Autism Services in Waterloo Region and Guelph/Wellington
An Analysis of Existing Service Pathways and Recommendations for Improvement

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Prepared by

CENTRE FOR
COMMUNITY
BASED RESEARCH

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Introduction

Autism, once considered a 'rare' disorder, is now diagnosed much more frequently. From a prevalence of 4-5 in 10,000, 15 years ago, rates of diagnosis of autism spectrum disorders had risen to at least 1 in 500 by 2001 (CDC)[1]. The accompanying large rise in demand for services, together with uncertainty regarding the extent to which the observed increases are due to a true change in risk, has made Pervasive Developmental Disabilities (PDDs) a major public health concern.

Currently, Autism Society Canada estimates that there are more than 100,000 individuals with Autism Spectrum Disorder (ASD) in Canada, and about 3,000 new cases of autism-related conditions are identified each year in our country.[2]

Children with autism spectrum disorders often require intensive, specialized support and treatment. Autism is difficult to diagnose, and it often comes along with additional physical, developmental, or mental health challenges. Getting children and families the help they need isn't always easy.

In Waterloo Region, Guelph, and Wellington County, as in most parts of Canada, the growing need to provide service to autistic children and their families has created challenges. Local stakeholders (service providers, funders and families) agree that the system of services for autistic children can be confusing and frustrating. Waitlists are often long.

At the same time, major strides have been made in recent years in the treatment of autism, and in developing appropriate forms of support for families. New types of therapy are available, training and teaching methods have changed. Policy makers are much more aware of the need to reform and improve services than they were 10 year ago. Grassroots groups like the Autism Society have created excellent on-line resources for families.

At a local level in Waterloo and Wellington, new approaches to family respite have been developed in recent years. Service resolution supports for families with complex needs have been created.

Purpose of this Project

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

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[1] Center for Disease Control, USA, http://www.cdc.gov/od/nvpo/fs_tableVII_doc2.htm.

[2] Autism Society Canada. (2003). Autism Facts in Canada. Author.

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 engage community stakeholders including parents and family members in dialogue that leads to
    - Identification of current service gaps
    - Identification of opportunities for coordination and linkages amongst programs to build capacity to deliver service
    - Clarification of routes through which services can be accessed.
- To develop a plan for Guelph-Wellington and for Waterloo that would utilize existing and proposed resources based on a "systems of care" framework in which services from a variety of sectors including mental health, developmental, education and rehabilitation (Speech, Occupational Therapy, Physiotherapy) work seamlessly together.

This service pathway document is intended to:

- Provide a comprehensive inventory of existing Autism programs, related services, and current linkages so that service providers are more aware of the resources and relationships that already exist.
- Act as a point of reference and a planning tool for service providers as they develop care paths for specific families, to ensure that there is "one team with one plan for one child/family"

This project builds on findings from a related project funded by the Lyle S. Hallman Foundation and carried out by the Centre for Community Based Research.

Methodology

The research presented here was carried out by a team from the Centre for Community Based Research. 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.

Potential interviewees were suggested to the team by members of the project steering committee. Interviewees were also asked whether they felt there were additional people who should be contacted and interviewed. Their suggestions led to a number of additional interviews.

Data collection took place between August and December of 2007. The interview questions used for this study are included in Appendix A.

In February of 2008, once data collection was complete, a preliminary version of this report (including recommendations) was presented to a group of key service providers in Guelph. This version of the report incorporates the feedback received at that session.

An Overview of the Current ASD Service Pathway:

A “service pathway” is intended to depict the current relationships between various types of services for children with autism (including healthcare, developmental, educational and rehabilitative services), and make recommendations for the creation of a more seamless, efficient and coordinated system. The pathway presented in this report considers in turn each of the major steps in the process of accessing support. For each phase, challenges are identified and recommendations for improvement are offered.

The phases used here were developed inductively through an analysis of interview notes, and confirmed through discussion with the project steering committee.

Once a potential developmental issue is identified **(problem identification phase),** families and other key caregivers seek information and support. This often triggers a **functional assessment** by a doctor, an early intervention specialist, or another service provider. This assessment, which may be informal, confirms the need for intervention and often leads to referrals for early intervention services like speech and language therapy. None of these early intervention services are specific to autism, and none requires a diagnosis for access. A functional assessment can also lead to a referral for formal **diagnostic assessment** by a paediatrician or a psychologist. This typically leads to some form of diagnosis, which in turn brings families to the point of **referral** for various types of more intensive, ongoing, and (in some cases) autism-specific services like Intensive Behavioural Intervention.

Referral leads in turn, to the **service provision phase.** There are many types of services available in Waterloo/Wellington. For the purposes of this report, we’ve grouped them into seven categories. These categories are explained in later sections of this report.

- Child Care and Education
- Treatment and Therapy
- Case Management
- Family Support
- Financial Assistance
- Respite and Recreation
- Other

This simple series of five basic phases is used to organize the findings in this report. In the sections that follow, each phase is discussed in turn. Challenges that arise are identified, and potential solutions are listed. Where possible, recommendations are made about how this phase of the process could be improved.

Problem Identification Stage

The service pathway begins when a parent or other involved person expresses concerns about a child's development, and begins to seek information. With the more severe types of autism, parents often begin to express concerns about development before the child turns two. Sometimes, it is another adult closely involved in a child's life, such as a child care provider or a Healthy Babies home visitor, who first raises concerns. In these cases, family doctors or pediatricians are often the first professionals that parents approach for assistance. It can often take many visits and repeated requests from parents before these gatekeepers initiate a formal diagnostic assessment process.

Autism presents itself in a wide range of ways, and some families do not identify a problem until the child is somewhat older. In cases where there are few behavioural problems, for example, detection can take longer. For children with Aspergers or milder forms of autism, parents sometimes do not begin to seek information and diagnosis until the child is entering school and they begin to get feedback from teachers. When families with young children are going through significant transitions, such as immigration to Canada, it can also take longer for them to identify a developmental concern or make contact with a health care provider.

Gaps & Challenges at Problem Identification Stage

Limited information among gate keepers

Interviewees told us that many family doctors and pediatricians don't know enough about the various ways in which autism may present itself to be able to give good advice to families and trigger the formal assessment process. Partly, this challenge arises because many other issues co-occur with autism. Not all children on the spectrum present with stereotypical autistic behaviours. ASD is difficult to diagnose. Gatekeepers are not always familiar with the assessment and diagnosis process. As a result, families often find that they have to express their concerns a number of times to several different types of gatekeepers before they are taken seriously.

A confusing array of services

Service providers and families both report that it is far from clear who does what and where to begin when you have concerns about a child's development. Although family doctors are the most typical starting point, they vary greatly with respect to how and when they refer, and the kinds of referrals they are likely to make. Early intervention service providers like Healthy Babies are helpful in overcoming this obstacle for families with young children, but confusion sometimes persists.

One of the key sources of confusion is that families don't understand the difference between functional assessment and diagnostic assessment. As a result, many families believe that support can only be accessed once a formal diagnosis has taken place. They do not voice their emergent concerns to service providers that can link them up to early intervention services without the need for a formal diagnosis.

For decades, debates about the most appropriate ways to treat autism or support autistic children have raged. These debates continue even today. Researchers, experts, grassroots groups and websites often send parents very different messages about the best way to proceed and the long-term prognosis for children on the spectrum. This can also add to the confusion.

Families that are marginalized due to (for example) poverty or recent immigration
Any family that embarks on the process of seeking support for a child who may be autistic faces challenges. For marginalized families that live in poverty or are recent immigrants to Canada, the process can be even more challenging. These families often have no ongoing relationship with a family doctor. They may have trouble knowing where to begin when they have a concern about a child's development. Several key informants made reference to this challenge:

> *Every once in a while I hear of families who have never heard of our services. I am finding this more so with families in the lower socio-economic families. They just don't have access to information or know how to access the information. There is definitely an information gap among the immigrant population.*
>
> *[People who fall through the gaps include] ESL families, many of our smaller communities, many of the families who are dealing with poverty. Every successful story has one person outside of that family or individual who is truly invested in that issue.*

Families can also become marginalized for other reasons. Parents who themselves struggle with disabilities or addictions often struggle to manage the process of seeking support for an autistic child.

> *Many services find it really hard to engage those parents who are struggling with multiple issues (poverty, addictions etc.) It speaks to the family's ability to commit and stay with the program*

Families and supporters that share incomplete or inconsistent information.
Sometimes, families are hesitant to share information that could aid in the process of problem identification. They may be concerned about their child becoming inappropriately labeled. They may worry that schools or child care centres will over-react or under-react to the information. This problem is exacerbated when the key people in a child's life can't reach consensus about whether a potential developmental concern exists.

Suggested Innovations: Problem Identification Phase

Interviewees suggested a number of innovations that they felt would help to address challenges at the problem identification stage. These included;

- Training of gatekeepers (including General Practitioners) about the diagnostic process and the importance of early intervention. Given the complexity of ASD and the challenges involved in making an accurate diagnosis, it is not surprising that gatekeepers are not always as informed as they should be.
- Awareness raising among parents about the signs of autism and the importance of early intervention.

  In the early stages after diagnosis, some families go through denial, or they think the only thing that will help is IBI. 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.

- Support for parents who are trying to understand the service system. Several entities, in both Waterloo Region and Wellington County, have made efforts to create directories of available services. At a provincial level, excellent websites and resource organizations exist. However, these directories have not typically been specific to autism, and they have not included explanations of the service pathway (i.e., the relationships between services, the referral paths, etc.).

Recommendation # 1

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. Ideally, the organization taking leadership in providing this information should not be itself a major service provider. It should have an independent voice and a commitment to monitor availability of all types of service, and to make this information available to all types of families by communicating in a variety of ways.

One of the messages that should be emphasized when educating parents and service providers is that there are several types of self-referrals that can be made in any case where there are developmental concerns. These services do not require a formal diagnosis or a doctor's referral. Examples include Infant Development and several KidsAbility services.

Functional Assessment Stage

Functional assessment refers to the process through which families, doctors, and other service providers reach the conclusion that some form of developmental concern exists, and begin to make referrals. Early intervention services such as Healthy Babies and Wee Talk incorporate a form of functional assessment, and they are designed to help parents of young children begin to access support quickly. They are able to act before the specific developmental concerns are diagnosed.   Functional assessment may also lead to a referral for formal diagnostic assessment.

One of the reasons why functional assessment is important is that it is not autism specific. Any family with a developmental concern about their child can access services like Healthy Babies or Wee Talk, and begun to receive the support that they need.

A form of functional assessment also takes place within school settings. Teachers or resource staff will often access various kinds of additional support for a child before a formal diagnosis is made.

Please see Appendix B for a list of programs and services that provide some form of functional assessment in Waterloo Region and/or Guelph/Wellington.

Gaps & Challenges at Assessment Phase

Supports for functional assessment are often focused on very young children. Quick access to services in the absence of a diagnosis is more difficult for school-aged children.

Functional assessment is often informal, and is rarely coordinated across agencies. The degree to which functional assessment leads to appropriate supports depends to a large degree on the judgment of the individual service provider and the family.

Please see the next section for suggestion innovations in the assessment process.

Diagnosis Stage

For most families, diagnosis occurs when their GP or pediatrician refers them to a specialist capable of making a diagnosis of autism (usually a psychologist or a pediatrician). This referral can happen as young as two years of age, but many families spend months telling various service providers about their concerns before a referral for diagnostic assessment is made. In some cases, it is not the family but a service provider treating the child for behavioural or speech & language concerns who identifies the need for a more comprehensive diagnostic assessment. Healthy Babies, Healthy Children home visitors or infant development workers may also make referrals.

Ideally, diagnostic assessment leads to a specific, individualized diagnosis of some kind. Sometimes, ASD diagnoses are differentiated in terms of level of severity. However, the specific formal diagnoses within the spectrum are Aspergers, Autism, Childhood Disintegrative Disorder, Rhetts Syndrome & Pervasive Developmental Disorder Not Otherwise Specified. Autistic children are sometimes difficult to diagnose because many other issues co-occur with ASD issues (including epilepsy, mental health issues such as attention deficit disorder, mood disorder or an anxiety disorder, communication impairments, and cognitive or learning disabilities).[3] Presenting symptoms often change as a child gets older. This is especially true for children with a dual diagnosis (mental health issues combined with developmental disabilities) and sometimes families find themselves seeking an updated diagnosis as their child enters adolescence.

Partly for these reasons, a child's diagnosis may be inconclusive. Some children require more than one type of diagnosis. A speech and language therapist, for example, may diagnose a speech problem and make appropriate referrals while a family is still in the process of getting a diagnosis of autism. A diagnostician may suspect that there is a dual diagnosis. There are multiple assessment tools available, and debates about the most effective tools in various situations. There are also debates about the minimum age at which ASD can be diagnosed.

Various programs and services exist in both regions that are designed to bring together service providers from various disciplines to problem solve around the needs of specific children in complex situations. These approaches, sometimes called service resolution, normally take place after diagnosis has happened, when it becomes clear that existing services cannot meet family needs. Strictly speaking, they are not part of the diagnosis phase of the service pathway. However, these teams sometimes identify a need for more extensive diagnostic testing.

Gaps and Challenges

For many local service providers, diagnostic assessment is the step in the service pathway where the most serious challenges begin to arise. Diagnosis is a necessary step in the

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[3] Dr. Peter Szatmari (2006). CAIRN Brief to the Senate Standing Committee on Social Affairs, Science and Technology Autism Spectrum Disorders: The Key Role of Knowledge Creation and Dissemination. Offord Centre for Child Studies. Ottawa, November 22, 2006

process of accessing more intensive and autism-specific services, and many of these services are most effective when children are young. However, the diagnostic process can be very slow. This basic challenge underlies many of the others listed throughout his report.

Wait times & the importance of early intervention

There is widespread acknowledgement in the research literature of the importance of early intervention[4]. Strain et al. (1998)[5] identified a number of factors that seem to facilitate early diagnosis and treatment:

- raising public awareness about the early indicators of autism
- building strong working relationships between family doctors, other referral sources, and diagnostic services.

Despite the importance of early intervention, families that have successfully convinced a gatekeeper to refer their child for diagnosis often face a significant wait for access to a diagnostician. There is no centralized provider of autism diagnosis in Waterloo Region or Wellington County. Families in Waterloo Region have access to a developmental psychologist skilled at diagnosis of autism who is based at KidsAbility, and this individual performs the bulk of publicly-funded diagnoses in Waterloo Region. Hospitals also make diagnoses, as do a small number of independent pediatricians. Because it is complex, diagnosis of autism can be very expensive.

One interviewee's comments illustrate the number of number of players that can get involved in the diagnostic process:

> *Children are waiting to receive a diagnosis perhaps longer than they should. That could be for a variety of reasons, including difficulty accessing a pediatrician, or having a pediatrician who is uncertain and does not want to over identify for diagnosis too soon. But this leaves the child waiting too long, and so they are put on the wait for psychology then go through that route. Sometimes there are very good reasons why the diagnosis is put off. An example would be a child who is placed in foster care. We would only make a diagnosis at the age of two when everyone is in agreement that the presentation warrants the diagnosis. It depends on the presentation of the child.*

Children who are undiagnosed or are left with incomplete diagnoses (e.g. "grey zone" kids who appear to have multiple challenges but may not qualify for a formal dual diagnosis) are limited in the services they can access. So are children that are diagnosed with mild forms of autism.

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[4] Lovaas, O.I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children in behavior therapy. *Journal of Consulting and Clinical Psychology*, 55, 3-9.

[5] Strain, P. S., Wolery, M., & Izeman, S. (1998). Considerations for administrators in the design of service options for young children with autism and their families. *Young Exceptional Children*, 5, 8–18.

> *The mild kids fall through the whole system in general. The whole community has to do better with describing severity.*

Inconsistent protocols and procedures

Partly because ASD is difficult to diagnose, and because there are debates in the research community about what kind of assessment is appropriate in various situations, there are inconsistent diagnostic assessment protocols across organizations. As a result, some services and referral hubs won't accept some kinds of assessments, and families sometimes go through the diagnostic process more than once.

Problems with inconsistent approaches to diagnosis can also arise when families choose to pay for an assessment or diagnosis from a private clinician. Although paying for services can be a way for more affluent families to reduce their wait times, private clinicians may use a variety of approaches. Some of these approaches may not mesh well with those used by the mainstream service providers. Private clinicians also vary in their level of understanding about the services and supports that are available, and may not refer families in the same way as the diagnostician housed at KidsAbility.

Late diagnosis

If children arrive in the system at an older age (as a result of immigration to Canada, for example) diagnosis can also be a challenge. Diagnosticians with appropriate experience may be difficult to find and have even longer wait lists.

Dual diagnosis

Kids with dual diagnoses aren't well served by either system, especially grey zone kids, and especially as they get older (16-18). This challenge arises at all stages in the pathway, but becomes especially clear at the diagnostic stage;

> *There may be a wait list for psychological assessment. We prioritize people who need it immediately for access to services. Our wait list is primarily people who had a psych assessment done at about age 10 and now need it for ODSP. Our philosophy is that if you had a diagnosis from age 8 or up that is your diagnosis for life. But for ODSP sometimes they want the diagnosis updated. In this instance individuals may have to wait for the assessment.*

The lack of support for families immediately after diagnosis

It often takes families a period of time to come to terms with a diagnosis of ASD. A form of grieving for what feel like lost hopes and dreams can take place. Although Kerry's Place and the Autism Society provide this type of support to some families, there is not currently any formalized form of post-diagnosis emotional support or guidance in Waterloo or Wellington. A family's reaction to the diagnosis can have long-term implications for ho they choose to interact with the service system, and so this lack of post-diagnosis support is an important gap in the current system.

Suggested Innovations: Assessment & Diagnosis Stages

> *People use different doors to access services. Mental health. Or Children's Aid. It would be great if we had a plan that they all do some type of assessment that is relevant, [and that allows for comprehensive] screening early on.*

Innovations suggested by interviewees included:

- The creation of a dedicated autism clinic in an accessible location (perhaps housed within an organization like KidsAbility or Trellis, or at a generic service provider such as a community health centre) that would increase the number of skilled diagnosticians available, improve consistency of diagnoses, deal effectively with atypical cases, reduce the number of incomplete diagnoses, and make it easier for parents and gatekeepers to know where to go for diagnosis. Such a clinic could also (interviewees suggested) bring together the various disciplines involved in diagnosis and do a better job of remaining current on the latest research on diagnostic tools and treatment best practices.
- Rationalization of the criteria for an acceptable diagnosis across services, in order to reduce the need for multiple assessments, to enable psychologists to share more of the diagnostic load with pediatricians, and to streamline the referral process.[6]
- Further exploration of the interface between those who provide diagnosis for children's mental health and developmental disorders.

Recommendation # 2

It is important to ensure that the system of services for children with autism is accessible through a multitude of different "doorways." Every family faces a unique constellation of challenges and resources, and there must be multiple routes through which services can be accessed. However, the lack of any single entity that plays a leadership role in diagnosis is a major source of confusion and frustration for parents. Fragmentation of services into silos begins at the point of diagnosis. **Local service providers should explore the possibility of adopting a common assessment tool.**

Local providers should also 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. Although the need for more intensive team diagnoses will persist for children with dual diagnoses or other complexities, the proposed team should be capable of playing a leadership role in a wide range of less complex diagnostic situations.

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[6] One interviewee reported that several developmental service providers in the Region of Peel have developed and implemented a standardized, shared assessment protocol.

Referral Stage

Usually, the family of a child with a new diagnosis of ASD is referred to several services at the same time. These may include (for example) occupational therapy, speech and language therapy, or Special Services at Home (a program that funds one-to-one, home-based workers for children with developmental disabilities).

Since the Making Services Work process of the mid 1990's, most communities have had some form of centralized access and referral for developmental services. The Developmental Services Access Centre (DSAC) in Waterloo Region and Access, Information and Referral for Developmental Services (AIR) in Guelph and Wellington do act as centralized referral sources for many types of services.

However, there are many situations in which families need access to services that are not managed through these central hubs. For example, some children with autism also have mental health diagnoses. In cases where a multiple diagnosis is suspected, additional assessments (through Trellis in Guelph or KidsLINK and Lutherwood in Waterloo Region) are often recommended.

If the case is seen as an appropriate candidate for IBI therapy[7], the child is referred to Erinoak where an assessment is completed to determine the severity of the case, eligibility for government-funded IBI treatment programs, and recommendations as to the amount and type of treatment required. The wait time from referral to Erinoak for assessment interview can be from nine months to one year. Referrals for IBI therapy are not managed through DSAC or AIR.

The figure below summarizes what we learned through the interviews about current referral patterns in Guelph and Wellington. The process of seeking support typically begins in one or more of the white boxes. Yellow boxes represent entities that play a leadership role in assessment, diagnosis, and referral. In Guelph and Wellington, these same entities are also the major service delivery agencies. Grey boxes represent other local services, and green boxes represent supports available outside of the community.

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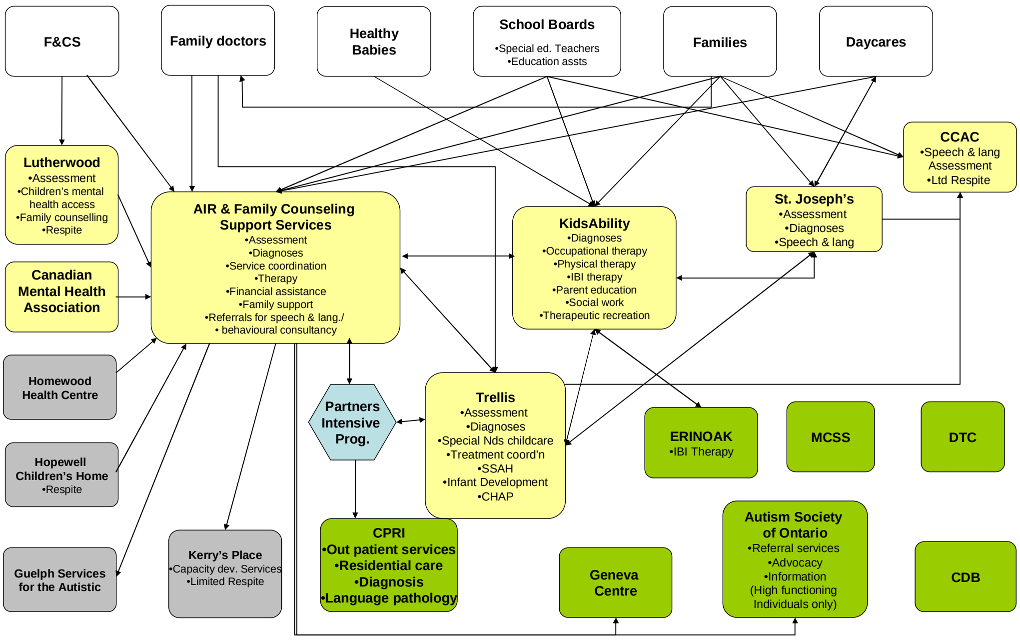
[7] IBI stands for Intensive Behavioural Intervention and is based on Applied Behavioural Analysis (ABA). IBI is individualized intervention program for children with autism which has clearly defined goals and uses systematic behavioural teaching methods. Generally, the child must be young, have fairly severe Autism, and have caregivers prepared to take on the responsibilities of supporting IBI. It is important to note that the principles of ABA are sometimes applied in the context of treatments other than IBI.

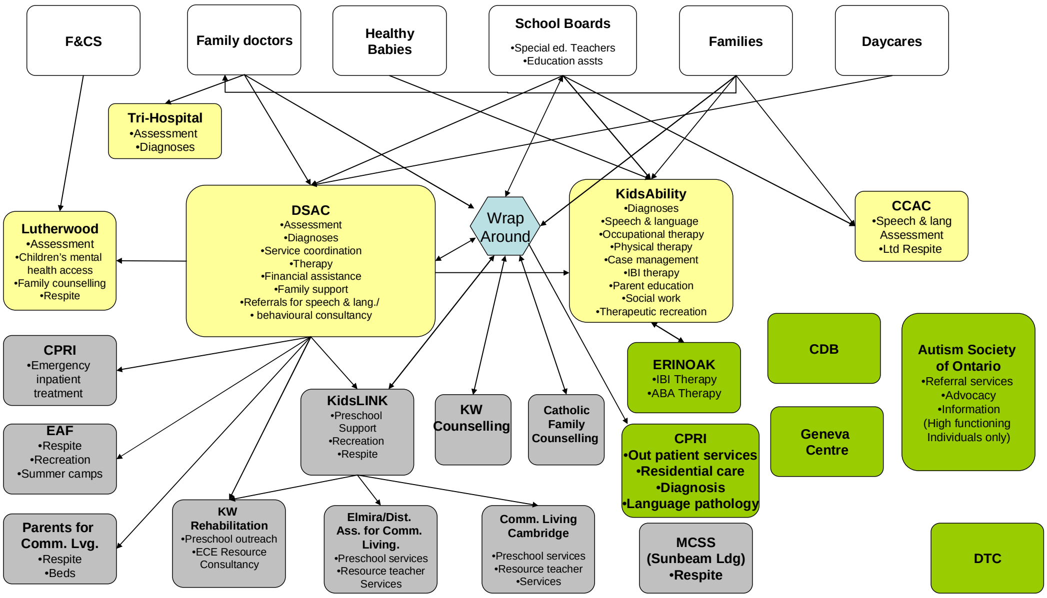
ASD Referral System Model: Guelph



This picture suggests that the key players in Guelph and Wellington collaborate closely with one another and make many different types of referrals, and this is in fact true. However, the referral process as a whole is not coordinated in any way. No organization ensures (for example) that families who have recently received a diagnosis always get referred to a social worker or Kerry's Place for support or counseling.

In Waterloo Region, more agencies are involved and the referral patterns are even more complex.

ASD Referral System Model: Waterloo Region



Gaps & Challenges at Referral Stage

Centralized referral sources only cover limited services

Of the seven major types of services identified in the service pathway at the beginning of this report, AIR and DSAC deal with only three; case management, respite and certain types of therapy (speech and language; behavioural). Family support services, specialized supports for children with autism in child care, school support, and other key services must be accessed through other channels.   This difference is a major source of confusion and frustration for families.

> *Interviewer: What happens when families come through your door looking for guidance about how to access the system?*
> *Key Informant: We no longer are able to do much for them. The powers that be would see that as DSAC's role.   We hope, with our new community development position, to do more linking of families with other families who have been through similar situations.*
>
> *Once they have a diagnosis they are then referred through AIR. Similarly with Kerry's Place they register all their clients with AIR. The one time they don't do that is if people are just signed up for a certain group or they are running a workshop then they don't have to be registered through AIR otherwise they do and that includes all the Community Living services and Torch Light services.*

The fact that DSAC and AIR don't manage all types of services also limits the capacity of these hubs to act as effective case managers.

The capacity of centralized referral to meet the needs of all types of cases is limited

Several interviewees felt that the capacity of staff at DSAC and AIR to understand the full context of a given family and help them choose appropriate services is limited. These hubs, some interviewees felt, don't have the resources to provide the comprehensive case management that is needed to manage multiple services and supports on an ongoing basis.

In particular, interviewees agreed that current referral centres are less effective when dealing with children that are diagnosed with Aspergers, kids that have serious behaviour problems, and kids that are dually diagnosed (or should be). This is true for several reasons.

> *Kids with Aspergers [are hard to refer because these families] really don't want to associate with developmental services. They don't see themselves as having a peer group with other ASD individuals. Trying to find a way that is respectful and supportive of people with Aspergers [can be a challenge].*

Lack of inter-agency understanding

Many interviewees admitted that they were not as informed as they felt they ought to be about the work of other local service providers.

> *We are least familiar with case management for people. We don't have the time or the knowledge to always help them solve their problems so we basically say 'call CMHC for this'. We know a lot about different types of therapy but very little about the other blocks of services.*

Some felt that other parts of the system do not have a full understanding of their services and needs.

> *More inter-ministerial collaboration would be great. One size does not fit all. For example, the monies given to the ASD consultants were not what all the schools board needed. Our board already had these systems set up. If we had been given a choice we could have done a much better job in augmenting services for children on the spectrum. We are all being forced into silos so it's really hard to collaborate.*

Managing the expectations of families

Some service providers pointed out that recent years have seen significant changes in the service options available to families, and a great deal of discussion about IBI and ABA-style therapies in particular. One side effect of this rapid expansion has been an increase in families hopes and expectations about the services they will be able to access, and the impacts these services will have.

Suggested Innovations: Referral Stage

The idea of a centralized referral hub is one that the majority of key informants support. Ideally, such a hub should simplify the process for families, reduce the need for duplicate assessments, prevent duplication of services, and help to ensure efficient use of available resources.

In a variety of ways, local service providers have worked to try to bring access to more services for more children under the same umbrella. KidsLINK and Lutherwood in Waterloo Region and Trellis in Guelph, as providers of both children's mental health and developmental services, have made some of these linkages internally. Several organizations that provide pre-school services have worked to build fee-for-service relationships with school boards so that families can have continuity as their children age.

Suggestions offered by interviewees as ways of improving the referral process included some ideas that have already been mentioned, including education of gatekeepers and awareness raising among families. In addition, the following ideas were mentioned:

- Creation of a true centralized hub that coordinates access to all types of services related to autism and is networked with similar agents in other communities. This hub should also be more closely linked to grassroots mutual support organizations that often act as informal referral agents. Although the Partners' program and Wraparound currently fulfil some of the roles suggested here in Wellington and Waterloo respectively, some participants opined that the roles of these two bodies ought to become more formalized within the autism service system. According to one key informant,

  "The big challenge with wraparound is [its] informal nature. When you are interacting with highly professionalized systems, that informal approach doesn't always work. [It] ends up looking more like advocacy as opposed to working together with professional services."

- Dissemination of the best research knowledge about effective treatment options to all staff at the diagnosis and referral stages to ensure more appropriate referral.

- Education of all service providers about the full spectrum of autism services, so that they can support the process of more effective referral. One interviewee commented:
  [we need] More collaboration between service providers so you know how you can help someone else who has that child after we have them

Service providers who participated in community meetings as part of this research project expressed concern that efforts to streamline ASD services might inadvertently create an “autism silo.” They felt strongly that any improvements in centralized referral should consider the needs of all children and youth with developmental concerns.

Recommendation # 3

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.

Recommendation #4

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 waitlist length and would be designed to streamline referrals and facilitate access to services. This database should be linked regionally or provincially.[8]

Referral is, in reality, one component of case management. Referral hubs should also consider taking on a stronger leadership role in the creation of a more truly independent and holistic case management function (this aspect of the recommendation is discussed in more detail below).

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[8] At least one example of such a system exists in Ontario. The Community Services Coordination Network (CSCN) serves individuals and families in London-Middlesex, Elgin, Oxford, Huron and Perth counties. It coordinates access to various services and supports for adults with a developmental disability and for children and adolescents with complex needs that may require a response from more than one service provider. Participation in the CSCN process is required for children and adults with a developmental disability who are pursuing accommodation supports and for children and adolescents seeking admission to a residential based treatment program or to the WrapAround process (http://www.cscn.on.ca).

Service Delivery Stage

The remaining sections of this report deal with the final stage of the service pathway – the delivery of service. For the purpose of this report, seven categories of service have been identified. Each category of service is considered in turn. Please see Appendix B for more detailed information about each category of service.

Service Categories: Case Management

> *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).*

One of the most frequently discussed components of the service pathway was the 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.

For the purposes of this report, case management is broadly defined to include any efforts to help families make strategic, coordinated use of multiple supports. This category includes case management services provided by a service agency (although this type of case management often encompasses only those services offered by that agency). It also includes Wraparound and other more intensive and independent forms of case management. Services that have multiple components (such as Infant Development or the Partners Intensive Program) are categorized under case management.

In the course of this project, there was much discussion about the most appropriate term to use for this part of the pathway. Case management is less than ideal, because it implies for many people a clinical focus rather than a consideration of the entire family system. However, it is used here because it appears to be the most commonly understood term among the options available.

The families of children under the age of 6 may get various forms of case management in a variety of places. For example, DSAC and AIR offer some case management support to this age group. If a family is receiving more than one type of service from an agency like Trellis, Lutherwood or KidsAbility, these organizations often offer some case management support (as well as social work services or counseling, in some cases) to help families coordinate these in-house services.

Once a child enters the school system, the school board often becomes the de facto case manager. The speech and language and OT services provided through KidsAbility, for example, are only available to children under the age of 6. School boards may choose to refer students to outside agencies for these services. In other cases, they attempt to address the issue through other types of services offered within the school (such as EA's or special needs teachers). Although the provincial government has recently committed new resources to a program designed to train school staff to support kids with autism, the turnover of responsibilities from one system to another is not always easy for families.

In some contexts, the term case management is also used to refer to clinical coordination of assessment data, which can involve very little direct interaction with the family. However, none of the interviewees contacted for this study used the term in this way.

Gaps & Challenges: Case Management

Definitions & scope

The range of services included in this category illustrates one of the key challenges identified by our interviewees. Case management, service coordination, service resolution and similar terms refer to different levels of service at different organizations. Most case management services currently available in Waterloo and Wellington (with the possible exception of Wraparound, the Service Resolution Facilitators and the Partners Intensive Program) focus their efforts on a limited range of services and supports. Interviewees told us that their case management services are not equipped to help parents access the full range of services and supports listed in the table attached to this report.

Lack of preventive, proactive case management

More intensive forms of case management, such as Wraparound or the Partners Intensive Program, are typically reserved for cases that are complex or for families that have already found that more typical service arrangements don't meet their needs. As a result, families are often in crisis by the time they are able to access a form of case management that looks at their situation in a more holistic way.

Suggested Innovations: Case Management

Innovative approaches to case management are already in place in both Waterloo and Wellington. Waterloo Region Wraparound works on a long-term basis with 18-25 families per year. They deal with families who present needs that cannot be met by any one service and work with the entire family. They assist families in accessing resources. They work with children from 0 -18 who have a dual diagnosis, mental health or developmental disorder. Referrals can come from agencies or the families themselves. They are located out of KW Counseling, and there is no cost for this service.

A service resolution facilitator is housed at Trellis. In Waterloo, there are service resolution facilitators housed at DSAC and also at KidsLINK. These individuals work with families who are in crisis because the plans made so far by various service agencies have been unsuccessful. The service resolution facilitator is part of a collaborative team which gets the top people together to talk about what can be done to meet the crisis or contain the crisis.

KidsLINK and Lutherwood have implemented an intensive case management program for children with mental health issues. The program, called Intensive Supports and Resource Coordination, provides dedicated case coordinators to work with children who have severe, chronic and complex needs[9].

Despite these innovations, interviewees continue to see a need for more intensive and independent case management for families. One interviewee felt that the kind of individualized support needed by families could only be provided through an individualized funding model.

> *For children with aspergers or high functioning they need individualized funding because these kids really need individualized plans.*

Recommendation # 5

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 a holistic way. The multiple, partial case managers within the service system contribute to parents' confusion.

Ideally, case management should be holistic, inclusive and independent. Referral functions should be considered as one component of case management, and case managers should take a leadership role in making the entire system simpler and more navigable. As part of an extended mandate which also includes more comprehensive centralized referral, AIR and DSAC should consider housing a stronger, consolidated case management function.

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[9] MacLeod, K. (2006). Pilot Program Evaluation, Intensive Supports and Resource Coordination Program.

Service Categories: Education & Child Care

"Education and child care" refers to the basic services provided by school boards as well as more intensive, specialized educational programs. This category also includes child care services for preschool children that are primarily educational in nature.

Special needs child care services assist families in finding child care, and provide resource consultants to support child care workers working with children who have ASD. Educational programs for school aged children include educational assistants (some of whom are specially trained to support autistic children), specialized classrooms, and child and youth workers.

Once children with ASD enter the school system, many service and supports that are nominally similar to those available to preschool children are accessed through the school board. These services are managed differently than preschool services and funded through a different provincial ministry (the Ministry of Education). As a result, the focus of these services (speech and language therapy or behavioural therapy, for example) shifts somewhat towards the need to support the educational process.

Some services (such as IBI) blend education and therapy. These are included in the "treatment" category for the purposes of this report.

Gaps and Challenges: Education & Child Care

The transition to school

In Waterloo Region and Wellington County, many types of services are provided by one organization for children up to the age of 6, and by another after that. Children's mental health services are divided this way in Waterloo Region. Speech & language services, occupational therapy and other forms of treatment are divided this way in both regions. For these reasons, the transition to school is often difficult for families.

Local school boards are aware of this challenge and have taken steps to address it;

> *Prior to children coming into the school there is a process for transitioning into school. Case conferencing with various agencies who are serving kids who will be moving into school takes place in May and June. This allows for the school board to allocate staff and funding to meet the needs of these kids.*

However, this support is often seen as insufficient. As one person put it:

> *Families often refer to (the transition to school) as the bottom falling out of their service plan, because they had built up such a strong relationship with the preschool services.*

Another key informant echoed this sentiment:

> *There is a gap in service delivery for children transitioning into the school system. They are not sure how the child's communications, sensory or behavioral needs would be approached or met. They are not always sure that the child will have access to all the services the child had because they are discharged from these services. The model is consultative without direct involvement of the parent. The hands on is done by the teachers in the classroom quite differently from what families had been accustomed to before school. It is difficult for parents to hear that there is no carryover of services.*

If the family has a child with Aspergers, they may be navigating the diagnosis and assessment system at the same time as their child is beginning school, and this can be very difficult.

The transition out of school

When youth with developmental disabilities reach the age of 18, the primary responsibility for funding services switches ministries a second time. As families are shifting from a focus on training to a focus on long-term vocational and living arrangements, they are once again faced with the challenge of understanding a new array of service providers and eligibility criteria.

Obstacles to service access for school-aged children

Families often feel they have to advocate in order to have their child placed in what they see as an appropriate school setting. Some interviewees felt that schools put up roadblocks to the integration of kids with ASD.

> *Sometimes the schools are putting up roadblocks. .For example, [some schools have said that] kids need to be toilet trained [in order to attend school] but really they don't need to be.*

Unclear or unrealistic expectations

Because there are so many students and so many schools, the transition process is not always handled as planned. For example, parents sometimes have expectations about their child's entitlement to a full time Educational Assistant that are unrealistic. Because they are frustrated and receive limited support, families often become angry with the school system.

Limited services

Overall, less support is available to children with ASD once they enter school.

> *Our system is set up to deal with the kids who will get better after two years of IBI. Mike Harris dismantled the group homes. All of our money is going to IBI. My children are lucky if they see a speech therapist once a year through school now (parent).*
>
> *Services for children beyond the JK years are limited. These children are now in school and the school board has to take over the services for these children. The*

> *board will do assessment and give them one block of therapy and then discharge. That is not very much if you are just finding out that your child has autism or complex needs. However, the board does not have the resources to offer more than that to older children. They don't offer ongoing services to children with autism from kindergarten on up. Unless they need seating and mobility services, the board will provide those or if they need augmented communication services. The board discharges from Speech and Language and OT. If a parent keeps a child out of school other agencies will continue to see that child only on a limited basis and it needs to be for medical reasons. There are some very specific parameters put in place.*
>
> *Some of the services seem to be so heavily taxed. One example would be about occupational therapy. The older the child gets, the more difficulty we have accessing that. We can wait quite a time for that. For things like case management, we have a good relationship with service agencies and we can connect the family.*

Providing support to "high functioning" children

One key informant reported that the school board often has trouble finding appropriate placements for kids with Aspergers. Children with this diagnosis vary greatly with respect to their cognitive ability (the same is also true for many other developmental diagnoses). Sometimes, children with Aspergers are capable of handling a more challenging curriculum than is typically offered in congregated classrooms, but are likely to struggle in a mainstream academic program. As "applied" secondary school streams have been eroded in recent years, "high functioning" ASD youth sometimes fall through the cracks.

> *Where there is a hole is for those who fall between developmental disability and average cognitive functioning. The Asperger's program in its inception was for those high functioning adolescents and we have been expanding that every year taking in more of the average children. But 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.*

Suggested Innovations: Child Care and Education

Interviewees offered a number of suggestions for improving services within the school. These included:

- Development of more robust transition services. Service providers and policy makers agree that families need more support when one type of service is coming to an end and another is taking its place. Transitions can take many forms, but are often especially stressful when children are entering elementary school, leaving high school, or coming to the end of a period of intensive therapy. Although new transition services have been developed recently, some interviewees felt that more of this type of support is needed.

- Fostering more open, frequent discussion among teachers, parents and ASD service providers throughout the school years. One step in this direction would be to adapt policies that restrict the information that can be shared between teachers and service providers.

- Maintaining consistent case management and coordinated referral through the transition into elementary school.

Service Categories: 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 are classified in our taxonomy as “treatment and therapy.” These may include but are not limited to intensive psycho-educational interventions such as IBI and social and developmental interventions such as occupational and speech and language therapy.

Gaps & Challenges: Treatment and Therapy

Wait Lists

Some types of treatment, such as IBI, have very long wait lists. Occupational therapy services at KidsAbility currently have a 7 month waiting list, and it has been as long as one year. Once families reach this point on the service pathway, they have often had to wait for assessment, wait for diagnosis and wait for referral, and so yet another delay is extremely frustrating.

Silos

Some interviewees pointed out that families sometimes become so deeply engaged in IBI treatment that they have little time to develop relationships with other types of services. The limited number of services that focus on children with Aspergers often find that families are resistant to participating in programs designed for children with more severe forms of ASD.

Lack of counseling services

Counseling for children who have a developmental disability is difficult to access in both regions.

Service Categories: Family Supports

Interviewees agreed that services for family members are pivotally important in any effort to foster healthy development of children with ASD. Programs included in this category include (for example) peer support groups, drop-ins, social workers, and educational programs for parents about parenting strategies or about autism. Grassroots self-help groups, such as the Autism Society in Guelph, have a long history of leadership in provision of family peer support services.

Several organizations that are now important developmental service providers (such as the Associations for Community Living and Extend-A-Family) grew out of grassroots parent movements.

As a category, family support services are least likely to be connected to any form of centralized referral or case management.

Gaps and Challenges

Capacity of generic family support programs

Family support is one domain of service where generic service providers play an important role. Early Years Centres and parenting programs often find that parents of autistic children come to them for support. They see themselves as well positioned to provide that support while helping integrate these families into the broader community, but they are often limited by the fact that they are not equipped to provide service to children with autism while parents participate in support programs.

The complexity of the system

The intense need for family support is, in some respects, a symptom of the frustration that goes along with trying to access services within a complex and confusing system. Often, other parents who have been through the system are the most reliable and helpful source of information for families attempting to access support.

Lack of counseling or social work services

Some interviewees identified a lack of counseling or social work services for families. Although KidsAbility and other agencies do have social work services available, resources are limited. The stress of caring for an autistic child can be to much for some families to manage, especially if they are already struggling.

> *Family counseling piece is really lacking. The [generic] counseling places are not really expert in this area. Case managers don't really do counseling. Erinoak social workers are focused on kids getting IBI treatment. If somebody had a social worker who could work with these families it would be ideal.*

Lack of resources

Some interviewees reported that there are simply not enough family support programs available.

> *We don't really have much of a parent support group or peer counselling. There used to be more support with the original concept of Extend A Family (in Guelph-Wellington) connecting families together so that they can 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.*

Suggested Innovations: Family Support:

Interviewees suggested a number of possible innovations around family support. Provision of information to families has been discussed in previous sections. The need for social workers or other counselors to work with families was also mentioned several times. One interviewee suggested:

> *We would like to have a therapist/social worker on staff to deal with grieving after diagnosis. Our staff aren't hired to do that, and the DSAC social worker is overburdened.*

Another suggested that there should be more support groups for parents, especially dads (who often don't participate in existing groups).

The importance of grassroots mutual support to families was discussed above in the assessment and referral stages, and recommendation 3 suggested the formation of stronger working relationships between referral hubs and family support services.

Service Categories: Financial Assistance

Financial assistance programs 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 are available from the Autism Society in Guelph, and some grants for families with complex needs are available through MCSS under special circumstances.

Service Categories: Respite & Recreation

Respite programs offer in-home or out of home services enabling parents and kids to take a break from each other. These services may include (for example) a worker coming into the home or group recreational outings for children. All publicly funded residential respite and day programs are accessed through DSAC and AIR in Waterloo Region and Wellington County respectively. Typically, these services also have other, equally important purposes. They provide an opportunity for children with ASD to interact with a wider range of people, participate actively in community life, and learn life skills. Often, this kind of social interaction is an important complement to clinical treatment of autism. Respite experiences can be steps on the road towards independent living for older adolescents.

Recreation programs such as integrated or specialized summer camps, teen movie nights or dances, or sports programs also meet the family need for respite while providing the child with an opportunity for social interaction and community participation.

Gaps & Challenges: Respite

Timing and availability

Most interviewees acknowledged that respite services are inadequate, and that they aren't always available when needed. After school respite, or respite for school holidays, is difficult to find in both Waterloo Region and Wellington.

Respite for children with behavioural issues

It can be very difficult to get respite for a child with severe behavioural issues.

> *Kids with severe behavioural issues are hard for us to serve. It is hard to find out of home respite. Sometimes we double up on staff members for one kid. The parents of kids like this are too tired to lobby for change.*

KidsLINK sometimes provides fewer hours of service when a kid with high behavioural needs is referred, but only reports one case that they were completely unable to serve.

> *Families wanting immediate respite are a challenge because we only have 10 permanent children resident beds in the region. People are prioritized based on need so we cannot determine the wait. In this case we try to enhance in home support and increase respite.*

Stephanie House offers some respite for children with serious behavior issues.

Lack of resources

Overall, respite services are seen to be under-funded. To qualify for SSAH or to get the maximum available resources for respite, one would have to be diagnosed as severe. Even the maximum of $10,000 or $12,000 per year is insufficient for daily respite service when a respite worker is paid at $22/hr.

Some interviewees reported that human resources are also scarce. It can be difficult to find qualified respite workers. As a result, in Waterloo, some SSAH workers end up providing respite services to the same families.

The changing role of the Community Care Access Centre in Waterloo Region illustrates this challenge. The services provided by CCAC are not mandated to serve children with developmental issues but for medically fragile children and adults. However, families and individuals with ASD are referring to CCAC because they are not able to access respite, or sufficient respite, based on the limited funding they have through the SSAH dollars. CCAC tries to expand their eligibility criteria for some of these ASD cases on an individual basis but at best individuals with ASD can only receive limited hours with a personal support worker. In addition, even though some may fit the eligibility criteria CCAC may not be able to find workers who are trained to deal with developmental disorders.

Suggested Innovations: Respite

Recent years have seen a number of creative new initiatives designed to address the need for more respite. The creation of the CHAT online directory of respite workers in Wellington is one example. The shift in focus of Stephanie House away from long-term residents' beds towards the provision of respite is another. Several organizations (like CCAC) are stretching their resources and mandates to help meet the need. In Waterloo Region, Extend a Family and KidsAbility are talking about developing a new program to provide subsidies and 1:1 workers knowledgeable about ASD for day camp programs.

Other suggestions offered for improvement in this area included:

- Increased coordination of respite across the whole community to ensure equal access.
- Development of more integrated respite opportunities that provide children and youth with opportunities to participate in community life.
- Development of a house specially designed to be appropriate for kids with severe behavioural issues could be used by 1:1 respite workers who would otherwise be forced to stay in the child's home.

Other Services

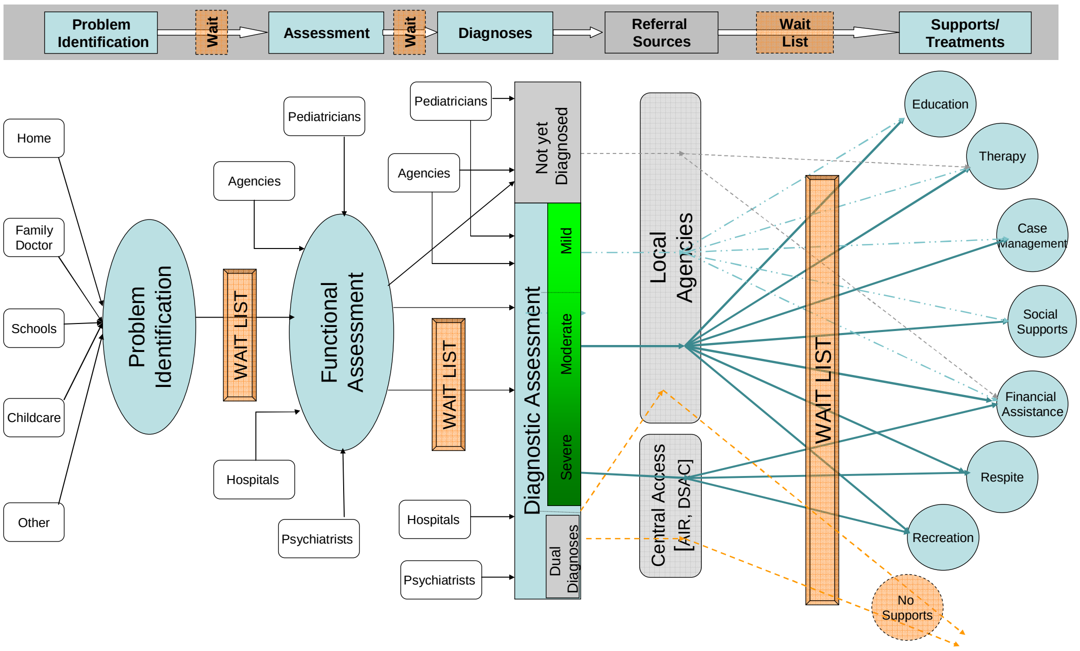
Families of children with ASD also make use of many other kinds of services. For example, some seek guidance from nutritionists. Parents of some children make use of sensory stimulation services such as snoezelen rooms[10]. Others seek out service dogs.

Summarizing the Current Service Pathway

The intent of the figure below is to depict the service pathway, as described above, and to illustrate how the pathway differs for children with specific types of diagnoses. This figure is a generic picture, intended to capture those characteristics of the service pathway that are common to both Waterloo Region and Guelph/Wellington. Key players at the problem identification and assessment stages are listed at left. The six major categories of service are listed at right.

This figure illustrates how responsibility for assessment and referral is diffused. It is difficult to identify any single entity with clear leadership responsibility for case management or parent education.

Current ASD Service Path Model



The current arrangement provides families with much needed support, but it faces a number of challenges. Most pressing among these are:

- the need to share information about ASD and available supports with families, gatekeepers, and other service providers.

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[10] Specially designed rooms for controlled sensory stimulation

- the fact that diagnostic assessment has long waitlists, is time consuming, and not practiced consistently.
- the confusing division of responsibility for referral and case management
- the lack of linkages between support for the child, family supports and informal supports.

Proposed Service Pathway

The findings of this report suggest that an ideal service pathway for children with autism should adhere to a number of key principles.

Key Principles

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. Preventive services need to be family support services that take into account the whole family system.

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

We know from our meetings with parents in Waterloo Region that other parents are often the ones shouldering the burden of teaching newly diagnosed families to access the system. 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.

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.

As leaders in Guelph, Wellington and Waterloo Region continue their efforts to improve the system, 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.

Summary of Recommendations:

Recommendation # 1

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. Ideally, the organization taking leadership in providing this information should not be itself a major service provider. It should have an independent voice and a commitment to monitor availability of all types of service, and to make this information available to all types of families by communicating in a variety of ways.

Recommendation # 2

It is important to ensure that the system of services for children with autism is accessible through a multitude of different “doorways.” Every family faces a unique constellation of challenges and resources, and there must be multiple routes through which services can be accessed. However, the lack of any single entity that plays a leadership role in diagnosis is a major source of confusion and frustration for parents. Fragmentation of services into silos begins at the point of diagnosis. Local service providers should explore the possibility of adopting a common assessment tool.

Local providers should also 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. Although the need for more intensive team diagnoses will persist for children with dual diagnoses or other complexities, the proposed team should be capable of playing a leadership role in a wide range of less complex diagnostic situations.

Recommendation # 3

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.

Recommendation #4

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 waitlist length and would be designed to streamline referrals and facilitate access to services. This database should be linked regionally or provincially.

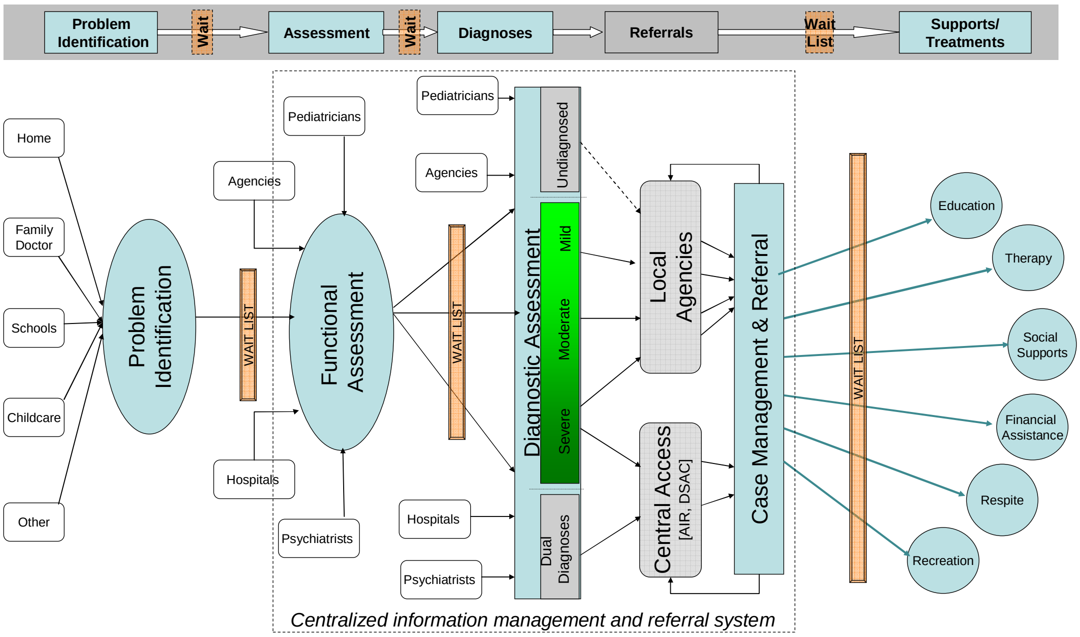
Recommendation # 5

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 a holistic way. The multiple, partial case managers within the service system contribute to parents' confusion.

Ideally, case management should be holistic, inclusive and independent. Referral functions should be considered as one component of case management, and case managers should take a leadership role in making the entire system simpler and more navigable. As part of an extended mandate which also includes more comprehensive centralized referral, AIR and DSAC should consider housing a stronger, consolidated case management function.

The graphic below provides a summary of how a streamlined service pathway might look.

Proposed ASD Service Path Model



Conclusions

This report has made an effort to depict the current system of services for children with ASD in Waterloo Region, Guelph and Wellington. However, this process is never completely finished. Despite the number of interviews conducted, refinements and clarifications of the factual information about available services included here continued even during the process of preparing draft versions of this report. If any inaccuracies remain, the authors take full responsibility.

Despite the complexity of the system, the core messages about the path forward that emerged through this project were clear and consistent. There is a need to raise awareness about autism in general, about services, and about the process of accessing support. Healthy children depend on healthy families, and families need support so that they can make use of multiple supports in a coordinated, strategic way. The management of referrals should support and enable this family-centred planning process. Diagnostic assessment is a bottleneck in the current service pathway, and practical ideas about how to address this challenge are emerging.

Appendix A: Data Collection Tools

Developing a Service Pathway for Children with Autism

Consent Form

I understand that I am being asked to participate in a project aimed at developing a comprehensive service pathway for children with Autism in Waterloo Region and Guelph-Wellington County. The Centre for Research and Education in Human Services was contracted by a project steering committee representing various organizations in Waterloo Region and Wellington County working in Autism to lead this project.

I understand that I have been selected as a key informant who may have some insights into how a service pathway for children with Autism in the Waterloo Region and Guelph-Wellington County could be developed.

I understand that all notes/tapes from this interview will be stored in a locked location to protect my confidentiality. I understand that only with my permission, my name will be included as a part of the key informant list appended in the project's interim and final report.

I understand that this interview will take approximately 45 minutes. I understand that this interview is voluntary and that I may withdraw my participation at any time without penalty. I am also aware that I may decline to answer any question or speak to any issue that I wish not to discuss.

I understand that if I have any questions, I can contact the project lead: Andrew Taylor at (519) 741-1318 x224 at the Centre for Research and Education in Human Services.

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

☐ Agree ☐ Disagree

I agree to have my name listed in the appendix of the final report:

☐ Agree ☐ Disagree

Name (please print):___________________________

Signature:___________________________

Date: ___________________

Developing a Service Pathway for Children with Autism

Key Informant Interview Protocol

Describing Your Services

- What type of services does your organization provide to persons with ASD?
- How are these services provided?
- Who refers to you? What are the criteria for referral?
- Do you have waiting lists? If so, how long are they and how do they work?
- To whom do you make referrals?

Describing the Current System

- Included is a preliminary diagram of available services in your region. Is anything missing from this picture? Is there anything in this picture that you don't feel you know enough about?
- Where do the gaps in the current system exist?
  - Are there people that you are currently unable to serve?
  - Do you ever have situations where you cannot find anywhere to refer a particular kind of client?
- Who most frequently falls through the gaps in the system?
  - Can you give me a concrete example of how this happens?

Recommendations

- How would you recommend the gaps identified be addressed?
- Where should current efforts in Autism service delivery be focused?
- What should a comprehensive service pathway look like?
- Do you have any cautions or concerns about the development of a service pathway? What possible mistakes should we avoid?

Developing a Service Pathway for Children with Autism

Information Letter for Families

Purpose and Scope of the Project
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, Community Mental Health Clinic, Lutherwood, Kerry's Place Autism Services and MCYS. The project outcomes will be linked back to developmental and mental health planning committees in both Guelph - Wellington and Waterloo.

The overall aim of this project is to develop a comprehensive vision about how services for children with Autism Spectrum Disorder (ASD) should be provided. The increasing demands on the service system highlight the importance of such a framework. This project will lead to the creation of a comprehensive "service pathway" for ASD in the Waterloo Region and the Guelph-Wellington County. This pathway will depict the current relationships between various types of services for children with autism (including healthcare, developmental, educational and rehabilitative services), and make recommendations for the creation of a more seamless, efficient and coordinated system.

The specific goals of this research project are:

- To engage community stakeholders including parents and family members in dialogue that leads to
    - Identification of current service gaps
    - Identification of opportunities for coordination and linkages amongst programs to build capacity to deliver service
    - Clarification of routes through which services can be accessed.
- To develop a plan for Guelph-Wellington and for Waterloo that would utilize existing and proposed resources based on a "systems of care" framework in which services from a variety of sectors including mental health, developmental, education and rehabilitation (Speech, Occupational Therapy, Physiotherapy) work seamlessly together.

The service pathway document, once it is created, is intended to:

- Provide a comprehensive inventory of existing Autism programs, related services, and current linkages so that service providers are more aware of the resources and relationships that already exist.
- Act as a point of reference and a planning tool for service providers as they develop care paths for specific families, to ensure that there is "one team with one plan for one child/family"

Project Lead

The Centre for Community Based Research (formerly the Centre for Research and Education in Human Services) was contracted by a project steering committee representing various organizations in Waterloo Region and Wellington County working in Autism to lead this project. The Centre is an independent, Kitchener-based non-profit organization with 25 years experience in community research, program evaluation, needs assessment and planning. In all Centre work, we use a participatory, action-oriented approach.

The Centre is committed to social change and the development of communities and human services that are responsive and supportive, especially to people with limited access to power and opportunity. Demonstrating leadership through research, education and community involvement, the Centre stimulates the creation of awareness, policies and practices that advance equitable participation and integration of all members of our community.

Data Gathering Methods and Use of Data

Several data gathering methods will be used in this project including key informant interviews with professionals and families,, focus groups and document reviews. The data gathered will be used solely to inform the development of the service pathway for ASD.

Your involvement

We would very much like to hear about your experiences with ASD services and supports. We would like to have an informal conversation with you, either by phone or in person, to hear your story about accessing services for your family.

Dissemination and Feedback

After we've received and analyzed your input we will host two community forums as a means of disseminating the findings and allowing for feedback and input from a broader cross-section of individuals and organizations working with ASD. We will also provide you with feedback on the outcomes of the project once it is completed.

For more information please contact

Andrew Taylor, Team Leader
or Jonathan Lomotay
Centre for Community Based Research
519 741 1318 x224 andrew@communitybasedresearch.ca
www.communitybasedresearch.ca

Developing a Service Pathway for Children with Autism

Interview Questions for Families

Problems identification:

1. Can you share the story of your child's journey with Autism with us?
    a. When was the problem first identified?
    b. Who identified it?
    c. What happened after that?
2. When was he/she assessed and/or diagnosed?
    a. How long did you have to wait?
    b. What were the challenges you faced during the period between problem identification and diagnoses?
    c. What services did your family have?
    d. What were the difficulties in accessing these services?
3. What happened after diagnoses?
    a. What services did you have?
    b. How long did you have to wait to get these services?
    c. Do the services meet your child's needs?
    d. What were the challenges you faced during this time?
    e. What would have been helpful during this time?
4. Over all, how would you assess the quality of services your child is receiving?

Appendix B: Inventory of Services and Supports for Children and youth with ASD and their Families in Waterloo Region and Guelph/Wellington

Service Category	Providers in Guelph/Wellington	Providers in Waterloo Region
Functional Assessment	Partners Intensive Program for Wellington County working with families who experience complex mental health and or developmental concerns. Families with mental health will be 0 – 18 and those with developmental concerns 0 – grade 8 working as part of the service collaboration mechanism to ensure that families are getting directed to the appropriate place within the community through regular community services. However if their needs supersede those service offered in the community a referral can be made to the partners program for numerous services. These services are uniquely tailored to the needs of the family and or individual. This program was created by a service providers' network in Guelph & Wellington.	No service directly parallel to Partners exists in Waterloo Region. The service resolution coordinator housed at the children's mental health access centre at Lutherwood sometimes facilitates the development of creative solutions for dually-diagnosed kids with complex needs.
	Kids Ability does assessment for occupational therapy, physiotherapy, therapeutic recreation and social work services.	Kids Ability does psychological diagnostic assessment
	The Wee Talk program does assessment of communication disorders, and also works together with Trellis (CMHC) to do team assessments. They also develop intervention plans around speech & language issues.	
	Healthy Babies, Healthy Children public health nurses and Infant Development workers often make referrals to KidsAbility for diagnosis.	Healthy Babies, Healthy Children public health nurses and Infant Development workers often make referrals to KidsAbility for diagnosis.

Service Category	Providers in Guelph/Wellington	Providers in Waterloo Region
	Trellis also does assessments for school-age kids on occasion, as requested by the school boards or by other community partners.	Lutherwood sometimes does assessments under contract to F&CS or other agencies. Although their primary focus is on assessing child mental health issues, they sometimes end up assessing kids with ASD or a dual diagnosis, especially Aspergers'. This service is not available to the general public.
		Under contract to the Catholic board, CCAC provides speech and language assessment and makes recommendations that are implemented in the classroom.
		DSAC does psychological assessment and diagnosis (or manages access to diagnosticians? Not clear).
Diagnostic Assessment	Grand River Hospital does some diagnosis. Diagnosis is also available from a small number of private practitioners for families who can afford it.	KidsAblity offers psychological diagnosis. Often, a qualified pediatrician can make the diagnosis more quickly. Sometimes the pediatrician and the KidsAbility psychologist work together on a diagnosis.
	Trellis manages a multi-disciplinary, multi-agency team called the Partners Intensive Program that handles diagnoses for more complex cases (also includes Wee Talk, for example).	There is no centralized provider of autism diagnosis in Waterloo Region. Assessments and diagnoses can come from a number of sources. Currently, the three hospitals and several community agencies are offering assessment and diagnostic services of some form. Diagnosis is also available from a small number of private practitioners for families who can afford it.
Referral Sources	AIR is the central point of access to developmental services in Wellington. They provide people with information about supports that are specific to Autism. Such information is obtainable from AIR's website or the Autism Resource Guide. People also call-in and ask for information about Autism.	DSAC is the central point of referral for respite and behavioural consultation, for families of children with autism up to the age of 18. They maintain wait lists for these services. DSAC also refers to CPRI (for emergency inpatient and stabilization treatment).

Service Category	Providers in Guelph/Wellington	Providers in Waterloo Region
		Region of Waterloo Childrens' Services runs the SNAP program, which is the single point of access for special needs services for children, 0—6, attending or planning to attend licensed child care in the Region of Waterloo. KidsLINK is the host agency for a worker who manages all referrals for services currently offered through the seven agencies providing special needs services. These are • KW Habilitation Services - Preschool Outreach • KidsLINK - Preschool Support Services • KidsAbility - SPOT Program • Elmira & District Association for Community Living - Preschool Services • Community Living Cambridge - Preschool Services (formerly Cambridge Association for the Mentally Handicapped) • Developmental Services Access Centre - Preschool Assessment Services • Family & Children's Services – to assist children in care who are accessing child care
	The Autism Society of Ontario (Wellington Chapter) offers referral and advocacy for services on behalf of persons with Autism and Pervasive Development Disorders (PDD) and their families.	K-W Habilitation Services runs the Preschool Outreach program. ECE Resource Consultants work with parents to help them find appropriate child care and other needed supports.
	A binder (called "In the Loop") has been created by the Wellington Development Services Planning Group that itemizes autism services in Guelph and Wellington.	Both school boards, working together with key local service providers, published "community connections: A resource guide on support services for individuals of all ages with special needs."

Service Category	Providers in Guelph/Wellington	Providers in Waterloo Region
	Trellis manages access to children's mental health services in Guelph and Wellington.	The Children's Mental Health Access Centre run by Lutherwood & KidsLINK is a centralized access point for mental health services. However, like DSAC and AIR, it does not manage access to all forms of mental health service. Hospitals, for example, are not part of the Access Centre.
		KidsAbility is the central point of access for speech and language services for children aged 0-5.
Child Care and Education: for children	Trellis runs the Special Needs Child Care program which provides support to front-line staff in child care centres who are working with children who have special needs.	K-W Habilitation Services runs the Preschool Outreach program. It includes ECE Resource Consultants, Kinesiologists and ECE Support Teachers who work with any licensed child care setting to facilitate the inclusion of children from 0 to 6 years of age who have developmental delays.
	KidsAbility provides OT and PT services in support of the Special Needs Child Care program.	The Elmira and District Association for Community Living and Community Living Cambridge both provides Resource Teacher services to children with developmental delays between the ages of 2 and 5 years. This service is available to families at home or at a child care setting.
		KidsAbility runs the SPOT program, which consists of workshops for child care workers designed to enhance the development of children in the Region of Waterloo licensed child care settings.

Service Category	Providers in Guelph/Wellington	Providers in Waterloo Region
	The New Heights New Hopes program run by both school boards and a coalition of local service providers is an orientation for parents of children who have developmental difficulties and ASD. It tells them what kind of services they can expect while the children are in school and the model of service for children with special needs. It is held in the spring of the school year. Any school in Upper Grand with a significant number of kids on the spectrum who also have a developmental disability is designated as a hub school. Erinoak consultants bring training and additional resources to hub schools. Also, the ministry assists in providing resources if needed. In some schools there are congregated classrooms with a maximum of 10 students. All EA's working in hub schools are specially trained in ASD, partly through the new program at the Geneva centre. Students receiving IBI have school schedules adapted to their needs.	WCDSB: Children with autism are fully integrated. All schools have spec ed teachers. Ed assistants are also available depending on site and needs. Depending on the needs of the child kids can be withdrawn to provide for their need. There are itinerant child and youth care support workers. In May & June of each year, case conferences with service providers are held to manage the transition into school for new students.
Treatment & Therapy	St Joseph's and KidsAbility together offer stay and play social skills groups for kids under 6.	Under contract to the Catholic board, CCAC provides OT and physiotherapy to school-age autistic children.

Service Category	Providers in Guelph/Wellington	Providers in Waterloo Region
	Wee Talk is the Speech and language service provider for Guelph/Wellington for all kids up to kindergarten age.	Kids Ability runs Preschool Autism Services, which includes: Speech and language service provider for the Region of Waterloo. Provided though individual sessions and/or small groups where children can practice communication skills. o Occupational therapy, physical therapy o Social work (e.g. Intake, supporting the family through the assessment, counselling sessions for the parents who may be grieving etc.).
	KidsAbility implements and manages IBI therapy through a contract with Erinoak. It also offers OT, PT, therapeutic recreation and social work services.	KidsAbility implements and manages IBI therapy through a contract with Erinoak.
	Trellis provides children’s mental health services including assessment, treatment, coordination and parent support.	KidsLINK children’s mental health services offer some services to “grey zone” kids who do not have a formal or complete diagnosis. Although this was not planned, it is an effort to meet the needs of kids who are otherwise falling through the gaps.
Case Management	Family Counseling and Support Services offers supportive counselling and advocacy services for all individuals and families including those with ASD.	Waterloo Region Wraparound works on a long-term basis with 18-25 families per year. They deal with families who present needs that cannot be met by any one service and work with the entire family. They assist families in accessing resources. They work with children from 0 -18 who have a dual diagnosis, mental health or developmental disorder. Develop plans of action looking at all the life domains areas. Sources of referrals can come from agencies or the families themselves. Partner with DSAC. Located out of KW Counselling. There is no cost for this service.

Service Category	Providers in Guelph/Wellington	Providers in Waterloo Region
	Kerry's Place offers time-limited consultation services for both children and adults, using a mediator model to help identify goals. This work may involve schools or places of employment. They work with children and youth of all ages, and especially with youth 10-16.	If needed, the various specialists at KidsAbility will do a collaborative assessment and plan for the family. However, this case coordination is limited to services provided to the family by KidsAbility.
	The Infant Development program at Trellis offers service coordination, parent support and growth monitoring for young children including those with ASD.	Region of Waterloo Children's Services runs the infant development program, which includes • Developmental Clinics • Early Intervention Services • Parent-Child Drop In • Specialized Workshops • Case Management • Support Groups • Developmental Screening • Developmental Assessment • Child Development Information • Linkages to other services.
	The Partners Intensive Program (described above under assessment) is also, in part, a case-coordination service. If a dually-diagnosed family's needs supersede those service offered in the community a referral can be made to the Partners Program for numerous services. These services are uniquely tailored to the needs of the family and or individual.	

Service Category	Providers in Guelph/Wellington	Providers in Waterloo Region
	A service resolution facilitator is housed at Trellis. This person works with families who are in crisis because the plans made so far by various service agencies have been unsuccessful. The service resolution facilitator is part of a collaborative team which gets the top people together to talk about what can be done to meet the crisis or contain the crisis.	DSAC has a service resolution coordinator who specializes in autism and works directly with about 20 families. The role of this person is similar to the service resolution facilitator housed at Trellis.
Family Supports	Kerry's Place offers intensive in-home support for families experiencing behavioral difficulties with their autistic children (as part of a larger program run in partnership with Family Counseling).	KidsAbility runs parent training programs for families involved with IBI.
	Family Counseling offers the Passport coordinator program for adults with ASD coming out of high school.	Lutherwood runs a number of family support services that are open to all families dealing with mental health issues including those who have a child with ASD. These services include: Family Counselling Services Youth Employment Services
	KidsAbility runs parent training programs for families involved with IBI, and offers social work services to families.	Together in Community is a support group for parents of children with ASD meeting 4 times per year. Meetings are held at one of the participants' home. They also run a youth group for youth between the ages of 13-25 with ASD
	Kerry's Place runs a resource library out of a location in Orchard Park.	
	The Autism Society of Ontario (Wellington Chapter) offers mutual support, and information to persons with Autism and Pervasive Development Disorders (PDD) and their families.	Autism Society chapters also exist in Waterloo and in Cambridge.
	Wee Talk runs a parent training program for ASD families.	

Service Category	Providers in Guelph/Wellington	Providers in Waterloo Region
Financial Assistance	The SSAH program, managed through Trellis, can be used by families to purchase a variety of types of service, including 1:1 support, community integration, respite, camp fees, transportation costs, housekeeping or other similar types of service. Trellis employs 4 SSAH coordinators and 1 recruitment and training coordinator. SSAH workers are hired directly by families.	Extend a Family manages the Special Services at Home (SSAH) program. EAF hires and supervises staff on behalf of families, which is different than the model used in Wellington. SSAH includes kids with autism. You are eligible if • You have a developmental challenge and are living at home (any age) • You have a physical disability, are living at home and are under the age of 18. Although DSAC does assessment for most of the services it works with, EAF does its own assessment for the purposes of SSAH.
	In special cases, the Ministry of Children and Youth services has advocated for funding for families in crisis. Sometimes this takes the form of one-time funding for a specific situation. In other cases, the ministry makes and effort to invest in such a way that other families in similar situations can benefit as well. Often such funding comes as a result of a recommendation from a multidisciplinary assessment team like the Partners program.	In special cases, the Ministry of Children and Youth services has advocated for funding for families in crisis. Sometimes this takes the form of one-time funding for a specific situation. In other cases, the ministry makes and effort to invest in such a way that other families in similar situations can benefit as well. Often such funding comes as a result of a recommendation from a multidisciplinary assessment team like the ones housed within KidsAbility and Lutherwood / KidsLINK.

Service Category	Providers in Guelph/Wellington	Providers in Waterloo Region
Respite & Recreation	The Community Care Access Centre sometimes provides respite support to families and individuals with ASD. In these cases, families are referring to CCAC because they are not able to access respite, or sufficient respite, based on the limited funding they have through the SSAH dollars. CCAC tries to expand their eligibility criteria for some of these ASD cases on an individual basis but at best individuals with ASD can only receive limited hours with a personal support worker. In addition, even though some may fit the eligibility criteria CCAC may not be able to find workers who are trained to deal with developmental disorders and therefore the problems of respite for families with ASD individuals is not solved.	KW Habilitation Services is mandated to serve children with developmental disabilities including ASD. They provide respite for children 6-18 years of age. Services are provided for 3 out of 4 weekends per month and they are able to serve approximately 6 children per weekend. All referrals are made through DSAC.
	The CHAP program, run through TRELLIS and Family Counseling, supports families in using SSAH funds. It includes four full-time SSAH Coordinators and one part-time SSAH Recruitment and Training /CHAP Coordinator. The CHAP Program aims to find a large base of workers interested in supporting persons with developmental disabilities including autism and/or physical disabilities to provide meaningful respite opportunities through community based options. Families are able to connect with workers after viewing worker profiles. Special Services At Home funding can be used to pay for independent respite work. Agencies are able to access workers to enable individuals to participate in community based respite opportunities.	Parents for Community Living have 8 group homes but only 1 home serving children. It is located in Waterloo for children up to 18. (2 permanent beds and 4 respite beds) and provides weekend and day respite. Referrals are made solely through DSAC.

Service Category	Providers in Guelph/Wellington	Providers in Waterloo Region
	One element of CHAP is a website called respiteservices.com that enables families and workers to register and link with one another.	Kids Link provides respite for two weekends a month every 1st and 3rd weekend of each month from September to June with extended hours over Christmas and extended hours over March break All referrals for this service must come through DSAC All meals are provided. Services are available to kids aged 5-12. Serves 6-8 children per session and is seeking funding to expand this to 12-14. These respite programs are heavily staffed (about 2 kids:1) in order to be able to serve kids with behavioural issues.
	Kerry's Place offers some limited respite, mostly on a project basis for limited periods of time. They also run social groups for children and adults, including an ongoing group for families dealing with Asperger's.	Extend a Family offers respite workers to families with children who have a developmental disability. Often, EAF SSAH workers also provide respite services. Access to respite services is via DSAC and it has a long waiting list Extend-A-Family also runs summer camps programs and manages "summer enrichment" dollars. Generally they integrate kids into mainstream summer camps.
	The Autism Society of Ontario runs a program through which families can obtain two weeks of partially funded one-on-one care or special needs camp experience for their special child.	

Service Category	Providers in Guelph/Wellington	Providers in Waterloo Region
	Hopewell Children's Homes Stephanie House is a five-bedroom house providing residential respite care for children up to the age of 18 who are experiencing behavioural challenges resulting from ASD, dual diagnosis or other causes. Stays range from 1 day to one month. Respite services also include: day respite support for children with a worker	Lutherwood offers short-term, 5-day respite housing through the Safe Haven program at Betty Thomson Youth Centre for you aged 12-15.
	KidsAbility runs teen groups for adolescents with developmental disabilities. These groups focus on building social skills and are also a form of respite.	Fee-for-service respite is available through Sunbeam Lodge and Pioneer Youth Services.
Other Services	KW Habilitation Services operates a snoezelen room to provide visual, olfactory and tactile stimulation to children and adults with a disability. Users of the room must come with a staff member from the referring agency who has specialized training in the use of the room.	The Guelph-Wellington Association for Community Living operates a snoezelen room to provide visual, olfactory and tactile stimulation to children and adults with a disability.
		National Service Dogs is a non-profit organization based in Cambridge that breeds, trains and places Labrador and Golden Retrievers with children who have autism. They work with families across Canada. Children must be between the ages of 2 and 8 at the time of application. Families interested in getting a service dog typically play an active role in fundraising the $18,000 required, and must also participate in training. The wait list for a service dog is currently 1 year.

Service Category	Providers in Guelph/Wellington	Providers in Waterloo Region
Systems Integration & Service Provider Training	The Wellington Developmental Services Planning Group (which includes Family Counseling, Trellis, and many others mentioned above) has been working to augment the existing continuum of respite supports in Guelph-Wellington. This group encompasses all developmental services for both children and adults.	Child Care Special Needs Resourcing Partnership (CCSNRP) is a partnership of 7 community agencies who work together to create and support child care services that meet the special needs of children and their families in Waterloo Region. CCSNRP meets monthly to confirm the provision of services for children with special needs, identify system wide priorities and challenges, and supports the service coordination of referrals from parents and community professionals to the Child Care Special Needs Access Point. The mandate of CCSNRP is narrower than that of WDSPG.
	Kerry's place offers capacity development services (e.g., training, workshops to community groups etc).	Kerry's place offers capacity development services (e.g., training, workshops to community groups etc). For example, they are working with KidsAbility right now to help them think through how social groups could be offered in waterloo on a train the trainer model.
	Erinoak and the Geneva Centre both run various types of service provider training programs.	Erinoak and the Geneva Centre both run various types of service provider training programs.