

The Integration of Health and Social Services for  
Young Children and Their Families  
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Report Prepared By:  
John D. McLennan & Michelle Caza

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Research Team:

Principal Investigator: John D. McLennan<sup>1</sup>  
Co-Investigators: Michael Boyle<sup>2</sup>, Robin McWilliam<sup>3</sup>, D. R. Offord<sup>2</sup>, Kent  
Rondeau<sup>4</sup>, and Debbie Sheehan<sup>5</sup>  
Research Coordinators: Michelle Caza<sup>6</sup>, Ellie Deveau<sup>2</sup>

Corresponding Investigator:

Dr. John D. McLennan  
Departments of Community Health Sciences  
University of Calgary  
3330 Hospital Drive NW  
Calgary, AB T2N 4N1  
Telephone: 403-210-8673  
Fax: 403-270-7307  
E-mail: [jmclenna@ucalgary.ca](mailto:jmclenna@ucalgary.ca)

Website: [www-fhs.mcmaster.ca/cscr/integration](http://www-fhs.mcmaster.ca/cscr/integration)

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<sup>1</sup> Departments of Community Health Sciences and Psychiatry, University of Calgary (previously at the Department of Psychiatry and Behavioural Neurosciences & the Offord Centre for Child Studies, McMaster University)

<sup>2</sup> Department of Psychiatry and Behavioural Neurosciences & the Offord Centre for Child Studies, McMaster University

<sup>3</sup> Division of Child Development, Vanderbilt University Medical Center, Vanderbilt University

<sup>4</sup> Department of Public Health Sciences, University of Alberta

<sup>5</sup> Public Health and Community Services, City of Hamilton

<sup>6</sup> Department of Community Health Sciences, University of Calgary

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Alberta Stakeholders: Alberta Children's Services; Alberta Health and Wellness; Alberta Learning; Alberta Mental Health Board; Aspen Regional Health Authority; Capital Health; Child and Adolescent Services Association; Edmonton and Area Child and Family Services Region 6; Region 7 North Central Alberta Child and Family Services Authority.

Ontario Stakeholders: Chedoke Child & Family Centre, Hamilton Health Sciences Corporation; Haldimand-Norfolk R.E.A.C.H.; Health & Social Services Department, Haldimand-Norfolk; Integrated Services for Children, Ministry of Community and Social Services/Ministry of Health and Long-Term Care; Ministry of Community and Social Services, Municipal Services, Hamilton; Public Health and Community Services, City of Hamilton; The Catholic Children's Aid Society of Hamilton; The Children's Aid Society of Hamilton.

Though many people and agencies were involved in this project, participation in this study should not be taken as endorsement of this final report. The opinions, results and conclusions are those of the authors and no endorsement by the Ontario Ministry of Health and Long-Term Care or any other funder is intended or should be inferred.

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## **KEY IMPLICATIONS FOR DECISION MAKERS**

A variety of health and social services exist for young children and their families although they were not initially developed in an organized or strategic way. There are now multiple attempts to integrate existing services. However, integration efforts do not often appear to be driven by an understanding of present service patterns or empirical research findings. This places integration efforts at risk for failing to make significant impacts on outcomes for children and their families. The findings from this study provide information to reduce this risk.

- An “integration-to-outcomes” model has been developed which identifies the pathways by which service integration efforts could improve clinical and functional outcomes. This tool could be used to guide and/or evaluate integration efforts.
- Stakeholders identified delivery of appropriate mental health services to child welfare clients as an ongoing problem. Without substantial support at multiple levels and significant new funding, children with mental health problems in the child welfare sector will continue to be inadequately served.
- Mapping out service utilization patterns of actual family experiences of seeking care for their young children was helpful in identify problems in service delivery, such as “dead-end” pathways and service clumping. Service utilization maps may be a useful tool to help identify problems in the service system, rather than reliance on perceptions and anecdotes.
- Though potentially inefficient, existence of multiple entry points into various services may decrease the impact of barriers to accessing services. Centralized intake efforts may address the inefficiencies, but should be rigorously evaluated to ensure that new barriers are not created.

## **EXECUTIVE SUMMARY**

A variety of health and social services exist for young children and their families although they were not initially developed in an organized or strategic way. There are now multiple attempts to integrate existing services. However, integration efforts do not often appear to be driven by an understanding of present service patterns or empirical research findings. This places integration efforts at risk for failing to make significant impacts on outcomes for children and their families. The findings from this study provide information to reduce this risk.

Four health regions were selected for this study (a rural and urban area in both Alberta and Ontario). Key approaches included individual interviews and focus groups with parents, service providers and administrators, the construction of service utilization maps, document reviews, and the development and distribution of a service utilization survey for parents of young children with special needs.

### **OBJECTIVE 1: Develop a theoretical model that attempts to link service integration to improved child and family outcomes.**

Our model proposes that a service integration effort must work through at least one of the following pathways in order to have an impact on child and/or family outcomes: (i) increase the extent to which services are effective; (ii) increase the use of services by underserved populations; and (iii) improve the timing of service delivery. This model may be useful for both planning and evaluating integration efforts.

**OBJECTIVE 2: Identify factors that influence service utilization for children with mental health problems in the child welfare system.**

The child welfare and child mental health sector interface was identified as one of the most common integration challenges. In particular, the difficulty in providing adequate mental health services for children in the child welfare sector was highlighted. Gross underfunding of the child welfare and mental health sectors, differing mandates, and inadequate support for substantial reform efforts limit movement forward in resolving this service problem. Without substantial support at multiple levels and significant new funding, children with mental health problems in the child welfare sector will continue to be inadequately served

**OBJECTIVE 3: Explore the use of service utilization maps to understand the organization of services and to identify service integration problems.**

A group of parents with young children with special needs were interviewed in detailed about services their children had received. This information was converted into pictorial displays, which provide useful depictions of the organization of services. Specific problematic patterns were identified within the service variations experienced by families. One problem pattern was labelled the “dead-end pathway.” In this pattern, a service provider did not provide a referral to specialty services so the parent took another service route. Service clumping was another pattern identified. Here some families received an “explosion” of service linkages following attendance at a tertiary care or specialty centre. Mapping actual service utilization patterns may be a useful strategy for exploring and evaluating the state of service organization in a community.

**OBJECTIVE 4: Investigate entry points into the service system.**

There was substantial variation in the pathways families took to enter specialty services. Common pathways to speciality care occurred via family physicians, community paediatricians and early intervention projects. Much of the participating families' experiences predated recent popular centralized intake efforts in the study regions. Though centralized intake efforts may provide more transparent pathways to specialty care, the previous existence of multiple entry pathways may have circumvented some of the dead-ends in the system of referrals. Centralized intake processes and other integration efforts should be rigorously evaluated to ensure that they enhance service delivery rather than create additional access barriers.

**OBJECTIVE 5: Develop a survey to explore key service utilization issues and problems faced by parents of young children with special needs.**

Over 200 parents with children with special needs from four different specialty centres participated in a survey to further identify service utilization patterns and associated difficulties. Analyses of this survey data are ongoing. One section of the survey had parents identify the most problematic area of service delivery. The top five concerns were:

(i) having to repeat the child's story to different professionals over and over again; (ii) a lack of information about services for their child; (iii) having to navigate the health and social services systems; (iv) long wait lists for assessments; and (v) an overall lack of services for their child. Parent surveys may be useful in evaluating the service system if they include specific service questions rather than only inquire about general satisfaction.

## **BACKGROUND**

Multiple government and non-government agencies have invested resources into a broad array of health and social services to improve the health and well-being of young children who have developmental or mental health difficulties. Historically, the development of these services has not occurred in an organized, strategic, or coordinated way. In recognizing that children and their families often have need of services from different agencies, there have been multiple efforts to integrate existing services. However, integration efforts do not often appear to be driven by an understanding of present service patterns or empirical research findings. This places integration efforts at risk for failing to make significant impacts on outcomes for children and their families.

Empirical findings from service integration experiments in the child mental health field have failed to demonstrate improved outcomes with increased integration of services. The Fort Bragg Study and the Stark County Study compared children who received services in a system of care model with those who received traditional services. Both found that there were no improvements in the clinical or functional outcomes for children in the integrated system of care despite increased service utilization and increased costs (Bickman, 1996; Bickman et al., 1997; Bickman et al., 1999). Another study of children's services found a negative relationship between the extent of inter-organizational service coordination and service quality (Glisson & Hemmelgarn, 1998).

These important findings do not mean that integrating services is an inappropriate reform effort. However, they do mean that integration efforts or greater integration cannot automatically be assumed to lead to improved service delivery and outcomes. Careful consideration of existing service patterns, mechanism of change, and empirical

research finding may inform integration efforts such that there is a greater likelihood that such a system level change will result in improved child and family outcomes.

## **OBJECTIVES**

The key objectives of this study were to:

- Develop a theoretical model that attempts to link service integration to improved child and family outcomes;
- Identify factors that influence service utilization for children with mental health problems in the child welfare system;
- Explore the use of service utilization maps to understand the organization of services and to identify service integration problems;
- Investigate entry points into the service system;
- Develop a survey to explore key service utilization issues and problems faced by parents of young children with special needs.

## **METHODS**

Four health regions were selected for this study (a rural and urban area in both Alberta and Ontario). Key methodological approaches included individual interviews and focus groups with parents, service providers and administrators, the construction of service utilization maps, document reviews, and the development and distribution of a service utilization survey for parents of young children with special needs.

### **A. Interviews and Focus Groups**

Semi-structured interview schedules were used for the individual interviews.

Providers and administrators were asked about their concept of integration, barriers and

facilitators of integration, difficult relationships with other sectors and how to improve the current arrangement of services for young children. The opinions and experiences of parents were also solicited in interviews regarding the services their child had received and problems with those services.

Individual interviews were transcribed verbatim and entered into the qualitative software program, NVIVO. Selected data from the focus groups and from government and other documents was also entered into NVIVO. Using an editing analysis style, members of the research team identified key themes. As key themes emerged, questions were incorporated into upcoming interviews to seek additional confirming and disconfirming data in an iterative process.

## **B. Service Utilization Maps**

The complexities of the service system that parents face were not always readily captured by text. Hence, the research team developed service utilization maps, a pictorial representation of the pathways parents took to obtain services. The interviewers used these as a tool in the interview to increase respondent recall and to maximize the accuracy of the data. The maps were analyzed by the team to identify patterns of services as well as to identify entry points into the service system, particularly into specialty health, education, and social services.

In addition to being a data-gathering method, the service utilization maps proved useful in analysis. Patterns of service delivery were identified and classified and hypotheses were generated. These maps were also presented to administrators and providers in several interactive dissemination activities.

## C. Survey

A parent self-report survey was developed and distributed. It asked for information on service utilization by parents whose children had received assessment and/or treatment at specific clinics for children with developmental and/or mental health problems in four specialty centres in three different health regions<sup>7</sup>. The purpose of this survey was to obtain additional data on service utilization to complement the information gathered in the qualitative interviews. The survey respondents constituted a larger and more representative sample to explore some of the early findings from the qualitative interviews and service utilization maps. The survey covered a number of areas including age at diagnosis, professionals seen, referral patterns between professionals, types of services received, and problems related to obtaining services.

The survey was developed in conjunction with a literature review, as well as with stakeholder and expert input, including a pilot of parents similar to the population of interest. Stakeholders reviewed the survey and many of their suggestions were incorporated into it. The survey was distributed to 1,095 parents who had had their child seen at one of four specialty centers between October 2000 and October 2002 and whose birth date fell after October 1996. The anonymous survey was sent out by each of the specialty centres.

A total of 235 surveys meeting the eligibility criteria were returned, for a response rate of approximately 22%. The response rate was lower than anticipated for this survey. Techniques to increase response rates such as telephone call follow-ups or targeted re-mailings could not be employed as the research team did not have access to the mailing list

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<sup>7</sup> Three of these centres provide services for clients beyond their specific region. Specialty clinics within the following four tertiary centers participated: Glenrose Rehabilitation Hospital, Edmonton; Child and Adolescent Services Association, Edmonton; Chedoke Child and Family Centre, Hamilton; and Haldimand-Norfolk R.E.A.C.H.

from the clinics and the surveys were anonymous (that is identifying information was purposely not included on the survey instrument). Though there may be some concerns about the representation of all children attending these centres (e.g., it may under-represent families of lower socio-economic status), it still represents a sizeable population of special needs children and the sample does contain a broad range of families with different socio-economic backgrounds and different child health problems.

Analyses of the survey data are presently underway. Initial univariate and bivariate analysis has been completed on parts of the data and some of these results are provided below. Other results will be forthcoming and presented at stakeholder meetings, posted on our website, and prepared for academic manuscripts.

## **RESULTS**

### **A. Integration-to-Outcome Model**

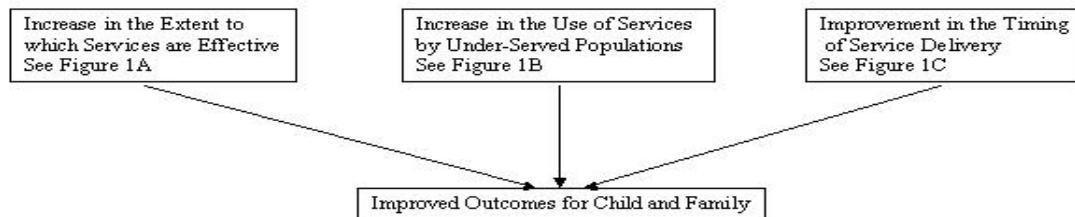
There was little operationalization as to how given integration efforts would actually impact child and family outcomes in the existing integration efforts considered in the study communities. The assumption appeared to be that the integration efforts would lead to positive outcomes despite the lack of identifiable mechanisms linking integration to outcomes. However, empirical research findings have demonstrated that improved outcomes cannot be assumed to occur even when there is some success in improving the extent of service integration.

To address this strategic gap, a model was developed that identifies specific mechanisms that need to be worked through in order for given integration efforts to have an impact on child and family outcomes. It would seem unlikely that positive outcomes would be achieved if integration efforts are not working through these pathways.

The model responds to two core questions. First, how can a change in direct services improve outcomes? And, second, how can service integration lead to a change in direct services?

Direct services could include any type of intervention service including clinical treatment, prevention or supportive directed toward the child and/or family. Figure 1 identifies three changes in direct services that could lead to improved outcomes for children and their families: (1) increase in the extent to which services are effective; (2) increase in the use of services by underserved populations, and (3) improved timing in the delivery of services.

Figure 1: Three Types of Changes in Direct Services

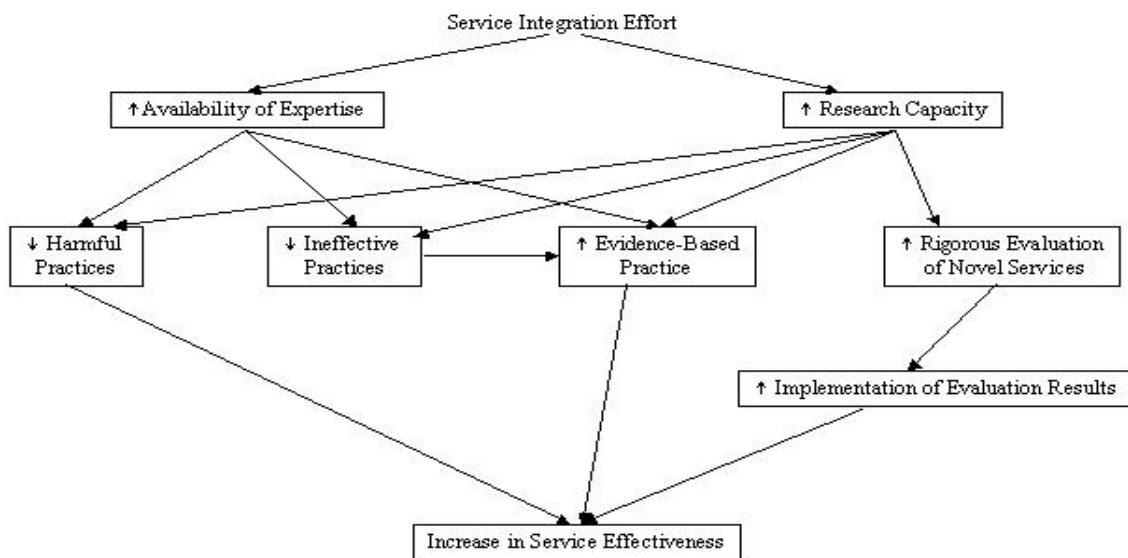


The next step is to determine how integration could lead to one or more of these three direct service changes. For example, how could integrating services lead to increasing the extent to which services are effective? Key pathways are to increase the availability of clinical or intervention expertise and research capacity, which in turn increases the likelihood

that ineffective or harmful services are decreased or eliminated and evidence-based practices are implemented (Figure 1A). Questions to be asked of an integration effort follow.

- Does the given integration effort...
  - ...increase the availability of expertise?
  - ...increase research capacity?
  - ...decrease the use of harmful practices?
  - ...decrease ineffective practices?
  - ...increase the use of evidence-based practice?
  - ...lead to the rigorous evaluation of novel services?
  - ...lead to the appropriate response to findings from the rigours evaluation of novel services?

Figure 1A: How Service Integration Can Lead to More Effective Services



Though there may be a tendency to assume that much of the existing interventions are evidence-based or at least effective and hence to assume that this component is covered, such assumptions are likely unfounded. There remains a critical need for stakeholders to scrutinize more closely the evidence for proposed and/or existing interventions.

Figure 1B illustrates how a service integration effort could result in an increase in service utilization by underserved populations. For planning or evaluation efforts, one should ask if the integration effort:

- ...increases access to new populations in the service system?
- ...increases outreach capacity to new populations outside the service system?
- ...increases the volume of services?
- ...introduces or expands screening and/or identification?

Figure 1B: How Service Integration Can Lead to an Increase in Service Use by Under-Served Populations

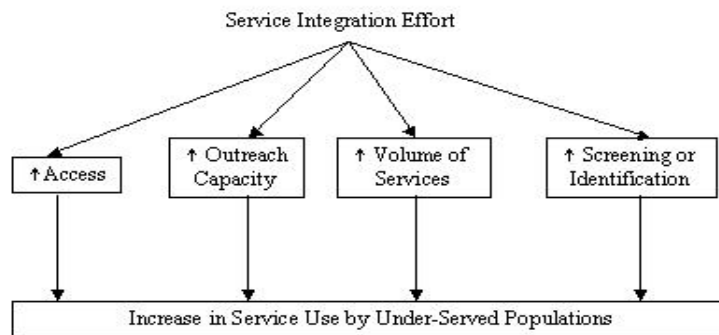
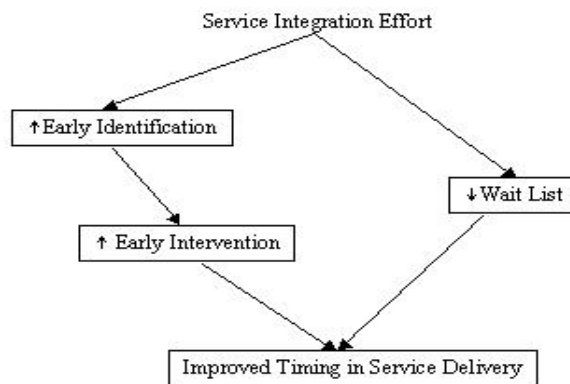


Figure 1C illustrates how a service integration effort could lead to improvements in the timing of the delivery of services. Does the integration effort lead to:

- ...earlier identification such as through screening or inclusion of experts?
- ...earlier intervention for those identified through earlier identification?
- ...the reduction of wait lists?

Figure 1C: How Service Integration Can Lead to Improved Timing in Service Delivery



There is overlap and interaction between these various pathways. The failure to address all pathways could undermine the potential impact of any single area of improvement.

## **B. The Interface between Child Welfare and Child Mental Health**

Included in the interview schedule were a number of questions regarding problematic relationships with other professional groups and/or other sectors. Several respondents indicated that the relationships between mental health and child welfare was very important but frequently problematic, and perhaps more so than the interface between other sectors. Hence we focused part of our inquiry on the interface between child mental health and child welfare. More specifically, we explored difficulties in obtaining mental health services for those children in child welfare with such needs.

Several focus groups and individual interviews were conducted with different stakeholders. In addition, there was a review of the literature. Several factors were identified that appeared to influence service utilization for children with mental health problems in the child welfare system. These included:

- Lack of service offerings in both mental health or child welfare sectors, in particular:
  - Lack of early intervention;
  - Lack of services for children needing the most restrictive care;
  - Lack of long-term care.
- Lack of awareness of the accessibility of service offerings of one sector by the other.
- Differing mandates between the two sectors.
- Difficulties posed by families not adhering to recommendations.
- Lack of mechanisms to bring mental health and child welfare together at an operational level.

- Transition problems for older children in child welfare exiting the child mental health systems and entering the adult mental health systems.

In addition to identifying difficulties, stakeholders proposed possible solutions to some of these difficulties.

- Increasing collaboration by establishing multi-disciplinary teams for complex children and multi-service centers and by including staff from the two sectors in relevant agency meetings as well as encouraging informal liaison.
- Providing educational and/or professional development opportunities to increase the awareness of mental health issues, and to communicate mandate issues and available services.
- Increasing advocacy efforts directed towards the ministerial levels to (a) change political will regarding the provision of adequate services to children in the child welfare system, (b) increase funding and (c) establish “pools” of funds sectors can draw upon for clients who “straddle” multiple sectors.
- Stakeholders proposed introducing mental health screening of children in the welfare system to improve identification of mental health needs. However, caution was also raised given the potential to identify children through screening but having little to no services to offer.

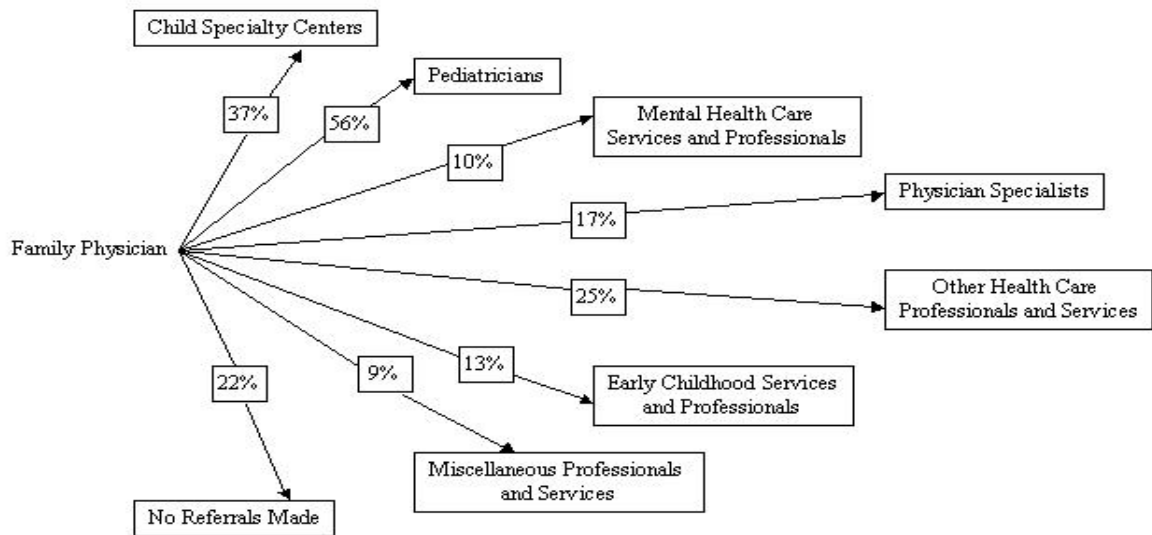
A recurrent theme was gross under-funding of both child mental health and child welfare.

There is clearly not enough capacity to address the current need. Though integration efforts may help to address some issues, their impact is likely to be minimal without substantial expansion of services through new funding.



In our survey data (discussed in more detail below) we found that 22% of those families who had a family doctor did not receive any specialty referral from him or her for their child. However, in the majority of cases, family doctors facilitated referrals to specialty centres or further assessment by a pediatrician (see Figure 2B). It is important to note that children and families considered in our study were recruited from specialty centres and hence we are unable to comment on the families who do not find alternative pathways to specialty care after a dead-end.

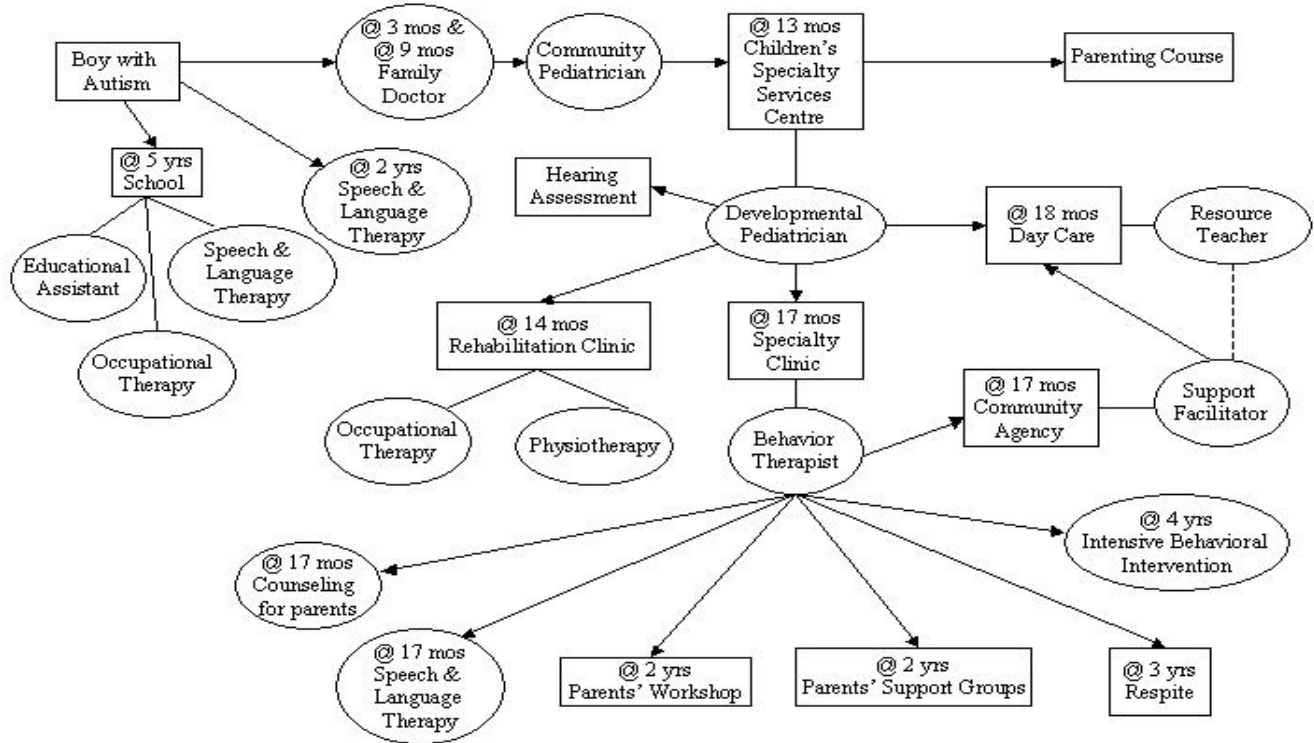
Figure 2B: Physician Referrals to Professional Services



Service clumping is a phenomenon where a family receives a broad array of assessments and services once they arrive at a specific point in the service system. This tended to occur once a child entered one of the specialty centres. An example of this is

illustrated in Figure 2C<sup>9</sup>. Though the child and family may have needs that require multiple assessments, professionals and services, this pattern may also contribute to waitlists and unequal distribution of services within finite service systems.

Figure 2C : Service Clumping



Some of the service utilization maps were quite complex with multiple pathways and many providers and assessments. Parents were typically the case managers and needed to navigate these complex pathways. Multiple entry points into specialty services may provide a necessary redundancy in the service system given the existence of dead-end pathways, but they may also lead to confusion and inefficiencies.

<sup>9</sup> Boxes indicate organizations; circles indicate professionals and services who may or may not be attached to an organization; straight lines indicate the professional or service is part of an organization while lines with arrows indicate referrals to a professional or service. Dashed lines indicate a relationship exists between the two services or professionals.

Additional service utilization maps are posted on the study's website at [www-fhs.mcmaster.ca/cscr/integration](http://www-fhs.mcmaster.ca/cscr/integration).

#### **D. Service Utilization Survey**

Analyses of the survey results are ongoing. The survey includes a sample of 235 young children with special needs who received an assessment and/or treatment at one of four specialty centres. Children included in this study had a broad array of serious developmental and/or mental health difficulties. Approximately 27% of the respondents indicated their child had been diagnosed with an autistic spectrum disorder. Other common diagnoses included communication disorders, developmental delays, attention deficit hyperactivity disorder, fetal alcohol spectrum disorder and reactive attachment disorder.

Among the questions included in the survey, parents were asked to rate the extent to which 19 different service delivery problems were an issue for them. The five posing the greatest problems for parents were: (i) having to repeat the child's story to different professionals over and over again; (ii) a lack of information about services for their child; (iii) having to navigate the health and social services systems; (iv) long waitlists for assessments; and (v) an overall lack of services for their child. In contrast, there was minimal concern regarding their child receiving too many assessments or having inconveniently scheduled appointments.

We have further analyzed data on the 64 children with autistic spectrum disorders in our study sample. Family doctors were the most common professionals to have seen these children first with regard to parental concerns about the child, followed by the pediatricians. The mean number of professionals seen by the children was 5.8 (SD 2.1)

with a range from two to eleven (not including the family doctor). Speech and language pathologists were the most common professional seen, followed by occupational therapists. Pediatricians were by far the most common referring agent. Their referrals included a broad array of professionals with other pediatricians (typically developmental pediatricians) being the most common referral group. Self-referrals and schools were the next most frequently identified referral agents. Further analysis of the data from this subsample is ongoing as is analysis of the entire sample. Select findings will be posted on the study's website ([www-fhs.mcmaster.ca/cscr/integration](http://www-fhs.mcmaster.ca/cscr/integration)), presented at upcoming meetings with stakeholders, and submitted in manuscript form to peer reviewed journals.

## **DISSEMINATION STRATEGY**

Several strategies have been used in an attempt to engage stakeholder partners throughout the study as well as disseminate preliminary findings from the study. The strategies included: (i) updating and discussion group meetings with stakeholders; (ii) individual meetings with stakeholders; (iii) newsletters sent to stakeholders; (iv) promotion of our website to stakeholders; and (v) e-mail solicitations of input of stakeholders at various points. The first two strategies engaged stakeholder participants the most, while the latter three generated little feedback. High turnover of representatives from some partnering agencies impeded participation.

We continue to update our website ([www-fhs.mcmaster.ca/cscr/integration](http://www-fhs.mcmaster.ca/cscr/integration)) to include further findings from ongoing analysis. The site describes the project, lists publications and presentations on the study, provides a sample of service utilization maps, provides preliminary results from the survey and discusses the “integration-to-

outcomes” model. The website was promoted in all communications with stakeholders, including parents who participated in the survey.

Several additional presentations are planned, particularly small group activities for targeted stakeholder groups, including:

- Presentation of survey results on service utilization patterns for children with autism to the (i) Chedoke Child and Family Center and R.E.A.C.H., Hamilton, Ontario Spring 2004 and (ii) the Autism Society, Spring 2004, Edmonton, Alberta.
- Presentation of survey results on service utilization on young children with special needs to staff at Glenrose Rehabilitation Hospital and at Child and Adolescent Services Association, Spring 2004, Edmonton, Alberta.
- Presentation of the “Integration-to-Outcomes” Model at a Joint Policy Forum for the new Ministry of Children’s Services of the Ontario Government, Spring 2004, Toronto, Ontario.

Preliminary results have been presented at several academic events including:

- The Canadian Public Health Association (CPHA) 94<sup>th</sup> Annual Conference, May 2003, Calgary, Alberta (*Exploring Service Utilization Patterns to Inform Child Service Integration Efforts*).
- Fourth International Interdisciplinary Conference: Advances in Qualitative Methods, May 2003, Banff, Alberta (*Exploring Service System Problems of Children with Special Needs through Service Utilization Maps*).

- The 31<sup>st</sup> North American Primary Care Research Group (NAPCRG) Annual Meeting, October 2003, Banff, Alberta (*The Role of the Primary Care Physician in Facilitating Access to Services for Special Needs Children*).
- American Academy of Child & Adolescent Psychiatry, 50<sup>th</sup> Annual Meeting, October 2003, Miami Beach, Florida (*Pathways into Child Specialty Services*).

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