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DATE 9 August 2000

TO/DEST. Coordinator, Community Services Committee

FROM/EXP. Social Services Commissioner

SUBJECT/OBJECT **SERVICES FOR FRANCOPHONE CHILDREN WITH AUTISM**

PURPOSE

This report which is for the information of the Community Services Committee and Regional Council provides information on the service needs of francophone children with autism, the gaps in services, and the planning initiatives and system changes currently underway at the Regional and Provincial level. The report also outlines a process, which the Social Services Department has embarked upon to address current needs while the service system is in transition.

BACKGROUND

At its meeting of May 4, 2000, the Community Services Committee heard a presentation on the current lack of services available to parents of francophone children with autism. In response to the presentation the Committee considered and approved the following recommendation:

CSC Motion No 55(00):

That the Social Services Department be directed to investigate the lack of services for francophone children with autism and report back to the Community Services Committee on how the Region can assist in addressing the gaps in service.

CURRENT SITUATION

Annex A of this report contains a background paper which addresses the service needs of francophone children with autism, the services available, the gaps in service, the planning initiatives

and system changes underway in the funding, planning and delivery of services at the provincial and regional level that impact on these gaps, and the issues to be addressed in transition.

It is clear from the material presented in that paper that the difficulties faced by families with children diagnosed with the autism spectrum disorder are well documented and that significant gaps in services particularly for francophone children have been identified.

The Province of Ontario through the Ministries of Community and Social Services and Health is the major player in both the funding and management of services available to address the needs of this population. The Region's current role in this system is limited to the funding and management of child care services for this population which are delivered, primarily by Children's Integration Service and Thursdays' Child Nursery School.

In its system management role the Province has acknowledged the need for changes in this area and has conducted two significant planning exercises (The Developmental Services Restructuring Project and the Health Service Restructuring Project). The Developmental Services Restructuring Project which is described in more detail in the background report has resulted in several changes which include a single point of access through Service Coordinator case workers located at the Child Development Service, additional resources to address the volume of assessments and additional parental support and psychological resources. In addition, in May 2000 the Province announced that the Ottawa Children's Treatment Centre had been selected as the lead agency to integrate four programs, Behaviour Management Program, Child Development Program, Communication Development Program (Children at Risk) and Infant Development Program under one governance structure. The goal of the integrated model is to streamline and simplify the service system for families. Particular attention is being paid to ensuring that services can be provided in both official languages.

The Province has also announced significant new funding for services and training through the Provincial Early Intervention Program for Children with Autism. In June 2000 the Province announced that for Eastern Ontario this project will be co-sponsored by five agencies with funds flowed to the Children's Hospital of Eastern Ontario. A management group is currently being formed to direct this initiative. The goal is to begin providing service to families based on individualized service plans in the fall of this year.

Implementation of the recommendations of the restructuring projects and program development related to increased funding are currently in progress and significant change will occur in the next year. During this transition period the Social Services Department will look at interim measures to support francophone families based on their individual needs.

PLAN OF ACTION

The Department has met with the Ministry of Community and Social Services and with the major service providers in this area. We are currently working with the Child Development Service

(CDS) at the Children's Hospital of Ontario (CHEO) to review the needs of individual francophone families whose children have been diagnosed with the autism spectrum disorder. Once this process is complete if there is sufficient demand, we will provide funding on an interim basis for a segregated program. This service will be established in a cost effective manner using existing resources where possible. At the same time the Department will be involved in an advisory capacity in the implementation of the recommendations of the Developmental Services Review and will monitor the implementation of the Provincial Autism Initiative. Future directions for child care funding for children with Pervasive Developmental Disorder and Autism will be addressed in the Child Care Service Plan.

*Approved by
Dick Stewart*

Attach. (1)

SERVICES FOR FRANCOPHONE CHILDREN WITH AUTISM

1. Purpose

This document will address service needs of francophone children with autism, the services available, the gaps in service, the planning initiatives and system changes underway in the funding, planning, and delivery of services at the provincial and regional level that impact on these gaps, and the issues to be addressed in transition.

2. Background

Over the past five years in Ottawa-Carleton, it has been well documented that the services available to meet the needs of children with Pervasive Developmental Disorder (PDD), including autism, have not been adequate to meet the many complex needs of these children and families. Several planning and system redesign initiatives have documented unmet needs and gaps in service. Francophone children have been particularly identified as a group requiring an enhanced level of service.

Since these needs were documented multiple planning and restructuring initiatives at the provincial and local level have resulted in numerous changes to the funding, organization, delivery and quantity of services available. Several changes have already been made and it is expected that the implementation of further changes will have an impact on the services available to meet the needs of children with autism and their families. However, as not all changes have yet been implemented it can be expected that there will be a period of transition before all historical gaps in service will be addressed and remedied. The capacity for the system to respond on an individual basis will be necessary throughout the transition phase.

These planning and restructuring initiatives include:

- The provincial Preschool Speech and Language Services Initiative resulting in the creation of First Words Preschool Speech and Language Services under the umbrella of Pinecrest-Queensway Health and Community Services (1998);
- The role of municipalities as child care delivery agents in the provision and funding of child care services as a result of amendments to the Day Nurseries Act (1998) and the Services Improvement Act (1998);
- Ministry of Community and Social Services Making Services Work for People and the Reinvestment Strategy for Children and Youth and system changes resulting from the Developmental Services Restructuring Project (1999);
- The growing recognition of the importance of the early years and the resulting partnership that has created Success by 6/6 ans et gagnant (1999);
- The introduction of the provincial Intensive Early Intervention Programs for Children with Autism (2000);

- The Health Restructuring Commission's recommendations resulting in a shift in the funding and delivery of most of the specialized psychiatric and mental health services for children sixteen and under from the Royal Ottawa Hospital (ROH) to the Children's Hospital of Eastern Ontario (CHEO) (2000).

3. Pervasive Developmental Disorder and Autism

Recent planning initiatives for the early years have resulted in the availability of considerable descriptive and demographic data for this age group.

Success by 6/6 ans et gagnant, using information from the Region of Ottawa-Carleton Health Department, estimates that there are approximately 67,700 children in the Region from birth to age 6. It is further reported that approximately 1% of these children are estimated to have a developmental disability (*Funders Working Group, 1999*).

The census conducted in 1997 for the Developmental Services Restructuring Project provided the first unduplicated count of children receiving these services: 432 children age birth to 6 (380 English-speaking, 57 French-speaking). [Note: these numbers did not include children on waiting lists or children who had not yet been identified and were therefore considered to be an under representation of the true need for service.]

In its Request for Proposals for Regional Intensive Early Intervention Programs for Children with Autism, it is estimated that between 1 and 2 per 1000 children require intensive behavioural intervention as a result of a diagnosis of an autism spectrum (*MCSS, December 1999*).

This report identifies the variation in diagnostic terminology in the literature and clinical practice. The report states that "autism can be viewed as the prototypical form of a continuum or spectrum of disorders known as Autism Spectrum Disorders which vary in severity but have certain common core symptoms."

The Diagnostic and Statistical Manual of Mental Disorders 4th Edition (DSM-IV) describes Autistic Disorder as one of the disorders that falls within the spectrum of Pervasive Developmental Disorders (PDD). The diagnostic features include:

- The presence of markedly abnormal or impaired development in social interaction and communication and a markedly restricted repertoire of activities and interests. Impairment in language development and communication is also marked and sustained and affects both verbal and non-verbal skills.
- By definition the onset of Autistic Disorder is prior to age 3 years and must be manifest by delays or abnormal functioning in at least one of the following areas prior to 3 years of age: social interaction, language as used in social communication, or symbolic or imaginative play. There is typically no period of unequivocally normal development. Approximately 75% of children with autism will have an associated diagnosis of mental retardation (DSM-IV).

The Report of the Developmental Services Children's Program Design Team states that "children diagnosed with communication disorders such as Pervasive Developmental Disorder and/or Autism present with specific difficulties with social interaction, connecting with their

environment, delay in spoken language, and stereotypical repetitive behaviours. Behaviour problems range from mild to severe aggression and outbursts." (*Allan and Koch-Schulte, 1997*)

Research on early brain development has proven that experiences in the first months and years of life has a profound influence on a child's development, health throughout life, behaviour and coping skills. It is now well recognized that the earliest possible identification, diagnosis, and intervention with a range of high quality therapeutic interventions is of particular importance for children with special needs.

The MCSS Request for Proposals summarizes the research and highlights the finding that when children with autism receive intensive intervention that begins at the earliest possible opportunity and is provided by well-trained therapists, children can make lifelong gains that exceed what was previously expected (*MCSS, December 1999*).

A diagnosis of autism or pervasive developmental disorder has enormous impact on the child and family. In addition to the availability of intensive services designed to meet the child's needs, parents need tremendous support throughout the process of identification and diagnosis of autism and throughout the intervention process. Support to find and access timely services, counselling, parent education, case management services, and adequate respite supports are essential.

4. Overview of Children's Developmental Services

As a result of the planning and restructuring initiatives identified in Section 2. the delivery system for children's developmental services has undergone many changes and is on the verge of implementation of major changes outlined in Section 5. The services and resources presently available are as follows:

- At the present time there are eight agencies funded by MCSS with developmental services dollars to provide diagnostic, assessment, intervention and support services to families and children from birth to age eighteen with a developmental delay, or at risk of delay, in the Ottawa-Carleton area.
- In addition MCSS child care dollars fund Children's Integration Support Services at Andrew Fleck Child Care Services and Thursday's Child Nursery School for anglophone children at Children at Risk.
- Children's mental health dollars fund the Kindergarten Day Treatment program at the ROH which provides service to several children with PDD/autism.
- In addition to services provided by agencies families are eligible for financial support through **Special Services at Home** (MCSS) to hire aids for in-home respite and behaviour support.

The developmental services programs are more fully described as follows:

- **Child Development Services** (CDS) at CHEO serves children in a multidisciplinary approach for diagnostic services from birth to age 18 for Eastern Ontario. Treatment and therapy, consultation and support are provided from birth to school-age for children in Ottawa-Carleton. Following assessment and diagnosis other community supports, services and funding

programs can be accessed. (Other services provided by CDS through Child Care funding allow for interventions in home, clinic or preschools. Special Needs Funding provides for home based therapies for children with physical and/or developmental disabilities). Services are available in English and French.

- **The Infant Development Program (IDP)** at Centretown Community Health Centre works with families of children with, or at risk of, developmental delay, through home-visiting and other activities to provide early intervention to children from birth to 4 years 11 months. The goal of the program is to promote the functioning and well-being of the children referred. Services are available in English and French.
- **Children At Risk** serves children from age 2-18 years with autism or pervasive developmental disorder by home visiting assessments and programs based on the Lovas model. The objective is to improve the child's communication, social and behavioural skills. Limited service is available in French.
- **Ottawa-Carleton Behaviour Management Program** at the Children's Aid Society is mandated to serve children and adults of all ages. Counsellors support families to maintain their children with developmental disabilities at home, in the school and community. The goal of the services is to promote independence and community integration by teaching new skills and reducing or eliminating behaviours which are dangerous, interfere with attaining new skills or prevent participation in the community.

[Note: As outlined in Section 5, as of June 2000, the Ottawa Children's Treatment Centre has the mandate to take the preceding four programs under its governance structure.]

- **Ottawa-Carleton Association for Persons with Developmental Disabilities (OCAPDD)** provides an Anglophone and a Francophone Respite service for children with a developmental disability (including PDD/autism if a developmental disability is present), with some restrictions. Children that are pre-school aged, have severe behaviour problems, or require extra equipment such as wheelchairs and cribs, are not eligible. The program is provided in two sites: Lavonne for Anglophone children and Bathgate for Francophone children.
- **The Ottawa Rotary Home** provides out-of-home respite to families of children and young adults from birth to 21 years of age. Eligibility is restricted to those with a physical disability, with or without a developmental disability as well. There are 8 beds plus 1 emergency bed and 275 families registered. Respite is available for French and English speaking children.
- **Ottawa Valley Autistic Homes (OVAH)** serves individuals with Autism in two long-term residences. Four children and youth between 12 and 21 years of age are receiving service through a Purchase of Service agreement with the Children's Aid Society. Service is provided for French and English speaking children and youth.
- **Service Coordination** serves families of children by providing Case Management services to school age children. Service is provided in English and French and is limited to families who do not receive case management assistance from other providers. The goal is to assist families to access supports and services, assist with future planning, and help parents become their own case managers when possible. Two case managers for children birth to age six are co-located

with Child Development Service at CHEO. **The Special Services Worker Bank** program at Service Coordination is funded by Special Services at Home (MCSS) as a resource to families. The Bank provides the families with workers to interview who can carry out developmental programming and provide parental relief. Parents pay them with funding received from Special Services at Home or Handicapped Children's Benefit. The workers are not employed, or directly supervised by Service Coordination.

5. Planning, Consultation, and System Changes to Services for PDD/Autism

Since 1996 the multiple restructuring initiatives that have been undertaken have had an impact on the services and supports available to children with autism and pervasive developmental disorder and their families. Consultation with parents and professionals highlighted the complex needs of these children and the gaps in service. Numerous system and service changes have come about or are in the implementation stage and are summarized as follows:

▪ **Preschool Speech Language Services**

In 1996 the provincial government announced increased funding to develop and enhance preschool speech and language services. The District Health Council (DHC) led a Task Group to review existing services, consult with parents and service providers and develop a plan to invest the new resources in an improved coordinated system of services.

The Comprehensive Plan for the Development of a Preschool Speech and Language Service System in Ottawa-Carleton (*DHC, 1997*) made numerous references to the service needs of children with pervasive developmental disorder (including autism), highlighted gaps in the service system particularly for francophone children, and identified the need for more resources. Two of the report's fifteen recommendations related to the needs of these children:

Recommendation 11

Recognizing the needs expressed throughout the consultation process and the significant increases in the number of children identified with pervasive developmental disorder, it is recommended that some additional resources [with both English and French components] be allocated to support development of speech and language services for children with PDD/autism.

Recommendation 12

Reflecting the current levels of confusion in roles and mandates of agencies providing services to children with pervasive developmental disorder, it is recommended that there be additional planning undertaken collaboratively by the service providers working in this area to enhance communication, and streamline the system. The need for enhanced resources recommended through this planning process should then be reevaluated.

Following acceptance of the plan, First Words was formed as a partnership under the leadership of Pinecrest-Queensway Health and Community Services and received \$1 million to deliver preschool speech and language services. One FTE position is designated to provide services for children with PDD/autism with a capacity to provide service in English and French. An additional .5 FTE is designated for children with special needs (including PDD/autism) to support programs in reducing waiting time for service.

▪ **Children's Developmental Services and Reinvestment in Early Intervention**

In 1997 the provincial government released Making Services Work for People, the Ministry of Community and Social Services plan to restructure Developmental Services and Services for Children. At the same time, the Ministry initiated the Reinvestment Strategy for Children and Youth which was designed to shift resources to effective models of intervention for children from birth to age six.

In Ottawa-Carleton the Developmental Services Restructuring Project conducted an extensive review of services and service delivery. The Report of the Children's Design Team summarized the review and consultation related to services for children with developmental disabilities (*Allan and Koch-Schulte, 1997*). In addition to the many recommendations to improve access coordination and delivery of developmental services to children, specific recommendations addressed the identified gaps for children with PDD/autism:

"It is recommended that the needs of children with pervasive developmental disorder/autism be particularly considered, including adequate clinical and direct therapy resources; adequate intensive early intervention for young children; access to out of home respite; behavioural support; community outreach; professional education and parent training." With respect to french language services it was further recommended that increased investment address "services to [francophone] children with PDD or autism and their families, specifically with respect to in-home supports and behavioural supports and direct clinical therapies."

The final Report of the Developmental Services Restructuring Project supported the recommendations of the Children's Design Team and numerous changes were recommended to improve access and delivery of services. Implementation by the Ministry of Community and Social Services of these recommendations and decisions related to the Reinvestment Strategy have resulted in the following changes:

- A single point of access through Service Coordination replaces the multiple intake systems of several agencies. Service Coordination case managers are now co-located at Child Development Service to improve coordination.
- Additional reinvestment resources have been provided to Child Development Service to address the volume of assessments. A Parent Support Worker and two FTE psychologists have been added to respond to the full spectrum of developmental disabilities including PDD/autism, and to provide supervision to behavioural support workers. These positions have the capacity for service in English and French.
- The Ministry of Community and Social Services conducted a Request for Proposals for a lead agency to integrate the four major programs providing children's developmental services, and announced in May 2000 that the Ottawa Children's Treatment Centre (OCTC) was the successful agency to integrate Behaviour Management Program, Child Development Program, Communication Development Program, and Infant Development Program under its governance structure. A Project Coordinator is being hired and an Interim Transition Committee, Family Advisory Committee and French Language Services Reference Group are being put in place to manage and guide the integration process.

"The new integrated model will have the capacity to provide a single point of access, eliminate any existing duplications and address waiting time for service and streamline and simplify the service system for families . . . and be able to provide services in both official

languages." (*OCTC, 2000*)

▪ **MCSS Early Intervention Program for Children with Autism**

In 1999 the province announced a \$15 million dollar initiative for an Early Intervention Program for Children with Autism under the Office of Integrated Services for Children. A Request for Proposals was issued in December 1999 for regional programs to provide intensive early intervention services to families and children age five and younger with autism. The funding is intended to provide individual service plans; intensive behavioural intervention; parent and professional training; and program evaluation. Services will be "sensitive to the family's values and preferences, cultural context, and language, including being available in French in designated areas." (*MCSS, December 1999*)

In Eastern Ontario the population for age 2 to 5 was estimated to be 54,741 children. Of this group of children the Ministry estimated that between 1 and 2 per 1,000 would require intensive behavioural intervention services. On that basis the projected allotment for Eastern Ontario was \$1,433,493.

In June 2000 the Co-Sponsors of the successful proposal in Eastern Ontario were advised. Five organizations will co-sponsor the new program including:

- Centre psycho-social pour enfants et familles d'Ottawa-Carleton
- Children's Hospital of Eastern Ontario
- Groupe Action - Hawkesbury
- Renfrew County and District Health Unit
- Stormont Dundas and Glengarry Developmental Services

The funds will be flowed to the Children's Hospital of Eastern Ontario. A Regional Management Group is being formed to direct and manage the implementation of the new program and will be chaired by Dennise Albrecht, Director of External Development for the Children's Hospital of Eastern Ontario. Their goal is to begin to provide services by September 2000.

▪ **Specialized Psychiatric and Mental Health Services Redesign**

The Transition Planning Steering Committee of the Royal Ottawa Hospital (ROH) and the Children's Hospital of Eastern Ontario (CHEO), in partnership with the Ministry of Community and Social Services and the Ministry of Health, is managing the redesign of Specialized Psychiatric and Mental Health Services for children and youth in Eastern Ontario (SPMHS). Communique #3 (1999) outlined the agreements for roles for the two hospitals. The hospitals are planning within existing resources.

The Children's Hospital of Eastern Ontario will be responsible for most specialized services for children up to the age of sixteen, while the Royal Ottawa Hospital will develop specialized services for youth 16-18 years of age. CHEO also has the mandate to provide services to children and youth with developmental disabilities and psychiatric disorders (dual diagnosis) up to 18. The hospitals are finalizing their proposed plan which will then be distributed for broad community consultation. The ROH Kindergarten Day Treatment program presently serves several children with PDD/autism. The implementation of SPMHS will therefore result in a transition process for families as the new SPMHS delivery model is developed. A partnership with the Developmental Services sector, which has the lead for children with

autism, will be established to ensure that the needs of children with PDD/autism are met within the new developmental services continuum.

6. Transition Issues for the Region of Ottawa-Carleton

Time will be required for implementation and program development related to increased funding and restructuring. In the interim it will be necessary for the developmental services sector in partnership with other children's services to have the capacity to address individual service needs. The Ottawa Children's Treatment Centre has made public its intention to make the transition process as smooth as possible with minimal disruption in service to clients. The Ministry of Community and Social Services has demonstrated a willingness in the past to fund individualized plans in partnership with service providers on an as needed basis.

The Developmental Services restructuring envelope did not include the funds for Children's Integration Support Services at Andrew Fleck or for Thursday's Child at Children at Risk, although representatives from both organizations participated in the consultation and planning process. Recommendations in the Children's Design Team Report and in the Final Report of the Restructuring Advisory Group supported their continued collaboration and joint planning as the new system develops.

The funding for the Communication Development Program presently provided by Children at Risk will shift to the Ottawa Children's Treatment Centre. It will be important for the Region to participate in the planning process and address the most appropriate role and location for Thursday's Child in the new continuum of services for children with PDD/autism. This will also present an opportunity to address the lack of a French component as a comprehensive continuum is planned.

Over the past several years there has been a strong trend towards integration of children with special needs. The creation of Children's Integration Support Services in shifted resources from a group model to an approach that supports individualized integration in mainstream early childhood programs. This approach is supported by the Ministry of Community and Social Services in its policy directions and funding decisions. Le Regroupement des services de garde has also supported this approach. There is a broad body of research and clinical literature that outlines the benefits of integration.

A review of the literature on effective interventions for preschool age children also provides support for a broad range of interventions, including intensive group intervention, that are well matched to the needs of the child and the wishes of the parents. The concept of a continuum of service that offers a range of program options and opportunities for varied intensity of service depending on a child's needs is well supported in the literature. The system changes and program development that is presently underway provide an opportunity to ensure a balance of programs and interventions are in place to ensure a comprehensive continuum that allows for intensive individual and group intervention and also supports ample opportunities for integration.

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