Ontario.

Matthew Jason Dever is an autistic adult with three children on the autism spectrum. He advocates for inclusion and acceptance of autistic individuals and for autistic people to have their own voice. Matthew is an active member of Autistics for Autistics (A4A), Ontario's autistic self-advocacy group. A4A is a collective of approximately 300 autistic adults advocating for reform to Ontario's approach to autism funding and services.

Alex Echakowitz is an autistic social service work student who specializes in disability justice and youth mental health. They are a member of the Centre for Addiction and Mental Health (CAMH) Youth Advisory Group, as well as a volunteer with the York Federation of Students Access Centre. They are also a co-founder and former board member of Ontario's first province-wide self-advocacy organization, Autistics for Autistics (A4A).

Cindy Harrison is a speech language pathologist and the parent of a young adult with autism. Cindy is senior faculty at Profectum, an international multidisciplinary facility that teaches and trains professionals to assess and intervene with children, youth and adults on the autism spectrum. She is also the co-founder and CEO of CommuniCare Therapy and ACT Learning Centre, both in Ottawa. Cindy holds a Master of Science in Speech Language Pathology and she has been working in the field of autism for more than 21 years.

Anne Huot is the vice-president of Child Development and Community Services at the Children's Hospital of Eastern Ontario (CHEO). A professionally trained social worker, Huot's portfolio includes autism, development and rehabilitation services, mental health, patient experience and complex care. She was the executive director of the Ottawa

Children's Treatment Centre when it amalgamated with CHEO in 2016 and led the integration of programs and services for children and youth.

Sheri Ketchabaw has a Bachelor of Science in Water Resources Engineering from the University of Guelph and a Business Accounting diploma from Mohawk College. She is also a parent of two adults on the autism spectrum. The elder attends university using all the accessibility supports available to support him to achieve his education goals, and the younger attends a Developmental Classroom Program at his local high school from where he will transition into Adult Disability Services – Developmental Services Ontario (DSO)/Ontario Disability Support Program (ODSP). She and her family live in rural Southwestern Ontario.

Laura Kirby-McIntosh is the proud parent of two teenagers on the autism spectrum. She holds a Bachelor's Degree in History and a Bachelor's Degree in Education from the University of Ottawa and has been a teacher for over 25 years. She has experience reviewing and writing curriculum with the Ministry of Education and has also written and edited for several educational publishing companies. She is a founding member and the current President of the Ontario Autism Coalition, a grassroots political advocacy group fighting for better services for autistic people and their families.

Dr. Julie Koudys is a clinical psychologist and a board-certified behaviour analyst at the doctoral level. She is an assistant professor at Brock University in the Department of Applied Disability Studies where she teaches courses in Applied Behaviour Analysis (ABA). She has provided clinical supervision in ABA and Intensive Behaviour Intervention (IBI) for nearly 20 years. She is an active member of the Ontario Association for Behaviour Analysis (ONTABA) and is the current chair of the Ethics and Jurisprudence Committee and the Ontario Scientific Expert Committee for the Treatment of Autism Spectrum Disorder (ASD).

Marie Lemaire is a member of Autism Ontario's French Services Committee. She has a child on the autism spectrum.

Christine Levesque is chair of Autism Advocacy Ontario, and a single parent of two neurodiverse children, one on the autism spectrum, the other in process of diagnosis. Levesque has been working on OAP committees, helping families navigate services since the former government's Autism Intervention Program (AIP). She is a passionate advocate for inclusive needs-based therapies.

Dr. Janet McLaughlin is an associate professor of Health Studies at Wilfrid Laurier University and is co-founder and co-director of the Laurier Autism Research Consortium (LARC). She recently led a major study of autism policy and family well-being in Ontario. She is a parent of a child on the autism spectrum.

Anne O'Brien is director of education at the Durham Catholic School Board. Anne is also the past president of the Canadian Association of School System Administrators. She has been a superintendent of special education and taught special education additional qualifications to teachers for many years.

Wendy Prieur is an executive director of North Bay Recovery Home and represents the mental health and addiction sector. She was in municipal politics for 13 years, six of which were as the mayor of the Township of Nipissing. Prieur has a Bachelor of Social Work from Laurentian University.

Sherri Taylor is a parent of four children who are neurodiverse. She has an extensive history of working with individuals with diversabilities in various settings such as the York Region District School Board as an educational assistant and behaviour itinerant, Community Living and Christian Horizons. Currently she works as the family care coordinator at Back to Life Rehabilitation and Sensory Integration Facility with many neurodiverse children and youth and their caregivers. Sherri is proud to be the director of education on the board of Autism Advocacy Ontario as well as a board member of the Ontario Disability Coalition fighting for all individuals regardless of age and diagnosis.

Dr. Mohammad Zubairi is a developmental pediatrician at Ron Joyce Children's Health Centre at McMaster University. He is a member of the McMaster Autism Research Team. He is on the steering committee for the Physicians of Ontario Neurodevelopmental Advocacy (PONDA) network and on the board of directors for the South Asian Autism Awareness Centre. He is a section executive with the Canadian Pediatric Society.

1.2 Mandate and Activities of the Panel

In spring 2019, the Ontario government engaged in a province-wide public consultation process which included an online survey of families including caregivers of children and youth on the autism spectrum, telephone town halls, Members of Provincial Parliament (MPP) roundtables and numerous written submissions from stakeholders and experts. Those who participated in the consultations provided the government with feedback on ways to better support children and youth on the autism spectrum and their families.

The Minister of Children, Community and Social Services also appointed a new 20-member Ontario Autism Program Advisory Panel, made up of parents with lived experience, autistic adults, experts and service providers from a range of disciplines.

The Panel was initially tasked to review the results of information and data collected through the public consultations process and to provide advice to the government on

how to better support children and youth on the autism spectrum who have complex needs, including through additional direct funding.

However, based on feedback from families of children and youth on the autism spectrum, as well as the Ontario Autism Program Advisory Panel, in July 2019 the Minister of Children, Community and Social Services expanded the scope of the Panel to provide advice on the design of new needs-based OAP.

Panel Mandate

The Advisory Panel was asked to provide recommendations that would help to inform an approach that is responsive to the individual needs of children and youth to improve their long-term outcomes, and provide advice on the design of a new Ontario Autism Program that is:

- Needs-based and addresses individualized needs of children and youth
- Sustainable within an annual budget of \$600 million
- Able to serve as many children, youth and families as possible
- Aligned and coordinated with schools and the health system to facilitate a child and youth-centred approach.

The Panel met for a total of 18 full day in-person sessions. The following report summarizes the outcomes of those sessions and outlines the Panel's recommendations for a new needs-based and sustainable OAP that would achieve the objectives listed above. The report outlines recommendations on an approach to describing and addressing need in a consistent, transparent and cost-effective manner within the fixed envelope of funding for the OAP with the objective of maximizing child and youth outcomes; describes roles and responsibilities of clinicians and/or others in the new program; and includes implementation considerations.

The Panel has also provided advice to the Ministry of Education (EDU) and the Ministry of Health (MOH) on how best to coordinate services and leverage investments in the OAP, education and child development sectors and the health system to facilitate a child and youth-centred approach.

1.3 The Vision of a New OAP: Measures of Success and Key Principles

As part of the Panel's work, measures of success and guiding principles were developed to describe the Panel's vision for a new OAP. These were used to help guide and form the foundation of the Panel's recommendations for the design of the new program.

Measures of Success

The Ontario Autism Program should:

- Improve the quality of life for people on the autism spectrum and their families by supporting their mental health wellness, their dignity and their ability to thrive
- Offer a continuum of evidence-based care through a broad range of services and supports, early intervention and support during challenging times such as adolescence and the transition to adulthood
- Be a needs-based and fiscally responsible program with an emphasis on long term planning
- Build on programs and resources that already exist across sectors
- Leverage technology to promote access and inclusion
- Provide families with help to understand different treatment approaches and to be empowered to make the best choices for their child and youth
- Incorporate approaches into program design and delivery that support the mental health of children and youth on the autism spectrum and their families
- Improve access and inclusivity for all, including:
 - Families from diverse backgrounds
 - Those living in rural, remote and Northern communities
 - Children and youth with co-occurring needs

- Apply innovative and research-informed best practices to program design and delivery to better support families
- Align and coordinate OAP services with the Health and Education sectors to facilitate a child and youth-centred approach
- Maintain and build capacity in the service system.

The Panel identified the following set of principles for the Ontario Autism Program:

Guiding Principles

The Ontario Autism Program should be guided by the following principles:

- Evidence-based
- Person-focused
- Fair and equitable
- Responsive and timely
- High quality and effective
- Stable
- Family choice
- Flexible
- Cost effective
- Integrated with Health and Education
- Accessible for all, including the most marginalized families

2. Recommendations

The Ontario Autism Program Advisory Panel offers the following recommendations to the redesign of the Ontario Autism Program (OAP).

2.1 Entering the OAP

Children and youth are eligible for the OAP if they have a diagnosis of Autism Spectrum Disorder (ASD) from a qualified professional. Panel members are aware of the significant barriers that some children, youth and families face in accessing a timely diagnosis of ASD. Feedback from the consultations noted that barriers are particularly significant in Northern, rural and remote areas of the province which cause delays for those families in accessing not only a diagnosis, but also the OAP. In addition, as per the position statement released by the Canadian Pediatric Society in October 2019, *Standards of diagnostic assessment for autism spectrum disorder*, ASD is diagnosed four times more frequently in boys than girls, and often girls are underdiagnosed for ASD.

In response to these concerns, the Panel strongly felt that children and youth with provisional diagnoses be permitted to register for the program. Given the fixed budget and the large number of children and youth waiting for service, the Panel decided that at the present time, only those children and youth with a confirmed autism diagnosis be eligible to receive services in the OAP. However, the Panel recognized the value of early intervention even for those with a provisional diagnosis. If, in the future, wait times are reduced, the Panel recommends that those with a provisional diagnosis should also be eligible to receive early intervention services, while being placed on the waitlist to access other OAP services once a confirmed diagnosis is received.

New families should enter OAP Core Services from the waitlist in sequential order based on the date of their initial referral to the program (see page 18 for a full description of OAP Core Services)

For all families, it is important that the entry point into the OAP be clear, easily accessible and as barrier-free as possible.

Panel Recommendation:

- Referrals to the program be accepted from families, qualified diagnosing professionals, and the regional diagnostic hubs
- Children with a formal diagnosis of ASD access all OAP services sequentially based on their date of referral
- Children with a written provisional diagnosis of ASD be registered and “time stamped” at the point of referral, but not receive any OAP services. If the child subsequently receives a diagnosis of ASD, they access OAP services based on their initial date of registration
- It will be critical that the waitlist and the process for managing the list be transparent and accessible to families
- Ongoing investments and capacity building initiatives in diagnostic services should be made to ensure that children are identified early, especially in those areas of the province where the average age of diagnosis remains high due to limited access to qualified diagnosticians.

2.2 Services and Supports

The Panel believes that services offered in the new Ontario Autism Program should be responsive to a child or youth’s needs and include a range of evidence-based clinical services such as early intervention, ABA, Speech and Language Pathology (SLP) services, Occupational Therapy (OT), mental health services and caregiver education. Targeted supports that ensure services are available and equitably accessed by children and families in underserved and marginalized communities should also be provided. These are described in detail below.

Specific Care Pathways

The Panel was asked to provide recommendations for a program that is sustainable within a fixed budget of \$600 million. This means that waitlists for some OAP services are inevitable. As part of their deliberations, Panel members considered the funding envelope, what they heard from families and other experts, and research evidence and identified three specific priority access care pathways. The Panel recommends that

resources should be allocated to the following priority pathways to reduce the wait to receive these services:

- Early intervention services
- Mental health services
- Urgent response services

Early Intervention

As wait times for the OAP have increased, fewer and fewer young children have received critically important early intervention. Research has shown that the right treatment and supports, particularly at a younger age, can help children on the autism spectrum develop skills, improve their overall well-being and functioning and achieve better long-term outcomes. Investments in early intervention have been shown to decrease long-term costs to the service system.

What we heard:

In stakeholder submissions, telephone town halls and MPP roundtables, the Panel heard about the importance of providing intervention in the early stages of a child's life prior to school entry.

The Panel considered a first-come, first-served approach to service with the evidence of the effectiveness of early intervention and recommends offering early intervention on a time-limited basis to all children under the age of six with a confirmed diagnosis of autism upon registering for the OAP. These services should be caregiver-mediated and evidence-based and target the core symptoms of autism. Families accessing early intervention services would maintain their spot on a sequential waiting list to access OAP Core Services (ABA, SLP, OT, mental health services. See page 18). These services are not intended to be a replacement for OAP Core Services.

Outcomes from high-quality research, cost-effectiveness and capacity in the service sector need to be considered when identifying the specific early intervention approaches to be included in the OAP. The implementation committee should be tasked with reviewing the available evidence in order to determine the early intervention services to be included in the OAP.

Panel Recommendation:

Children with a confirmed diagnosis of autism up to age six can access autism-specific, evidence-based, caregiver-mediated early intervention services on a time-limited basis upon registering for the OAP.

Mental Health Services

It is imperative that MOH invest in providing health, mental health and crisis supports for children and youth on the autism spectrum (see page 40 for details). The integration of autism services with children’s mental health services is critical as children and youth on the autism spectrum experience mental health challenges at a staggering rate compared to the general population. As children on the autism spectrum approach and enter adolescence, it is estimated that up to 70% will be diagnosed with a mental health challenge. Due to current gaps in accessibility and expertise, it is recommended that short-term, episodic, evidence-based counselling approaches such as, but not limited to, Cognitive Behavioural Therapy (CBT) be available to families when needed, including while they are waiting for other OAP Core Services, such as, but not limited to, circumstances when these mental health services are not available through a child’s mental health program.

Panel Recommendation:

Children and youth who meet certain needs-based criteria through a standardized process should receive short-term episodic, evidence-based mental health services prior to receiving OAP Core Services (ABA, SLP, OT, mental health services).

The autism and mental health working group described in the MOH section below should develop specific criteria for this service.

Urgent Response Services

Panel recommendations regarding timely access to early intervention and mental health services are meant to be proactive and mitigate the need for urgent response services. However, urgent needs can still arise, especially for those families with children with complex needs or who may be waiting for OAP Core Services.

What we heard:

The Panel heard about the desperation that some families can experience as a result of a behavioural or mental health crisis with their child. One stakeholder submission detailed an approach that included specialized urgent response teams that can be activated quickly to address such situations.

It is recommended that urgent response services be jointly funded by MCCSS and MOH, and that existing services and teams be leveraged and combined with advice from those with clinical/research expertise in the field of autism (see page 34) to develop this service and clarify who qualifies.

Interdisciplinary urgent response services should be available to provide time-limited crisis prevention support to children and youth who meet specific criteria. All OAP service providers should be equipped with the tools and training to help families identify urgent need and to connect them with this service.

Panel Recommendation:

That eligible families have access to an Urgent Response Pathway upon registration and confirmed diagnosis that may include, but not be limited to, the following services:

- Intensive service coordination in collaboration with the Care Coordinator
- Respite that is not available through other means
- Access to a Registered Dietitian as recommended by a medical professional
- OAP Core Services.

Foundational Family Supports

Responses from the provincial consultations highlighted the importance of foundational and ongoing supports for families of children on the autism spectrum. For many families, the service system can be challenging to navigate, especially for families with a new diagnosis, those who do not speak English as their first language or those who

face other barriers. Many families feel they need support to navigate the service system and a touchpoint that is a source of unbiased information and direction. It is proposed that the new OAP provide universal access to foundational supports that families can choose to access at any time throughout their service journey.

What we heard:

Caregiver training, capacity building, and service navigation are also much-needed services to support families of children on the autism spectrum.

Foundational family supports should include a diverse selection of universally available needs-based supports for all families such as:

- Caregiver training and education, including workshops and related follow-up consultation
- Support groups
- Transitional supports for youth who are aging out of the program
- Information and resources

Foundational family supports should consider the needs of families at various stages of their journey and the use of technology to ensure that families are provided with meaningful information in flexible, cost-effective and convenient formats.

Panel Recommendation:

Foundational supports should be universally available to all children and youth with a confirmed diagnosis of ASD and their families immediately upon registering for the OAP and throughout the child or youth's and family's time in the program as required.

OAP Core Services

Evidence-based clinical services are at the core of the OAP. In the recent autism online survey, most families reported that, if given the choice, they would choose clinical

services such as ABA (80%), SLP (58%) and OT (58%) for their child. Families of adolescents also identified the need for mental health services.

It is important to recognize that children and youth on the autism spectrum vary greatly in terms of their specific needs and the intensity and scope of services required to meet those needs. As such, OAP Core Services must reflect the needs of children and youth on the autism spectrum and provide evidence-based clinical services at a range of intensities to meet those needs.

Panel Recommendation:

Children and youth with a confirmed diagnosis of ASD in the OAP should have access to evidence-based clinical services that are responsive to their need. OAP Core Services should include:

- Applied Behaviour Analysis
- Speech Language Pathology Services
- Occupational Therapy
- Mental health services, including time-limited psychotherapy and/or counselling delivered by regulated professionals who have the controlled act of psychotherapy in their scope of practice
- Access to technology, including Augmentative and Alternative Communication (AAC), at the recommendation of a regulated health professional or Board Certified Behaviour Analyst (BCBA).

The Panel believes that mental health services should be funded through MOH. Further, partnerships should be established between MCCSS and MOH to develop evidence-based services that build on existing capacity. While these services are being developed, time-limited mental health services including psychotherapy and counselling should be available through OAP Core Services to those children who have not been able to access them through MOH programs.

It is recommended that access to evidence-based technology, including AAC, at the recommendation of a regulated health professional or BCBA, be provided to support the inclusion and full participation of children and youth on the autism spectrum who require technology to communicate. Technology should be available through the OAP only after other means of funding have been pursued. The implementation committee should be tasked with determining the parameters for the use of technology in the OAP (see page 47).

The new OAP must meet the needs of priority populations including those with significant challenges due to complex needs (see page 15). Family choice, accessibility, provider capacity and the needs of marginalized families and children and youth with complex presentations should be considered in the delivery of OAP Core Services.

Demand for OAP Core Services currently exceeds the available resources and continues to grow. The Panel spent significant time weighing the competing priorities of providing service at clinically-supported intensities and duration while also balancing the key objectives of serving as many children and youth as possible in a sustainable way. The Panel's position, which was supported by stakeholder survey data, is that families would prefer to wait to access OAP Core Services than to receive services at sub-clinical levels. The recommendations below have taken into consideration the fixed budget for the OAP, potential limitations in sector capacity and the objective to serve more children in the program. It is recommended that these resource allocation measures only be implemented until such time as there is a significant decrease in wait times for the program and the capacity of the service sector grows.

Panel Recommendation:

Until there is a significant decrease in wait times for the program, it is recommended that the following resource allocation measures be implemented while maintaining clinical effectiveness:

- Clinical Best Practice Guidelines, to be developed by clinicians/researchers with expertise in each field, should outline tiers of service caps, and intensity and duration of each treatment corresponding to various levels of clinical needs, with exceptions
- An annual service cap and discipline-specific service caps, recommended by clinicians/researchers with expertise in each field, that specify the maximum total amount of OAP Core Services a child can receive each year
- An approach to treatment intensity that supports children to progressively increase their skills in multiple environments, including at home, school, and in their community and gradually reduce their service intensity. Lower levels of continuous and episodic needs-based services should still be available as clinically required until their 18th birthday

- Service caps should be loosened over time once the current backlog of clients has been addressed and wait times are minimal or eliminated.

Respite

Many of the participants in telephone town halls and MPP roundtables recommended that respite be excluded from the OAP so that finite resources could be directed to providing clinical services. Other participants indicated the need for respite services to be available, either through the OAP or through other government funded programs. The Panel unanimously recognizes the fundamental importance of respite programs and agrees that respite should continue to be made available through other MCCSS-funded programs outside of the OAP.

Panel Recommendation:

- Families be supported to apply for all available respite programs
- Respite only be included in the OAP urgent response services (see page 15)
- MCCSS adequately fund respite services such as Special Services at Home (SSAH) and conduct a review of these services to identify and address service gaps to ensure all families have access as needed.

Targeted Supports

The Panel recommends that the needs of marginalized populations such as Indigenous, low socio-economic status, Northern, rural, remote, non-English speaking, Francophone and new Canadian families be considered in the implementation of the new OAP.

Through the public consultations and stakeholder submissions, concerns were raised regarding the shortage of Francophone and First Nations service providers, the lack of general access to services in the North, rural and remote areas of the province and limited services that are responsive to local needs and are culturally safe. It is recommended that the ministry engage with Northern, Francophone and Indigenous communities through implementation of the new OAP to ensure that the service delivery model is responsive to their unique needs.

The recommendations outlined below have been identified through written submissions from stakeholders in the North as well as through previous ministry discussions with First Nations, Inuit and Métis partners. The Panel has made the decision to adopt these recommendations in full to accurately reflect stakeholder feedback. The recommendations outlined below also include input received from several non-speaking youth.

Panel Recommendation:

Supporting Indigenous Families

- Indigenous community leaders and organizations should be engaged in the development of guidelines for OAP service providers on how to provide culturally-appropriate and culturally-safe services, including by cultivating local partnerships to share information and to support family referrals
- Options should be considered for co-locating OAP services and supports in Indigenous service provider organizations to improve access to culturally-safe services for families
- Culturally-appropriate resources should be co-developed with Indigenous leaders and organizations so that families have a better understanding of autism, know how to access services and supports and can access the training and information they need to support their child at home and in their community
- Capacity building in communities should be supported by working with Indigenous educational institutes to offer training opportunities and provide grants for individuals to gain the qualifications required to deliver OAP services in their communities
- Access to diagnosis should be improved for First Nations, Inuit and Métis communities, particularly in Northern, rural and remote communities
- Access to evidence-based services that focus on holistic health and family wellbeing and are responsive to local needs should be provided

- Expectations should be created that OAP service providers consider and are educated on how autism connects to the full spectrum of unique needs that Indigenous families might have, including but not limited to access to housing and food, inter-generational trauma, Fetal Alcohol Spectrum Disorder (FASD) and mental health
- It should be mandated that all OAP service providers receive cultural competency training and that, wherever possible, they access this training locally from Indigenous partners
- Youth mentorship programs to promote acceptance and inclusion in communities should be developed.

Supporting Francophone families

- French language services must be available across the province and the ministry should invest in increased capacity to provide services in French.

Supporting other marginalized families

- Targeted supports should be available for families for whom English/French is not their first language, including the following:
 - Interpreters to support OAP registration and service navigation
 - Resources and website information available in multiple languages, including contact information for interpreters.

Supporting Non-speaking children and youth

- The needs of non-speaking children and youth are specialized and access to AAC to provide them with the means to improve their communication skills is critical
- Services for non-speaking individuals must be available across the province and the ministry should invest in increased capacity to provide these services.

Supporting Northern, rural and remote families

- Families should have access to services in their home community provided by qualified professionals

- Policies for compensating travel costs should be developed ensuring that travel costs are not absorbed by a family's OAP annual funding/service allocation, by the family out of pocket or by the provider
- Acknowledging that there are barriers to accessing the internet, technology should be leveraged to build capacity in the North and to offer remote consultation and ongoing support
- Technological aids for remote consultation should be funded in addition to funding for service
- Mobile services should be provided by funding the costs associated with service providers travelling to communities
- Some of the OAP funding should be utilized to restore the capacity of service providers in Northern Ontario
- Culturally-inclusive services should be made available through the OAP
- Representation from Northern, rural and remote areas should be included in implementation planning.

2.3 Needs Determination, Assessment and Care Planning

Defining Need

Through the recent provincial consultation process, respondents frequently expressed the importance of understanding and supporting the individual needs of each child and youth on the autism spectrum and their family when making decisions about services that would best support their unique strengths and needs. This is a key program feature that is required in the new OAP.

What we heard:

Childhood Budgets are not based on individual needs and there is a lack of flexibility to support varied levels of need.

Panel Definition of Need:

When the range of an individual's deficits and challenges interfere with their strengths and ability to achieve their goals, reach their potential and experience quality of life and mental health wellness as they and their family define it.

The amount of support required to address the discrepancy between an individual's skills and the requirements to participate in a variety of contexts and accounting for barriers in their environment, including physical, academic, social, vocational and cultural settings.

Panel Definition of Complex Need:

Requiring intensive support on a consistent and daily basis.

The presence of challenging or interfering behaviours and/or co-occurring physical, neurodevelopmental and/or mental health conditions that can have a multiplier effect.

Posing a significant risk to oneself, others or property.

At times, a precursor to crisis. Crisis can be defined as an ongoing situation and/or sudden event that causes an individual or their family significant distress or an inability to cope.

Influenced by family, sociocultural and environmental factors such as:

- Periods of significant transition and change
- Finances and financial pressures
- Culture, language and immigration status

- Family capacity and living arrangements which may include the number of individuals with special needs, family composition, and/or mental health challenges
- Involvement with child protection
- Geography, especially Northern, rural and remote areas
- Accessibility, availability and proximity to services and supports.

Services and supports delivered through the OAP should be determined based on the individual needs and priorities of the child, youth and family.

The Care Coordinator and Determining Support Needs

In the OAP, it is important that the child, youth and family are at the core of all service planning and delivery of care. Family members know their children best and should be key partners in determining their child or youth's care and be actively engaged in the process of identifying and determining their child or youth's priority needs.

Care Coordinator

To ensure the future sustainability of the OAP, project future demand for the program, manage annual funding amounts, and encourage collaboration between multiple disciplines, it is recommended that each family registered in the OAP be assigned a Care Coordinator.

What we heard:

The need for care coordination was heard from families who identified challenges in having to coordinate various services, and stakeholders who noted the importance of bringing together families, community agencies and schools. The need for support to navigate the service system transitions was also noted in stakeholder submissions.

The Care Coordinator should assist families by:

- Acting as a point of contact to answer questions and provide general support

Recommendations for a New Needs-Based Ontario Autism Program

- Supporting families in navigating the program and accessing all available sources of funding
- Providing case management services and supports
- Providing support with navigating transitions (school, adolescence, adult services)
- Helping families to access other services and sources of funding in their local community
- Identifying the need for and support families to access urgent response services
- Leading the process to forecast a child's support need (detailed below).

In instances where a family may be accessing services from more than one service provider, the Care Coordinator should support the family with the development and maintenance of an integrated plan of care. This includes assisting the family with bringing providers together to share information and promote a coordinated and collaborative service experience for children and youth and their families, as well as allowing for ongoing data collection.

Further, strategic investments in digital infrastructure are recommended to support the development of a secure web-based portal to store all records, including each child's integrated plan of care. This would create efficiencies for the coordination and integration of care, increase opportunities for interprofessional collaboration among professionals delivering services to the child, and improve accessibility of information from a broader provincial perspective.

As noted in the Panel's guiding principles, it is important for families to have choice when determining the services they feel are most appropriate for their child, selecting service providers to deliver those services and the amount of support they feel they need to help them in making these choices. Some families will feel well equipped in making choices for their child and family and navigating the system. But other families might feel challenged, as was noted in the autism consultations, and would welcome some assistance in navigating and coordinating services for their child or youth. Families accessing OAP services should be able to choose to access or opt out of service navigation support at any time in their service journey.

Determining Needs

Panel Recommendation:

A standardized clinically-informed process developed by discipline-specific clinicians and researchers with expertise in the field of autism should be used to forecast each child's support needs to the ministry, to enable other children to be moved off of the waiting list. This process should be developed by clinical and research experts and implemented by a Care Coordinator.

Navigation services should be delivered through an independent Care Coordinator, separate from individuals and organizations who are delivering other services in the program to mitigate the risk of conflict of interest.

Feedback provided to the Panel through MPP roundtables and written submissions discussed the importance of accessibility, program sustainability and provincial consistency. To ensure these objectives are met, it is recommended that members of the clinical sub-committee of the implementation committee (see page 47) develop, validate and evaluate a standardized, clinically informed process. The Care Coordinator is responsible for working with families using this process to forecast each child or youth's support needs within annual service caps. This process would allow the ministry to move other children off the waiting list. Each family and their Care Coordinator should work collaboratively to identify potential service options for the child or youth.

Once the family receives their discipline-specific clinical assessment(s), it is recommended that the clinicians report their proposed service plans back to the Care Coordinator, who would then be responsible for updating/refining the forecasted service plan and funding needs to the ministry. It is recommended that all clinicians delivering OAP Core Services work within the discipline-specific caps and be consistent with Best Practice Guidelines, as developed by the implementation committee (see page 47).

As the process for forecasting support needs is new in the OAP, it should be evaluated early in the implementation process (e.g. within 6 to 12 months) and frequently over time to ensure the process aligns with OAP Best Practice Guidelines and clinical recommendations for the nature and intensity of different OAP Core Services. Where possible, opportunities to expand upon existing tools (e.g. practice management processes and software) and system capacity should be considered to maximize the resources available to children and families.

As required, it is also recommended that in very specific circumstances where there is no ability to separate the function of the care coordination from service delivery due to challenges with capacity, such as in Northern, rural and remote areas, exceptions such as leveraging local service providers to deliver both program components to families may need to be considered.

Considering that the demand for the OAP currently outweighs the available resources, the Panel recommends that, where possible, families should be supported by their Care Coordinator to identify other sources of funding and/or services they may be eligible to receive outside of the OAP to complement their child's integrated plan of care (e.g. mental health services, respite).

Importance of Clinical Assessment

Responses reported by participants in the province-wide online survey were in support of clinicians conducting clinical assessments to inform decisions related to the direct delivery of OAP Core Services. Further, respondents highlighted the importance of these clinical assessments to inform the type and amount of treatment children and youth receive through the OAP. The Panel strongly believes that clinical judgement and assessment should be used to guide recommendations related to the type, nature and intensity of clinical services.

What we heard:

No professional is an expert in every field, therefore individual professionals may not be able to recommend a full suite of services. Inter-professional collaboration may be required to meet diverse needs.

OAP clinicians should support children and youth and their families by guiding them through a discipline-specific clinical assessment of need, setting goals, development of a treatment plan and monitoring and evaluating the child or youth's progress on an ongoing basis with regular updates provided. As children and youth's needs change over time, reassessment of need and revisions to the treatment plan may be required. Discipline-specific OAP Best Practice Guidelines should be developed in collaboration between relevant professional organizations and those with clinical/research expertise in autism on the implementation committee (see Implementation Section for details). OAP services delivered by clinicians should be informed by discipline-specific

parameters and determined based on these guidelines to ensure consistency, sustainability and equity.

Panel Recommendation:

Families should receive discipline-specific clinical assessment(s) from clinicians of their choosing from the OAP provider list to determine the right approach to treatment and the treatment plan to meet their child or youth's needs, based on OAP Best Practice Guidelines.

OAP clinicians should work in collaboration with a family and their Care Coordinator to develop an integrated plan of care within the family's individual OAP annual allocation within service caps.

The OAP should promote collaborative partnerships between care providers, children and youth and their families. OAP clinicians, each with their own set of skills and expertise should contribute to the development of the child or youth's integrated plan of care. OAP Best Practice Guidelines can ensure all professionals working with children and youth meet predetermined standards of practice and competencies to establish a standard quality of care.

2.4 Capacity Building and Oversight

Capacity Building

Service provider capacity across the province is a longstanding concern. With the recommended inclusion of SLP, OT and mental health services in the OAP, it will be important to understand available capacity to support children and youth on the autism spectrum through the OAP.

A gap analysis of current capacity and a resulting strategy to maintain and support existing expertise, provide stability to the sector and build the foundation for changes to the program in April 2020 is required immediately. Specific attention should be given to Northern, rural and remote areas. The Panel's recommendation regarding the funding approach in the Implementation section below takes into consideration the importance of family choice and contributes to building capacity, particularly in Northern, rural and remote areas. MCCSS should also permit the use of OAP funding to purchase services in other provinces in the immediate term while capacity is being enhanced in Ontario over the longer term.

Children and youth mental health and autism services have traditionally been delivered in silos, resulting in little knowledge translation across the sectors. This is at odds with the data that shows the high rate of co-occurrence. Investment in building the capacity of providers in both autism services and children and youth mental health is required to ensure that children and youth and their families receive appropriate service when and where they need it.

Panel Recommendation:

- Invest in innovative approaches that build capacity and include a focused effort to recruit diverse candidates, including those from Indigenous and Francophone backgrounds
- Create specialized resource teams to consult with service providers to bridge the knowledge gap and facilitate the integration of mental health and autism expertise
- Improve families' access to ASD diagnostic services and improve the process for identifying children and youth with early red flags to enable timely entry into the program by identifying standardized screening tools, continuing to build the capacity of MCCSS' five diagnostic hubs and diagnostic capacity in the sector in general
- Encourage the Ministry of Colleges and Universities to use the results of the gap analysis to create funding initiatives to develop capacity in the fields of:
 - Applied Behaviour Analysis
 - Speech Language Pathology
 - Occupational Therapy
 - Mental health: psychology, medicine, social work
- Base funding tied to service delivery targets should be provided to public providers on an ongoing basis to ensure the needs of complex, marginalized and under-served families (e.g. Indigenous, Northern, rural and remote) are consistently met while maintaining capacity.

Oversight and Accountability

As the OAP expands to include a wide range of services and supports, the need for adequate oversight to protect children, youth and families from potential harm is magnified. Families need to be assured that they are receiving appropriate services from professionals who have the expertise, qualifications, training and adequate supervision to ensure positive outcomes.

What we heard:

The overwhelming need for accountability and oversight in the OAP was captured in the words of an autism advocate at one of the MPP roundtables: “There is a huge need for licencing, regulations, inspections, and governing associations to monitor and facilitate guidelines for individual service providers.”

The Panel recommends that the government expand the current OAP provider list to include qualified professionals from all disciplines of services delivered through the OAP. All providers on the list would be required to follow OAP Best Practice Guidelines and be subject to both random and targeted audits. These measures would promote the delivery of evidence-based service and adherence to consistent OAP business practices and program expectations, provide an additional safeguard for the appropriate use of public funds and promote ongoing sustainability of the program.

The Panel applauds the government’s recent announcements regarding the intention to regulate ABA therapists, which will ensure standardization of professional practices related to assessment and treatment, as well as compliance with ethical billing practices and provincial legislation. Further, regulation will ensure that children, youth and families in the OAP receive safe, competent and ethical ABA services from qualified professionals.

Panel Recommendation:

The following recommendations could help to improve oversight and accountability for families and program sustainability over the long term:

- Clinical Best Practice Guidelines, to be developed by clinicians/researchers with expertise in each field, would outline tiers of service caps and intensity and duration of each treatment corresponding to various levels of clinical needs, with exceptions
- An annual service cap and discipline-specific service caps that specify the maximum total amount of OAP Core Services a child or youth can receive each year
- An OAP provider list that includes training and experience criteria for all clinicians delivering OAP Core Services and supports families to find qualified providers
- MCCSS and MOH to work towards the regulation of ABA professionals as quickly as possible
- The implementation of standardized reimbursement rates for all Core Services
- Random and targeted audits for OAP service providers
- Practice management software for providers.

Evaluation

Given the scale and complexity of some of the recommended changes, the Panel recommends that a robust program performance measurement framework be developed so that data can be collected and analyzed to continuously inform program improvements. Results of this evaluation should be used to revise the process used to forecast children and youth's support needs. Ongoing evaluation is also required to ensure that capacity and availability of service throughout the province is balanced against efficiency and consistency. The Panel recommends considering establishing partnerships with universities and research consortiums and leveraging existing ministry partnerships to develop and implement measurable clinical and program outcomes. The Panel also supports increased research and evaluation on the efficacy and long-term outcomes of the OAP as well as long-term outcomes of adults on the autism spectrum. The process of providing stakeholder feedback and the results of program evaluation should be made publicly available.

3. Alignment with Other Ministries

The Panel established sub-committees to examine how autism services offered by the Ministry of Education (EDU) and the Ministry of Health (MOH) could be more closely aligned with the OAP. This section contains recommendations from the Panel to these two ministries.

3.1 Ministry of Education

The new OAP needs to be better aligned and integrated with autism services offered by Ontario's public school system. Too often, barriers between service models in different ministries negatively impact children, youth and families and reduce the potential of all services to be delivered efficiently and to maximum capacity. Services, experiences and understanding of autism can vary widely between boards and between individual schools within the same board.

The Panel strongly believes that the public school system should be a beacon of equity, inclusion and diversity. The recommendations below cover a wide range of options and choices and are intended to help EDU better align services with the OAP and further improve services to students on the autism spectrum in Ontario schools. The Panel believes that these options should be funded by EDU.

It is recommended that an education advisory committee on autism be formed before the end of 2019. It should include stakeholders from the education sector, MCCSS, MOH, parents and autistic individuals. This Panel can provide recommendations by the spring of 2020 to the Minister of Education on the most effective ways to meet the needs of students on the autism spectrum, including ways to align MCCSS and EDU services for autistic students, as well as the implementation of education-related policies, programs and professional development.

Panel Recommendation:

The education advisory committee on autism should endeavour to:

- Design best practice guidelines to address school board implementation of special education policy and regulations specific to autistic students/students on the autism spectrum to support effective programming and consistency across the province
- Review the implementation of Regulation 181/98, Identification and Placement of Exceptional Pupils, as it pertains to students on the autism spectrum and create best practice guidelines to support adherence to this regulation across school boards
- Conduct a review of school board adherence to Individual Education Plan (IEP) Standards
- Implement a process for collecting data on the topic of both formal and “soft” exclusions, modified days and students being sent home
- Phase out the practice of using seclusion rooms in a systematic manner that maintains the safety of all children and youth and school board personnel. Review policies related to classroom removal/exclusions (e.g. use of calming, exclusion or sensory rooms) and establish standards to ensure safe and ethical use that contributes to student success
- Develop guidelines to ensure that parents are aware of all special education programs and services at their local school and in their local school board and their rights by:
 - Ensuring that upon entry to school families are provided with a package detailing the special education programs and services available, including information related to the Identification, Placement, and Review Committee (IPRC) process and the Ontario School Roadmap for Children with Special Needs
 - Informing parents of a child or youth on the autism spectrum registered to attend a public school of their legal right to an IPRC, regardless of their specific Board

- Developing an IPRC package for families, including the Ontario School Roadmap for Children with Special Needs upon registration to any public school in Ontario
- Design and implement strategies to mitigate the negative impact of policy changes such as class size and e-learning expansion on autistic students
- Review the 2016 advice/report from the Multi-Sector Working Group on the Transition to Postsecondary Education for Students with Disabilities with an Early Focus on Students with Autism Spectrum Disorder. Consider this advice regarding the core components of an individualized transition process, transition partners' roles and responsibilities, and responsive environments to help students with ASD get the right support at the right time, as one of many ways to strengthen the mandated transition planning process out of secondary school into adult life.

The following recommendations are aimed at improving access to integrated community and school-based supports for students on the autism spectrum to support meaningful access to education.

Panel Recommendation:

- Develop protocols to facilitate meaningful collaboration between OAP providers and the accepting school. This may include continuing *Connections for Students*, as well as identifying and removing barriers to direct observation and support within the school
- Support wraparound services by developing mechanisms to allow meaningful collaboration between the school team, and clinicians/therapists

- Undertake a comprehensive review of provincial policies including Policy and Program Memorandum (PPM) No. 140, Incorporating Methods of Applied Behaviour Analysis (ABA) into Programs for Students with Autism Spectrum Disorders (ASD) and PPM 149, Protocol for Partnerships with External Agencies for Provision of Services by Regulated Health Professionals, Regulated Social Service Professionals, and Paraprofessionals with a focus on resolving conflicting messages and integrating approaches to reduce the potential for barriers
- Support development of collaborative partnerships among Board Certified Behavior Analysts (BCBAs), regulated health professionals such as Speech Language Pathologists (SLPs) and Occupational Therapists (OTs) and educators, in schools to determine the most effective ways to integrate these services into a child or youth's education plan. Consideration should be given to the integration of more direct service as appropriate and based on student need
- Expand the *Pilot to Improve School-Based Supports for Students with ASD* focusing on dedicated space. Continue to evaluate the outcomes of the pilot and use that information to design program components that are supported by evidence from the pilot
- Dedicate space in schools for all therapies such as ABA, OT and SLP
- Expand Care, Treatment, Custody and Corrections (CTCC) programs to guide ongoing service development for students. These classrooms offer the opportunity for collaboration between OAP service providers with expertise in ABA, educators, as well as regulated health professionals including OTs, SLPs and mental health professionals. These classrooms should be expanded to ensure ongoing access to evidence-based school and community agency collaboration within the education system
- Expand the number of mental health workers and Educational Assistants (EAs) to support autistic students/students on the autism spectrum in schools with due consideration of appropriate representation in both elementary and secondary schools.

To enhance access to evidence-based ABA, OT and SLP supports for children and youth on the autism spectrum in school boards, PPM 140 and PPM 149 should be modernized to include updated, evidence-based standards for the implementation of ABA educational practices and those services provided by Regulated Health Professionals, Regulated Social Service Professionals, and Paraprofessionals.

Panel Recommendation:

PPM 140 and PPM 149

- Include a broad range of services, both consultative and direct, which consider the varied needs of students on the autism spectrum
- Require the staff designing and implementing ABA educational practices to have the appropriate qualifications (e.g. BCBAs, Registered Behaviour Technicians)
- Reduce barriers to access to facilitate strong partnerships between schools and external agencies, including OAP ABA, SLP and OT providers
- Develop strategies to support adherence to best practice standards
- Add a parent/student survey to monitor implementation
- Implement requirements for ongoing data collection and analysis.

PPM 149

- Reduce barriers to access by facilitating strong partnerships between schools, external agencies and external regulated health professions, regulated social services professionals and paraprofessionals for students on the autism spectrum.

Improved professional learning and training supports for educators and professionals supporting students on the autism spectrum is recommended through the following:

Panel Recommendation:

- Review Ontario's Initial Teacher Education and relevant Additional Qualification Courses to enhance content related to the development, implementation and monitoring of IEPs, behavior and safety plans for students with special education needs, including students on the autism spectrum
- Ensure that all members of the child or youth's education team receive the training required to support the mental health needs of students on the autism spectrum
- Develop a provincial in-service curriculum for educators, educational assistants (EAs) and school administrators specific to supporting students on the autism spectrum, including registered behavior technician training. Basic training should also be provided to office, and caretaking staff and bus drivers
- Ensure that appropriate training is provided for all educators working with non-speaking, minimally speaking and unreliably speaking autistic students on AAC. Training and communication support should be collaborative in nature and involve experts in communication training for children and youth on the autism spectrum, including SLPs, OTs, and BCBAs
- Work with relevant ministries to ensure that the curricula for post-secondary programs for teachers, developmental services workers, child and youth workers, early childhood educators, educational support workers and regulated health professionals include content related to best practices in supporting children and youth on the autism spectrum, including an understanding of common co-occurring conditions and learning requirements
- Review the current positive practices in Ontario's school boards to promote consistency and continuity of EAs working with students on the autism spectrum to minimize in-year staffing changes where possible. Where this is not possible, ensure that policies and practices are in place to support warm transfers and seamless transitions.

The School-based Rehabilitation Services (SBRS) program, delivered by Children's Treatment Centres, should be utilized to achieve the government's goals of cross-ministerial integration to improve services to students on the autism spectrum through the following.

Panel Recommendation:

- Review and amend PPM 81, *Provision of Health Support Services in School Settings* that splits the responsibility for speech and language between SBRS and school boards' SLPs to allow all SLPs working in the school setting to intervene using a holistic approach that addresses the speech and language challenges of children/youth on the autism spectrum
- Standardize the interpretation of the SBRS mandate across the province, specific to autistic students/students on the autism spectrum. At present, the interpretation of the SBRS mandate varies. The mandate is interpreted more narrowly in some areas of the province thereby restricting the scope of practice for therapists
- Recognizing that the needs of children and youth on the autism spectrum are not well met by consultative models alone, amend the service delivery model of the SBRS occupational therapy program (which is primarily consultative) to embrace tiered service delivery models which provide consultative approaches, and group and direct therapy approaches depending on the needs of the child/youth
- Consult with key stakeholders (stakeholders from education, MCCSS, SLP, OT, parents and people with lived experience) prior to any transitions in service provision or changes in service delivery model in the SBRS program. Approach to transitions should have as a guiding principle that any change should prioritize the minimization of disruption to continuity of care (including disruptions during the school year) and/or any reduction in service levels for children and youth on the autism spectrum.

3.2 Ministry of Health

The Panel's first identified measure of success for developing a new Ontario Autism Program is that it should ***“improve the quality of life for people on the autism spectrum and their families by supporting their mental health wellness, their dignity and their ability to thrive.”*** As previously noted, mental health challenges occur in much higher rates among autistic people than the general population. Serious mental health challenges may begin in young children (e.g. ages 7-11) and continue through adolescence and into adulthood.

A child or youth's mental health challenges can negatively affect the mental health and capacity of their parents and caregivers. Supports need to be put in place for the whole family to help prevent caregiver and child burnout. Currently, the alternative for many families is visiting emergency departments, accessing child protection services, or pursuing a residential placement.

What we heard:

One submission noted, “just under half to approximately three-quarters of children diagnosed with Autism Spectrum Disorder may also be diagnosed with another mental health disorder and are at increased risk of a co-occurring mental health disorder than the general population. Neither child and youth mental health service providers nor autism service providers are well trained to work with children and youth with co-occurring mental health challenges and ASD and as a result, these children and youth do not have access to services that meet their needs.”

Failing to adequately invest in mental health will translate into longer-term costs and consequences, as autistic people with unmet mental health needs may be unable to fulfill their potential. Most alarmingly, needless suffering and crises, including suicide and suicidality, are a reality of many autistic people and their families. It makes little sense to only invest money in reactive crisis supports. Instead, the government must invest in providing preventative and proactive supports to better support children and youth on the autism spectrum and their families, which will lower the need for more expensive crisis services and will ultimately save costs while improving individual and family well-being.

Currently in Ontario, there is limited access to mental health services generally. For example, the Ontario Psychological Association report notes that there are insufficient graduate-level training programs and residency positions, and a severe shortage of psychologists in under-serviced areas outside of the Toronto core. These barriers lead to very long waits for psychological services for many children and youth. Similar capacity challenges are found for other mental health professions as well.

What we heard:

One of the stakeholder submissions recommended that MOH "support up to five sites to pilot the provision of integrated and enhanced services to children and youth on the autism spectrum with mental health challenges – including the identification or development of evidence-based treatment to support better diagnosis, treatment and evaluation."

For those families who have access to professionals in their regions, paying for services is an additional barrier to access. Families without insurance, with lower incomes, or on social assistance may have absolutely no access to appropriate mental health services.

Crisis expertise is also inadequate throughout many areas of the province and there are few crisis beds, many of which are typically occupied by older teens, leaving significant gaps for younger youth with mental health concerns.

Given these interrelated concerns, there is a significant need for children and youth on the autism spectrum to receive effective mental health services from qualified mental health providers. However, a one size fits all approach will not work. The mental health needs of autistic people are as diverse as the spectrum itself. As such, mental health services need to be broad enough to account for the diversity of presenting mental health challenges *and* the diversity of autistic individuals.

What we heard:

Many of the consultation submissions suggested that treatment for children and youth on the autism spectrum be funded and delivered by MOH and not MCCSS to ensure that all people with disabilities have access to medically necessary therapies they need to thrive and achieve their full potential across their lifespan, without discrimination based on age or diagnosis.

The shortages in availability of children's mental health services are compounded for children and youth on the autism spectrum as many mental health specialists do not have training in autism or in how to adapt their treatment to suit the unique needs of children and youth on the autism spectrum. Many organizations and mental health workers turn away autistic people with mental health conditions *because* of their autism diagnosis. Improving access to adequate mental health services for children and youth on the autism spectrum requires a strategic and targeted capacity-building initiative to increase interdisciplinary expertise in the health and mental health of children and youth on the autism spectrum, including at times of crisis. Building upon existing training initiatives such as the Extension of Community Healthcare Outcomes (ECHO) Ontario Autism (Holland Bloorview Kids Rehabilitation Hospital) as a mechanism for wide-scale delivery of training is recommended.

It was a consensus of opinion amongst Panel members that mental health services for children and youth on the autism spectrum, like mental health services for all children and youth, should be funded and delivered by MOH, not through the OAP. However, in light of the real absence of accessible mental health services for children and youth on the autism spectrum as described above, the Panel agreed to include mental health services in OAP Core Services to be accessed by children/families who are not able to access them otherwise through MOH. Inter-ministerial approaches to proactive mental health services, timely treatment and crisis services to address the health and mental health needs of children and youth on the autism spectrum are needed. MOH is urged to build on its initiatives and leverage the current transformation of the sector to fully fund mental health services for children and youth on the autism spectrum. The recommendations below are specific to the delivery of mental health services in the OAP.

The Panel was tasked to provide advice to the ministries on how best to coordinate services and leverage investments across systems to facilitate a child-centered approach. The high-level recommendations below are aimed at broadly improving

children's mental health services delivery for children and youth on the autism spectrum and building the capacity of the sector to provide high quality service. Given the importance of these issues for children and youth on the autism spectrum and the need for better alignment and coordination of services, further detail on these recommendations has been provided in Appendix B.

Panel Recommendation:

- Until MOH fully and adequately funds mental health services, it is recommended that MCCSS and MOH work collaboratively to co-fund, develop, pilot and provide the specialized mental health services to be included in the OAP
- Expand the capacity of existing OAP providers to offer cost-effective, empirically-supported, time-limited mental health programs.

Panel Recommendation:

Capacity Building

- Develop and implement mandatory training for medical practitioners in training as well as practicing front-line health professionals, including, but not limited to, emergency and family physicians, psychologists, nurses, occupational therapists, registered psychotherapists and social workers on autism spectrum disorder and co-occurring mental health challenges
- Provide training to publicly funded mental health service providers so that they are enabled to fully include autistic people in their client-base. Incentivize children's mental health providers to enhance capacity beyond delivering workshops, including tiered supervision by established experts until trainees develop sufficient competency and comfort to address the specific needs of autistic people

- Enhance capacity among family physicians, general and specialist pediatricians, child and youth psychiatrists, and child and youth psychologists in the detection of autism (early red flags and diagnosis) and co-occurring mental health conditions. As signs of autism may vary early in development, in girls and in those from culturally-diverse communities, training should also focus on these areas. Continuing education leveraged through technology should be considered (e.g. Extension for Community Healthcare Outcomes)
- Build better connections for mental health services between hospitals and surrounding communities. This is especially important in Northern, rural and remote regions, and for families with diverse backgrounds
- Encourage and provide the necessary supports (e.g. billing reimbursement) for diagnosing professionals to directly refer children and youth to the OAP upon confirmation of an autism diagnosis (or when faced with red flags/provisional diagnosis if this is supported by the new OAP).

Service Delivery

- Fund interpreters for ASD diagnostics for families who do not speak English or French
- Consider the call from many submissions to fund all medically-necessary therapies and treatments
- Invest in specialized interprofessional mental health inpatient and community outpatient treatment teams for children and youth on the autism spectrum
- Increase the capacity of group treatment homes, safe beds, and transitional (step-down) homes in the childhood developmental sector
- Mental health treatment which has been empirically demonstrated to be effective for children and youth with specific mental health challenges (e.g. anxiety and depression) should be adapted by competent qualified professionals and made available to children and youth on the autism spectrum and their family members

- Explicitly mandate children’s mental health providers to serve children and youth on the autism spectrum and adapt their services accordingly
- Establish clear pathways for families who are receiving OAP services to access children’s mental health services
- Provide urgent funds for families in crisis to support more complex mental health challenges through interdisciplinary teams
- Expand adequate community supports and access to community mental health professionals to allow children and youth on the autism spectrum to receive appropriate in-community or at-home care, rather than housing autistic patients in hospitals and psychiatric wards due to inadequate and/or inappropriate community supports.

To further the work integrating children’s mental health and autism services, and to guide the implementation of mental health services in the OAP, an autism and mental health working group should be formed. The recommendations below are specific to the work of this group.

Panel Recommendation:

The Autism and mental health working group should endeavor to:

- Establish a system of program evaluation and identification of individual and system-level outcomes
- Review evidence and develop best practice guidelines on mental health approaches for the OAP including suggested eligibility criteria, caps, guidelines regarding goal-setting and measurement of individual outcomes/response to treatment. A list of approaches may be identified via the Society of Clinical and Child and Adolescent Psychology of the American Psychological Association Effective Child Therapy or other reputable sources
- Establish standards for the qualifications of approved OAP mental health providers. It is recommended that only regulated professionals with sufficient training in both autism and empirically-supported mental health services should be added to the OAP mental health provider list

- Conduct a gap analysis to better understand the availability and accessibility of children’s mental health services for children and youth on the autism spectrum in Ontario, including consideration for:
 - Crisis management
 - Short-term respite and group placement
 - Mental health expertise among school personnel
 - Hospital care (emergency and inpatient) and community supports
 - Parent and caregiver support
 - Funding
 - Access to psychotherapists and other regulated professions, such as Canadian Certified Canadian Counsellors and Mental Health Occupational Therapists registered under the College of Occupational Therapists of Ontario (COTO)
- Create a plan of action to fill identified gaps and increase capacity in autism and mental health expertise among both autism therapists and evidence-based mental health service providers.

4. Implementation Considerations

The Panel recognizes that the successful implementation of the recommended design for the new OAP will require ongoing input and consideration. As a result of its work, the Panel has identified several transition and implementation considerations that should be factored into the planning process as the government prepares to begin to implement the new program in April 2020, such as coordinating the timing of when some children and youth transition into the OAP with school year schedules.

Implementation Committee

To assist in this next phase, the Panel recommends that an implementation committee be formed to provide ongoing input and support to the government on the Panel's recommendations and support planning for the transition to the new OAP.

Selection of committee members should be through a transparent process and include, but not be limited to, former Panel members, parents/family members, autism self-advocates, those with lived experience including non-speaking autistics, those with clinical/research expertise in autism and scientific experts representing the disciplines included in OAP Core Services, system experts, researchers, representatives from Northern, rural and remote communities and Indigenous partners.

Panel Recommendation:

As noted throughout the body of this report, it is recommended that the OAP implementation committee be tasked with developing the following:

- Reviewing available evidence in order to inform the design, criteria and eligibility for:
 - Early intervention services
 - Mental health services
 - Urgent response services
- Reviewing and synthesizing the evidence to develop OAP Best Practice Guidelines including the nature of service, tiers of service caps, and intensity and duration of each treatment corresponding to various levels of clinical needs
- Eligibility for funding of AAC through the OAP

- Development of a clinically-informed process to guide the forecasting of a child's support need and annual allocation
- Standardized rates of reimbursement for clinicians
- Development of family transition plans to support families in understanding the impact of the changes to the OAP
- Development of criteria for OAP providers to be included on the Provider List
- Investigate the potential for insurance reform to increase access to available OAP resources in the future.

This would be one overarching implementation committee with the establishment of subcommittees, including a clinical and scientific expert subcommittee, as required, to do more detailed work. Some of the specific work of this group is outlined in the recommendations above.

Transition to the OAP

All families currently receiving service, either through an OAP Behaviour Plan or Childhood Budget, will require a specific transition plan to the new OAP. The Panel recommends that the development of a process of transition for all children and youth be tasked to the implementation committee, as noted above.

Panel Recommendation:

- All children and youth currently receiving Childhood Budgets should be assigned a Care Coordinator and receive consultation and support to guide their transition into the new OAP
- All children and youth currently receiving OAP services based on an existing OAP Behaviour Plan should meet with a Care Coordinator as close as possible to their completion date to discuss their next steps and their transition into the new OAP. The Panel recommends that if necessary, current OAP Behaviour Plans should be extended until a meeting with the Care Coordinator is arranged and a transition plan is in place.

Communication Strategy

Panel members also recognize that significant program changes can be difficult for many families and at times overwhelming to navigate. A comprehensive communication strategy is required and should be targeted to all stakeholders. OAP information packages and detailed, family-friendly transition plans should be developed and made publicly available in multiple formats and multiple languages to support families and professionals in understanding changes to the program and what those changes mean for them. Specific communication aimed at community health care providers and diagnosing professionals would ensure families with a new diagnosis know how to access the OAP.

Service Delivery

It is recommended that the implementation planning process include careful consideration of offering families a choice between receiving service from either public providers (previously known as direct service) or receiving direct funding to purchase service from independent providers (previously known as direct funding). The Panel recommends that the OAP include both approaches, with consideration of variables such as cost-effectiveness and whether some components may lend themselves to one approach or the other (e.g. foundational supports). All OAP providers should work collaboratively as a community of practice.

Panel Recommendation:

- Foundational services, other than Care Coordination, should be provided by public providers of autism services. All other services, including early intervention, urgent response services and OAP Core Services should be available through both independent providers and public providers, based on family choice
- Base funding tied to service delivery targets should be provided to public providers on an ongoing basis to ensure the needs of complex, marginalized and under-served families (e.g. Northern, rural and remote areas) are consistently met
- Beyond an interim period, public providers should be funded at the same rates as independent organizations for OAP Core Services, as long as capacity is not negatively impacted

- An evaluation and consultation process should be undertaken to consider the implications of these recommendations for all OAP providers and ensure program efficiency and effectiveness while maintaining clinical capacity
- Implement a direct billing mechanism to minimize the administrative burden on families and standardized rates for reimbursement for OAP providers.

5. Conclusion: Looking Ahead

With this report, the Ontario Autism Program Advisory Panel is asking the Government of Ontario to consider the proposed recommendations for the design of the new OAP commencing April 2020.

The Panel has appreciated the opportunity to provide advice on the design of a new needs-based OAP and recognizes the government's commitment to building a strong relationship with families, service providers and other members of the broader community. It should be noted that the scope of the Panel's work was limited to services for children and youth, but we are concerned about the needs of autistic adults and we encourage the government to review this situation.

We recognize that waiting lists and service caps would not be necessary in an ideal scenario, and we all look forward to the day when neither exist. Until that day, however, the OAP must concentrate on serving as many children and youth as possible, as fairly as possible, while maintaining clinical efficacy. Our goal is a balanced, equitable and needs-based program.

Transition planning and implementation of the new program will be challenging and complex. However, maintaining trust, transparency and communication will support successful implementation of a new program in April 2020.

We call on the government to harness the enormous dedication, passion and commitment in the broader community to ensure that Ontario becomes a leader in supporting families of children and youth on the autism spectrum.

Appendix A. What We Heard

The Ontario Autism Program Advisory Panel was established as part of a broad public consultation plan initiated by government to seek input and advice from key autism stakeholders, including parents of children and youth on the autism spectrum. Through a variety of public consultation activities and approaches, the Ministry of Children, Community and Social Services (MCCSS), the Ministry of Education (EDU) and the Ministry of Health (MOH) sought feedback on how to better coordinate health, education, and social supports to support the needs of children and youth on the autism spectrum and their families.

In order to hear directly from stakeholders, the government developed and publicly posted a province-wide online survey, held phone-based town halls, and requested feedback through written submissions and through community roundtable discussions hosted by Members of Provincial Parliament (MPPs).

Online Survey

- The online survey was available for the month of May 2019 to hear from families and caregivers of children and youth on the autism spectrum, as well as others interested in participating and sharing their perspective
- A total of 3118 surveys were completed, with the majority completed by parents and caregivers, followed by professionals.

Telephone Town Halls

- Seven telephone town halls were also held throughout May 2019. The town halls were phone-based public forums hosted by a professional, non-partisan moderator. Each town hall was delivered in segments where participants had the opportunity to directly share views and perspectives on the OAP based on key themes of the consultation.

Written Submissions

- MCCSS received over 50 written submissions from key stakeholders including service provider organizations, autism self-advocates, clinical experts,

researchers and advocate groups outlining recommendations related to the design of needs-based enhancements to the OAP, all of which were shared with the Panel.

MPP Roundtables

- MPPs hosted 17 roundtable discussions across the province and documented feedback from families of children and youth on the autism spectrum as well as autism service providers, representatives of autism advocate groups and educators.

To inform our advice and recommendations, Panel members worked together to review and analyze the input received from the online survey, telephone town halls and written submissions as well as to consider other relevant evidence, science and data. Below is a summary of what we heard and the key insights and concerns that helped shape our recommendations.

What We Heard

Services and Supports

- The majority of survey participants identified a need for improved access to evidence-based behavioural services, speech language pathology and occupational therapy. Overwhelming support for access to these services was echoed in the telephone town halls and written submissions. Many parents and caregivers also cited the importance of mental health services in the program, particularly for youth
- A number of stakeholders advised that children should receive treatment immediately following diagnosis when it is most critical and effective
- Many families indicated the need for respite services. Caregiver training, capacity building and service navigation were also cited as much needed services to support families of children on the autism spectrum
- Concern and frustration were expressed over lengthy waitlists for OAP services, with little communication of information to families while on the waitlist. However, a majority of respondents indicated that they would prefer a waitlist to enter the OAP as opposed to age or spending caps if resources and capacity are limited in a needs-based program

- Stakeholders highlighted that additional supports need to be made available for the specific goal of running targeted programs to ensure the inclusion of vulnerable or under-served clients (e.g. Indigenous, refugee, low socio-economic status, Northern, rural and remote, non-English speaking, recent immigrant)
- Frustrations and concerns related to the longstanding shortage of Francophone and First Nation service providers and, more broadly, a lack of access to services in Northern, rural and remote areas of the province, including a lack of services that are responsive to local need and culturally safe
- Written submissions underscored the need for urgent response services to support families and children identified as having an emerging urgent need and to reduce the likelihood of urgent need escalating to crisis
- Recommendations that more resources and supports be made available in schools, including access to trained Educational Assistants (EAs) and clinicians in the classroom.

Needs Determination, Assessment and Care Planning

- The most common theme across the telephone town halls, survey and written submissions was the desire for a needs-based program
- Families were most critical of Childhood Budgets, arguing that they will not meet the individualized needs of most children. Participants advocated for the removal of a flat rate for funding, instead asking that funding be based on individual needs
- Many roundtable participants called for the use of a consistent process to determine a child's support needs and to support the development of individualized, clinically recommended treatment plans that recognize and are responsive to the changing needs of children over time
- Submissions and roundtable discussions highlighted the importance of service coordination and clear referral pathways as well as open communication and collaboration needed between the individual receiving support, family members and support workers at each step of the assessment and treatment process.

Oversight and Capacity Building

- Overwhelming support that behavioural clinicians should be a regulated profession, supported by data from polling conducted during the telephone town halls and online survey

- Many stakeholders called for an updated set of OAP Guidelines to establish clear expectations for service providers and help families understand what they can expect when accessing services in the OAP.

Alignment with Other Ministries

- Strong recommendations that more resources and supports be made available in schools, including access to trained Educational Assistants and clinicians in the classroom
- A number of written submissions stressed that both the child and youth mental health and autism sectors must work together to coordinate and integrate services given that such a high proportion of children and youth with ASD have or will have mental health needs.

Appendix B. Detailed Mental Health Recommendations

1) Expand Autism Expertise in the Mental Health Sector to Ensure Full Inclusion of Autistic Individuals

Expertise in the provision of child and youth mental health services exists within community mental health organizations. However, many mental health specialists do not have training in autism or in how to adapt their treatment to suit the unique needs of children and youth on the autism spectrum, and many organizations and mental health workers turn away autistic people with mental health conditions *because* of their autism diagnosis. Mental health services and autism supports need to be better coordinated so that children and youth on the autism spectrum can access services in a responsive and timely manner that adequately provides for their unique mental health needs. The following recommendations address this concern:

Provide training to publicly and privately funded mental health service providers so that they are **enabled to fully include autistic people** in their client base.

- Enhance accessibility to existing mental health services for autistic individuals and their families. Existing publicly funded mental health service agencies should be *explicitly mandated* to include autistic people in their client base, where appropriate. They should adapt their services for autistic people (with added training), rather than excluding them
- Strict guidelines must be established to ensure that agencies that receive public dollars to provide mental health services are not allowed to deny services based on an autism diagnosis alone. Providers in these agencies should be mandated to receive explicit training and support to work meaningfully with autistic individuals
- If providers feel unable to clinically provide a service to an autistic person, they should be encouraged to report this, so that MOH can find ways to enhance training and support to ensure increased access
 - Not every child or youth on the autism spectrum will be suited to the community mental health agency's suite of treatment, as a result of the kinds of mental health conditions that are present, the level of the child or youth's intellectual functioning, or other clinically-relevant characteristics. In

cases where a child or youth is not well suited (e.g. not a good fit) for a particular treatment, clinical reasons for denying care must be articulated that go beyond simply a policy directive that autism is an exclusion criterion. There needs to be a reason that is individualized to the child or youth. MOH should gather this data to determine ways to build capacity, in order to reduce these exclusions and service gaps in the future.

2) Expand Capacity by Developing Inter-Ministerial Approaches to Support

Mental health services for children and youth on the autism spectrum (like mental health services for all children and youth) should ultimately be funded by MOH and/or other existing programs, not through the OAP. While it could take years for MOH to build these supports within their ministry, MCCSS and MOH can partner in the context of developing and co-funding pilot project initiatives to build the capacity of the Ontario mental health provider network to support children and youth on the autism spectrum. Additionally, the ministries can fund OAP recipients to be able to access those supports that currently exist in their communities.

Some of the submissions reviewed by the Panel pointed out initiatives and directions currently in progress that aim to develop specialized mental health services for the autistic population. For example, the Kinark Position Paper recommended that MOH should "support up to five sites to pilot the provision of integrated and enhanced services to children and youth on the autism spectrum with mental health challenges -- including the identification or development of evidence-based treatment to support better diagnosis, treatment and evaluation."

As another example, in the Ottawa Infant, Child and Youth Mental Health (CYMH) System Three Year Action Plan for 2019-2022, "Mental Health and Autism" is named as a priority for the next three years. Objectives planned for year one, 2019-2020, include:

- Reviewing and gathering evidence-based mental health treatment for children and youth on the autism spectrum
- Assessing the baseline of CYMH service providers' knowledge, skills and perceptions in relation to providing services to children and youth on the autism spectrum with mental health challenges
- Completing an environmental scan of the current state of services available to meet the needs of children and youth on the autism spectrum with mental health challenges.

Our Panel supports these directions outlined for the Ottawa region and encourages an expansion of this type of work across the province in collaboration with CYMH lead agencies.

We encourage the government to:

- Leverage the current transformation of the children's mental health sector to develop inter-ministerial policies to address the specific mental health needs of children and youth on the autism spectrum and their families/caregivers. For example, support sites to develop and pilot integrated and enhanced services for children and youth on the autism spectrum who have and mental health challenges
- Create a strategic and targeted capacity-building initiative to increase interdisciplinary expertise in the health and mental health of children and youth on the autism spectrum, including at times of crisis by:
 - Developing and implementing a mandatory curriculum for medical practitioners (e.g. psychologists, pediatricians, psychiatrists, and family physicians) at both postgraduate and continuing education levels on autism spectrum disorder and co-occurring neuro-developmental and mental health challenges
 - Creating cross-sector opportunities for collaboration, mentoring and incentives for consultation among professionals in developmental services and children's mental health
 - Examining current initiatives, such as the ECHO Ontario Autism (Holland Bloorview) and an ECHO program focused on mental health (Children's Hospital of Eastern Ontario [CHEO] is the lead for the CYMH-ECHO program & and the Centre for Addiction and Mental Health [CAMH] is lead for adult mental health program), as a mechanism for wide-scale delivery of training
 - Considering incentivizing children's mental health providers to enhance capacity (such as a formal request for proposals [RFP], funding allotments for supervision of clinicians to improve their skills, or placing requirements on mental health agencies to report on the number of children and youth on the autism spectrum provided with care for mental health challenges and the percentage of their client base with this identification)
 - Training for prospective providers including not only workshops, but also tiered supervision, by established experts until trainees develop sufficient competency and comfort to address the specific needs of autistic people
 - Training should be paid for by MOH

- OAP funding may need to be allotted, in partnership with MOH, to co-design this capacity development in the short-term given the current dearth of programming and lack of immediate commitment from MOH.

Other inter-ministerial recommendations include:

- Providing access to mental health workers in both elementary and secondary schools, trained to work with all children and youth, including those on the autism spectrum
- Building better connections for mental health services between hospitals and surrounding communities
 - This is especially important for ensuring connections to services in Northern, rural and remote regions, and for families with diverse backgrounds.

• **Create an Autism and Mental Health Working Group for Program Development and Evaluation**

- **An Autism and Mental Health Expert Working Group** should be assembled to identify the best evidence for treatment, gaps and priorities, inform program implementation and identify enablers and barriers to capacity building and collaboration among autism therapists and evidence-based mental health service providers. This working group will endeavor to:
 - Identify the best evidence for mental health services for children and youth with on the autism spectrum (e.g. cost-effective, empirically-supported approaches that are accessible and sustainable) by:
 - Reviewing and synthesizing existing research evidence
 - Best practice guidelines on mental health approaches tailored for children and youth on the autism spectrum (See: Additional Notes on the Identification of Appropriate Mental Health Treatment below)
 - Conduct a **gap analysis to better understand the availability and accessibility** of children's mental health services for children and youth on the autism spectrum in Ontario, including consideration of:
 - Crisis management
 - Short-term respite and residential placement
 - Mental health expertise among school personnel

Recommendations for a New Needs-Based Ontario Autism Program

- Hospital care (emergency and inpatient) and community supports
- Parent and caregiver support
- Funding and sustainability
- Access to psychotherapists and other regulated professions, such as Canadian Certified Counsellors and Mental Health Occupational Therapists registered under the College of Occupational Therapists of Ontario (COTO)
- Create a plan to fill identified gaps
- Make recommendations for cost-effective, empirically-supported treatment from regulated health professionals in a manner consistent with evidence-based practice
 - A list of approaches may be identified via the Society of Clinical and Child and Adolescent Psychology of the American Psychological Association: Effective Child Therapy or other reputable sources
 - Treatment should be tailored to the individual needs of the client, including the specific presenting mental health challenge(s) and the language, social skills, and cognitive abilities of the individual
 - Recommendations could also include suggested eligibility criteria, caps, guidelines regarding goal-setting and measurement of individual outcomes/response to treatment, etc. as is required for all OAP approved providers
- Establish standards for the qualifications of approved OAP mental health providers
 - Only regulated health professionals with sufficient training in both autism and empirically-supported mental health services should be added to the OAP mental health provider list
 - All OAP service providers should be subject to the same standards of audit and monitoring to ensure appropriate care
- Devise a plan of action to increase capacity in autism and mental health expertise among both autism therapists and evidence-based mental health service providers
- Co-design innovative integrated models of care to address identified gaps; pilot and evaluate new models
- Establish a province-wide system of program evaluation and identification of individual and system-level outcomes.

4) Create Wraparound and Crisis Supports

Develop **inter-ministerial programs dedicated to proactive mental health services, timely treatment, and crisis services** to address the health and mental health needs of children and youth on the autism spectrum, such as:

- OAP interdisciplinary **urgent/crisis supports** should be jointly funded by MCCSS and MOH and should include medical professionals (e.g. child and adolescent psychiatrists, developmental pediatricians and pediatricians) and other clinical disciplines
- Ensure that crisis supports can draw on inter-professional mental health teams including psychiatry, behaviour analysis, psychology, and nursing for complex cases
- Increase the capacity of residential treatment homes, safe beds, and transitional (step-down) homes in the childhood developmental sector.

5) Provide Mental Health Service Navigation

Service navigation in the OAP must involve effective and comprehensive understanding of the full range of mental health programs and services within each community. We recommend that the government establish **clear pathways** for families/caregivers who are receiving OAP services to access children's mental health services.

OAP Care Coordinators should be enlisted to help direct and refer clients to all available community supports, regardless of funding source, to enable seamless, wraparound service supports and simplified navigation for families. The family Care Coordinator should work with the individual to determine the best way to access the most appropriate mental health services within the individual's local community while minimizing barriers to access as much as possible. This should be accomplished by identifying existing services funded through other ministries and programs (being mindful of wait times that may exist for these public services) and/or direct funding for the provision of evidence-based mental health services.

Additional Notes on the Identification of Appropriate Mental Health Treatment

A mental health working group should be assembled to identify cost-effective, empirically-supported approaches, current system gaps and opportunities, and ensure broad accessibility and sustainability. The following are preliminary recommendations

from clinical experts in the field and should be considered by the mental health working group:

- We encourage the working group to examine the recommendations from the consultation submissions that focus on mental health (such as those prepared by Kinark, McMaster and the Ontario Psychological Association) for more detailed recommendations on mental health
- Mental health services for children and youth on the autism spectrum should include a diverse array of effective, empirically-supported treatment tailored to the individual needs of the client, including the specific presenting mental health challenge(s) and the language, social skills, and cognitive abilities of the individual
- Mental health treatment which has been empirically demonstrated to be effective for children and youth with specific mental health challenges (e.g. anxiety and depression) should be available for children and youth on the autism spectrum after making any necessary adaptations (e.g. based on language-level, abstract thinking skills, cultural identity, etc.) to the treatment that is required to enable the children and youth on the autism spectrum and their family members to participate
 - These adaptations should be made by regulated health professionals who have the controlled act of psychotherapy within their scope of competence *and* autism experience
- Children and youth with an intellectual disability and/or profound communication challenges would be better served by professionals with expertise in meeting the specialized needs of individuals with developmental disabilities (e.g. Children's Treatment Centres)
 - Behaviour therapists, in consultation with psychologists or other regulated health professionals with mental health treatment within their scope of practice, may be best suited to provide therapeutic supports for such clients who may not necessarily benefit from traditional mental health services (such as standard psychotherapy)
- Some existing OAP providers currently offer cost-effective, empirically-supported, manualized and time-limited mental health programs, such as *Facing Your Fears*
 - The capacity of existing OAP providers to offer these manualized forms of treatment should be identified and expanded, including expanding capacity within existing child and youth mental health agencies within the community
 - Such cost-effective, empirically-supported, manualized and time-limited mental health programs should continue to be funded by the OAP

Recommendations for a New Needs-Based Ontario Autism Program

- Other programs, such as the Canadian Mental Health Association's Bounce Back Program and the Big White Wall Program, should be considered for inclusion based on evaluation of the evidence by the mental health working group.