

# Autism Services in Waterloo Region and Guelph/Wellington

## An Analysis of Existing Service Pathways and Recommendations for Improvement

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### Purpose of This Report

The current system of supports for children with ASD and their families in Waterloo Region, Guelph, and Wellington County is complex, and it can be confusing for families and for service providers. There is a great deal of consensus around the need for change, and pockets of innovation are already emerging throughout the region. This report presents the findings of a research project intended to develop an integrated vision for Autism services in Waterloo Region, Guelph and Wellington County. The recommendations included here are designed to aid local leaders in their efforts to create a seamless “pathway” for families seeking support in their efforts to raise healthy, happy children.

This project was conceived by representatives from KidsAbility Centre for Child Development and the Community Mental Health Clinic as a way to integrate services for children with ASD, and to help families make sense of services. The Ministry of Children and Youth Services (MCYS) was approached to support the project and at their recommendation a project steering group was formed including representatives from KidsAbility, Trellis (formerly the Community Mental Health Clinic), Lutherwood, Kerry’s Place Autism Services and MCYS.

The specific goals of this research project are:

- To identify current service gaps
- To identify opportunities for coordination amongst programs to build capacity to deliver service
- To clarify routes through which services can be accessed.
- To develop a plan for Guelph-Wellington and for Waterloo Region that would utilize existing and proposed resources based on a “systems of care” framework in which services from a variety of sectors work seamlessly together.

### Methodology

This report is based on information from the following sources:

- Interviews with 20 local key informants, including service providers actively involved in serving families and children with ASD, school board and government representatives.
- Short phone consultations with an additional 6 local service providers.
- Interviews with 4 service providers from other communities.
- Individual interviews with four parents of autistic children.
- Information from available research literature and existing service directories.
- A feedback forum with service providers from Guelph and Wellington.

This report was commissioned by a committee of service providers in Guelph, Wellington County, and Waterloo Region. Members were:

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## Stage

## Explanation

Problem Identification	The service pathway begins when a parent or other involved person expresses concerns about a child's development, and begins to seek information. Families often approach child care providers, teachers, Healthy Babies home visitors, or family doctors for guidance.
Functional Assessment	This assessment, usually completed by a doctor, an early intervention specialist, or another service provider, may be informal, but it confirms the need for intervention and often leads to referrals for early intervention services that do not require a formal diagnosis. It may also lead to a referral for a formal diagnosis.
Diagnostic Assessment	A psychologist or a pediatrician with special expertise makes a diagnosis of Aspergers, Autism, Childhood Disintegrative Disorder, Rhetts Syndrome or Pervasive Developmental Disorder Not Otherwise Specified. This process often involves long waits and multiple visits. Some children receive multiple diagnoses or inconclusive diagnoses.
Referral	Depending on the specifics of the diagnosis and the age of the child, the family of a child with a new diagnosis of ASD is typically referred to several services at the same time. Centralized referral hubs exist (AIR and DSAC) help to manage this process. Certain kinds of service (child care supports, IBI, and family supports, for example) are not managed through these hubs.
Case Management Services	Supports that are available to help families develop overall plans, manage multiple services, link formal and informal supports, and generally navigate the "system" in an effective, strategic way. Available in various forms from a variety of agencies.
Child Care & Education Services	The basic services provided by school boards as well as more intensive, specialized educational programs for children with special needs. Also, child care services for preschool children with developmental challenges that are primarily educational in nature.
Treatment & Therapy	Interventions aimed at lessening the deficits and family distress associated with ASD and at increasing the quality of life and functional independence of autistic children (e.g. intensive psycho-educational interventions, occupational and speech and language therapy)
Family Support	Services for family members include peer support groups, drop-ins, social workers, and educational programs for parents about parenting strategies or about autism. Grassroots self-help groups have a long history of leadership in provision of family peer support services.
Financial Assistance	Services that provide families with resources that they can use to access other kinds of services. The primary form of financial assistance in both regions is Special Services at Home. However, summer camp subsidies and other forms of financial assistance are available.
Respite and Recreation	In-home or out of home services enabling parents and kids to take a break from each other. May include a worker coming into the home or group recreational outings for children. These services also provide an opportunity for children with ASD to interact with a wider range of people, participate actively in community life, and learn life skills.
Other	Other types of service available include nutritionists, Snozelen rooms and service dogs.

# the Current ASD Service Pathway

## Challenges Within Current System

- Gatekeepers (family doctors and others) often have incomplete information about assessment and services. Referral practices are inconsistent.
- Families have incomplete or inaccurate information about services.
- Marginalized families may not be able to make contact with gatekeepers.

- Often informal, and rarely coordinated across agencies (meaning that some families miss opportunities for early intervention).
- Often focused on younger children who are candidates for early intervention.

- Wait times are long.
- Inconsistent protocols and procedures for diagnosis across clinicians can create confusion. A dual diagnosis or an incomplete diagnosis can leave next steps unclear.

- Centralized referral hubs do not manage referrals for all types of services.
- The referral process often changes once kids enter school.
- Inadequate communication across agencies about referral and follow-up

- Many agencies offer forms of case management, but definitions differ and the support provided is often limited in scope or in time. Many families do not have reliable access to someone who can help them plan.
- Some existing case management services are reactive rather than proactive and preventative.

- Once children enter school the process for accessing some services changes. The types and amounts of services available change as well.
- Kids with some types of Aspergers can be difficult to place appropriately.
- The transition out of school can be challenging.

- Waitlists for intensive treatments are long
- Specialized forms of treatment are not always well coordinated with more mainstream supports. Silos exist.

- Family support services are not well connected to other kinds of services; Family support is rarely included in case management plans.
- Informal and grassroots supports not well linked to formal services.
- Family support at and shortly after the time of diagnosis is needed.

- Resources are inadequate

- It can be difficult to find respite for children with serious behaviour issues.
- There is a need for after school respite.

## Possible Solutions

- Awareness raising efforts aimed at families and gatekeepers need to focus on the process of accessing services as well as ASD itself.
- A clearinghouse for information about services.

- Adoption of a common assessment protocol.
- Extending the use of centralized, multidisciplinary diagnostic clinics or service resolution teams to more families, earlier in the service pathway before crises develop.

- More formal linkages between the referral functions currently managed by AIR/DSAC, the school boards, Trellis and KidsLINK and KidsAbility/Erinoak.

- Referral hubs should consider taking on a stronger leadership role in the creation of a more truly independent and holistic case management function.

- More coordination among school boards and other referral agents is needed (described above)

- Streamlined, coordinated referral would help.

- A more holistic approach to case management (described above) would incorporate family support.

- Several innovations in respite services are already underway locally.

Efforts to improve the current system of services should consider the following key principles.

*“I am very proactive in finding what is out there for my children. But not all parents are. What they really need is someone to sit down and tell them what is available. That’s difficult. There is never going to be enough services for the family, because it is such an all encompassing thing. They don’t recommend everything because they know there isn’t enough to go around” (parent).*

### *A focus on prevention and on family support*

- When cases fall through the cracks or have demands that outstrip the system’s capacity to respond, the families involved have typically been seeking help unsuccessfully for years. While families are on waiting lists for diagnosis, clinical services, or respite, stress increases. The lack of preventive services for children and families that are not yet in crisis (i.e., guidance about navigating the system, support to develop realistic expectations for one’s child, simple strategies for behaviour management, and opportunities for social interaction with other kids) means that family dynamics deteriorate. Sometimes, cases become ‘complex’ or fall through the cracks as much because of the family dynamics involved as because of the specific developmental problems of the child.

### *A focus on awareness raising*

- Families, family doctors, child care workers, teachers and others need to have access to more information about autism and about the full range of available services. According to some sources, the huge demand for IBI arises in part because parents have unrealistic expectations about what it can achieve, and limited understanding of the other options that do exist.

### *A focus on linking formal and informal supports*

- Parents who have experience with the system are often the ones shouldering the burden of teaching newly diagnosed families how to access services. Where family support services do exist, they are generally not connected to the formal service system. These grassroots informal supports are pivotally important and need to be taken seriously as a key component in the service system.

*“We don’t really have much of a parent support group or peer counselling. There used to be more connecting families together so that they could provide respite for each other and so on but in Wellington any way that is not a strong component at all. We need to really work on that.” (service provider)*

# Key Principles

## *A focus on true case management*

- Autism is a complex disorder that co-occurs with many other kinds of issues. Even in an ideal world, families will continue to need many kinds of services from multiple locations. Although there are many places throughout the system that claim to do case management or service coordination, none have the capacity to perform this function in a comprehensive way for a wide range of families before they reach a crisis.

## *Recognition of the uniqueness of each family*

- Autism presents in a variety of ways. Even more importantly, the support needs of any given family are a product of many factors in their lives, and not just the diagnosis of their child. Any system of supports needs to be open to the possibility that solutions that have worked in the past will not meet the needs of every family in the future. Families need choice and support to make informed decisions.

## *A focus on cross-stakeholder engagement and ongoing feedback*

- Families need to play an active and ongoing role in discussions about improvement of service. Their right to provide feedback and to advocate for change should be respected. Service providers funded by different ministries, working with different age groups and dealing with different kinds of diagnoses need to be open to sharing resources and power. Ongoing measurement of results and collection of feedback from stakeholders will be pivotally important.

## *A focus on meeting the needs of all children with developmental challenges*

- Although this report is concerned with services for children with ASD, any changes to the system should avoid creating a new “autism silo” that excludes children with other kinds of developmental issues.

*“It can be very difficult to communicate with families at very beginning. We need some strategies to communicate with families about all options. Kerry’s Place is really good at this. They are trying to educate families about all of the other things they can be doing in addition to or after IBI.” (service provider)*

*“Where there is a hole is for those who fall between developmental disability and average cognitive functioning. The ones we really have to work on are those who if they did not have Asperger’s would probably be diagnosed with a mild cognitive disorder.” (service provider)*

## Improving the System: Recommendations

The following specific recommendations arose in the course of this project

- There is a need for a stable, comprehensive information clearinghouse that can provide complete, up-to-date information for the general public, gatekeepers and service providers about ASD, the diagnostic process, and the pathways involved in accessing services.
- Local service providers should explore the possibility of adopting a common assessment tool.
- Local providers should explore the possibility of extending the use of centralized, multidisciplinary diagnostic clinics or service resolution teams so that they can be the first point of contact for all families seeking ASD-related diagnoses.
- Existing referral hubs at AIR and DSAC should explore the possibility of more formally linking the referral functions currently managed by the school boards (i.e., treatment and specialized education for school-aged children) Trellis and KidsLINK (i.e., child care) and KidsAbility / Erinoak (IBI). These hubs should also become more actively involved in making referrals for family support services (for which there is currently no clear centralized referral source) and in working together with grassroots parent support programs. These hubs should not be autism specific, but should manage referrals for all developmental concerns among children and youth.
- The possibility of a centralized referral management service should be explored. Such a system would list all developmental services, along with referral protocols, current levels of availability and/or information about wait-list length and would be designed to streamline referrals and facilitate access to services.
- Stronger, more holistic and more ongoing case management for children with autism and their families is needed. Of the major categories of service discussed in this report, case management is spread across the largest number of different organizations. Each defines case management somewhat differently. All readily admit that they do not have the resources or the mandate to consider the needs of families and the available services in an ongoing, holistic way. The multiple, partial case managers within the service system contribute to parents' confusion.