

**For Immediate Release
To Canadian Media and All Canadian Political Parties**

November 15, 2000

**Universal Health Care's Forgotten Children
The story of Canada 's Medicare orphans**

The federal government and the provincial governments have failed miserably to ensure that adequate health services meet the five conditions of the Canada Health Act for children with autism. Essential, universal, accessible, comprehensive, publicly administered and portable, autism treatment is NOT being delivered to **thousands of Canada's young children** who suffer from one of the most serious neurological disorders of the brain, autism spectrum disorder and related pervasive developmental disorders.

On the front page of the Toronto Star newspaper on November 14, 2000 Allan Rock is quoted as saying "To me, two-tier means paying out of pocket for things that should be provided publicly, ... [and] If an MRI is medically necessary it should be provided publicly, it's as simple as that." This is exactly the problem for Canadian families who urgently require early childhood treatment of autism for their young sons and daughters.

On the matter of essential specialty autism treatment for young children, today across Canada there is a two-tiered health care service with almost no essential intensive treatment in the public health care system. The current treatment choices are between grossly unavailable to virtually non-existent universal health services, and available but unaffordable high cost therapy that families must purchase privately, often using treatment planning, supervision and training from experts in the United States.

Canada's Prime Minister the Hon Jean Chretien and his Health Minister the Hon Allan Rock proclaim themselves to be the protectors of a universal health care system that provides medically necessary services to all Canadians on the basis of need and not the ability to pay. This is not true for young children with autism. Instead for these children in Canada there is a medicare tragedy of major proportions.

Autistic children have a neurological disorder that interferes with their day to day function. They live a lot in their own minds. They have motor, sensory and cognitive difficulties. They have great difficulties learning communication skills including language, and many will remain profoundly handicapped. They don't know how to interact socially and therefore are frequently excluded from peer groups. They play by themselves alone at home, day care or school. They exhibit self-stimulation

behaviors such as rocking, head banging and flapping their hands in front of their eyes.

Autism is not a rare condition. Although estimates of the prevalence rates for autism spectrum disorder in the general population vary with improved clinical recognition, an accurate and conservative estimate is that it affects one in every 500 to 1,000 people. There are indications that in the future that autism may become as common as one in 250 people or lower. It is more common in the pediatric population than cancer, diabetes, spina bifida, and Down syndrome.¹ In comparison to US rates there are likely between 6,000 and 11,500 children under 15 years of age in Canada who meet diagnostic criteria for autism.

Autism is a medical disability just as cancer is. Both require specialty treatment. Without autism treatment, the future is bleak for these young children. It is well known that without treatment autism is a lifelong condition that results in placement of over 90% of untreated children in group homes and institutions. Only one in 64 children will show any improvement without treatment.

However, with early and intensive treatment amazing and positive results occur in large numbers of children.

As the Ontario Government reports on its web site, “Until recently, only a small proportion of children with autism were expected to achieve independent functioning as adults. Most were expected to require life long health, education and social services. That expectation is now changing with evidence that outcomes for many autistic children can be dramatically improved when they receive intensive early intervention services.”

The miracle is that with individual one-to-one intensive behavioral therapy of 35 to 40 hours a week, begun at an early age and provided over several years with trained therapists, full remission of the disorder of autism is possible almost 50% of the time.

In fact, with intensive early behavioral treatment almost all children can show dramatic improvement. This therapy, sometimes called ABA or applied behavior analysis, is so effective that in later grades at school, 40% to 50% of children who have received treatment are able to function as regular students. They have excellent grades, functional communication skills and social skills. Classroom teachers can not distinguish many from other students when not told which children are autistic.

¹ Filipek, P., Accardo, G., Baranek, E., Cook, Jr. G., Dawson, B., Gordon, J., Gravel, C., Johnson, R., Kallen, S., Levy, N., Minshew, B., Prizant, I., Rapin, S., Rogers, W., Storne, S., Teplin, R., Tuchman and Volkman, F. 1999: “The Screening and Diagnosis of Autistic Spectrum Disorders”, **J. of Autism and Dev. Disorders**. Vol 29, 439-484. [p 440]

With such effective treatment available it is a national shame that ordinary Canadian children and their parents have been abandoned by the health care system designed to serve them. Citizens of Canada have to be wealthy or mortgage their family home in order to pay for essential treatment needed by their autistic children. Indeed, with few exceptions, proper therapy for a young child with autism is only afforded by wealthy Canadians at a cost of \$45,000-\$60,000 a year.

The Prime Minister of Canada claims that he is committed to making universal health care work better. Well it does not work for children with autism.

In the year 2000, in every province across Canada preschool and older children are being denied “medically necessary” services to which they are entitled by law under not just under the Canada Health Act, but under Canada’s Constitution and various provincial statutes.

The Canadian tragedy is more than just the extreme neglect of this medical condition by Canada’s universal health care system. Worse still is that provincial governments and their health and social service ministries who are responsible for ensuring that childhood cancer is treated, regularly and irresponsibly continue to refuse medically necessary treatment for children with autism. Where is the leadership needed by the federal government?

It is very painful for families with young autistic children to witness all political parties in the current federal election profess commitment to universal health care. These families know that even as the politicians speak today, medically necessary and urgent needs of their children are being ignored. The result is that their children will suffer a life long sentence of severe and permanent disability.

It is an undeniable fact that provincial governments across Canada are actually withholding services from small children who suffer this serious brain disorder. Even when parents have taken provincial governments to court and won, some governments still refuse to provide adequate funding of medically necessary treatment services.

For example, the BC government, which is an NDP government, has appealed the case of Auton et al. versus the government of BC through the Attorney General and the Medical Services Commission. The crown lost the case this year in the Supreme Court of British Columbia. In this case Madame Justice Allan agreed with the families and their autistic children who were petitioning the court that the government was discriminating against the petitioners and violating their constitutional rights by failing to provide effective treatment for autism. [para 156 and 158]

Justice Allan wrote in her conclusions that “The infant petitioners suffer from a serious mental disability for which effective treatment in the form of ABA is available. The inability of the petitioners to access that treatment is primarily an

issue of health care, not education or social services. [para 153] The court also wrote that "The Crown and specifically the Ministry of Health, provides no effective treatment for the medical treatment of autism." [para 154]

Believe it or not the BC government's argument, rejected by the judge, was that their failure to provide effective treatment for children with autism was justified on the basis " that its health care resources are limited and that the effect of funding treatment for autistic children would direct resources away from other children with special needs." [par 145]

In Alberta, on paper and in policy the government has done better than in BC. Since May 27, 1999 the child and family services authority may on the diagnosis of a medical practitioner, provide funding ranging from \$45,000 to \$60,000 per child for in-home, early intensive behavioral intervention for up to 40 hours a week for up to three years. That sounds good, except the responsible provincial ministry regularly and repeatedly denies these benefits to which people are entitled under law. The practice is so common that a parent organization in Alberta called FEAT, for Families for Early Autism Treatment, has on its website specific guidelines on how to appeal.

In Ontario, the provincial government has begun to put in place what in the future may become a clinically good service. The government is to be commended for investing an \$19 Million to start a province wide program called Integrated Services to Children [with Autism]. This is a funding and training vehicle to establish a network of autism services for preschool children across the province. The goal is to provide intensive treatment to children under 6 years of age.

But after months of setting up local service providers across the province that are funded and directed by Integrated Services for Children, few children have been approved as eligible, too few therapists have been trained and hardly any children have received treatment.

Further, there are huge problems with the program that are not being addressed.

The Ontario program with its local preschool autism service agencies in place is currently denying services to **hundreds** of young children under the age of six years because the province has not provided even 25% of the money needed to treat this brain disorder in Ontario's children.

The government is not being responsive to a huge surge of requests for service that can only be described as of epidemic proportions. In some areas applications for service are more than 50% higher than anticipated last summer.

The response by the new preschool autism service programs to coping with their totally inadequate budgets is horrific. Instead of getting more funds to treat a condition that is recognized as critically in need of early intervention, families are

being denied essential services. Because of totally inadequate funding by the Government of Ontario some local programs are planning to deny service to over 50% of the autistic children who have applied for intensive behavioral treatment.

Service providers are busy trying to determine eligibility of large numbers of applicants for treatment with inadequate numbers of staff. There are too few psychologists to review files and complete eligibility interviews. There are too few staff who are trained and ready to start individual therapy with children. There are too few senior therapists to supervise the treatment plans, the front-line therapists and liaise with families.

Staff makes political rather than clinical decisions as they try to dole out a totally insufficient service equally across a politically defined geographic area, spreading a little here and a little there.

Parents have been told that because the province intends to discharge children from the program when they reach 7 years of age, six year old children are a priority before they no longer qualify for service within the next 12 months. Meanwhile children under 5 years of age who because of age have a better treatment response are less of a priority and grow older while they wait. It is wrong to have these kinds of arbitrary cut-offs. This hurts children of all ages. .

Organizing services for children by age only works if there is a comprehensive range of service that is sequential and continuous, without gaps between the age categories. For example, kindergarten and grade 1 would not be followed by kicking children out of school at the end of grade 2. That would be ridiculous. The problem is easily resolved if all children get the autism treatment that they need, for as long as they need it, whether they are under or over 7 years of age.

Further, staff are making decisions on whether to prioritize the more severely disabled leaving the moderately disabled further down the list.

Worse, is that the mildly afflicted autistic children are being **denied** service altogether. These families have been told that they can find appropriate services in the community. This is patently untrue.

All of the preschool autism service programs are too poorly funded to give adequate intensity of treatment to all applicants. This is not universal, accessible or comprehensive treatment as guaranteed under the Canada Health Act.

Is this any way to treat children whose needs are so critical that if they don't start intensive behavioral intervention at the earliest possible age and carry on with it as long as they need it, they will lose a tremendous developmental advantage? It is common knowledge that all preschool children learn language much faster and easier than when they get older. It is well known that if the brain networks of young

children are not appropriately stimulated that atrophy and unnecessary loss of intellectual capacity will occur. The critical need for early autism therapy is also well documented over the past 25 years in scientific studies of the treatment effects of applied behavior analysis, now also referred to as intensive behavioral intervention. **This does not mean that public agencies should be directed by government policy to stop treatment for autistic children at age 6 or 7 years.**

Treatment sensitivity to key developmental stages of life is critical if autistic children are to get maximum benefit from treatment. Time is of the essence for young children with autism. The province of Ontario is doing too little too late.

Further, it is also public knowledge amongst families with autistic children that because of inadequate budgets local programs are planning to offer only about half of the level treatment needed to get the best possible treatment outcome.

Generally, Ontario programs are planning to offer a maximum of only 20 hours of treatment a week while it is common knowledge among parents and experts that based on the scientific literature treatment should be from 35 to 40 hours a week.

The determination of how much treatment each **individual** child needs should be left to the treating professionals, referring physicians and psychologists of each individual child. Cookie cutter solutions where bureaucrats arbitrarily set limits of treatment regardless of need and prescriptions made by clinicians are dangerous. This puts children's lives at risk.

The fact is that some decisions on dosage levels in the Ontario programs are being dictated by budgets and administrative decision-making and not by clinical decision-making that has the best interest of the children in mind. The fact is that most children in the programs need to be prescribed more intensive treatment intervention than the government is willing to provide. And even where the clinical opinion of a paediatrician and clinical psychologist have determined that 40 hours of intervention are indicated, families have been advised that administrative and budgetary decisions rather than clinical decisions are limiting recommended treatment dosage to a maximum of 20 hours, with no guarantee that there will be even that few hours.

This type of non-clinical decision-making dramatically reduces the quality of life of small children for political and budgetary purposes. Some of the above-noted methods of administering treatment services are of questionable ethics under any North American jurisdiction including the USA.

Even US managed care health providers and the related American insurance companies don't just pay for only half of what a patient needs because there is an unexpected rise in the need for treatment. Imagine if doctors and hospitals decided to treat only half of their child cancer patients with only half of what is considered essential treatment, with the rationale that the government did not give

them enough money or that a public servant or politician directed the treatment guidelines.

If cancer therapy for children was only given to half of what was needed and to only half of the children who had cancer, most of the children would die. One of the differences with children with autism is that inadequate treatment hours will not result in all of them dying. They will however be severely incapacitated for life as a result of poor treatment regimens. When it is known what treatment works and it is not provided, is this not unethical and a failure to provide necessary service?

In the year 2000 is poor treatment of autistic children by the Ontario government how we as a society chose to treat our children? Is this how our children are protected by the government of Canada? Where are our children's public protectors and who are they anyway?

A ministry budget should not prevent young children with cancer or autism from receiving the level of treatment that is determined by competent clinicians to be the optimum level of treatment. Would we want the government to say that children with cancer can only get half the chemotherapy or half the radiation therapy they need because the budget is insufficient. In fact governments go over budget, out of province and even out of country to supply treatment for childhood and adult cancer if it is not available in a timely way in Canada. The same thing should be done for autism treatment. Young children are suffering permanent damage because governments' lack understanding about childhood autism and are too miserly with budgets for the medically necessary needs of autistic children.

It does not even make economic sense for a program to put an arbitrarily low ceiling on treatment dosages or the number of individual therapy hours a child gets each week. Sadly, in the end, all of society will pay as untreated or inadequately treated children head for institutions later in life, a cost that will far exceed treatment in the earlier years. And many of these children would have otherwise been self-sufficient and fully employed in Canada's labor or business force.²

With proper treatment there are children who have had complete remission of symptoms and who no longer qualify for the diagnosis of autism. Proper therapy has raised measurable intelligence from the mental retardation range to average, above average and superior levels. There is a Ph. D. university professor who gives advice on the internet who was formerly an autistic child.

Further, the Ontario government is intentionally excluding children, who are **mildly autistic**, from the new autism service program, when it is well known that these children will benefit even more than children whose condition is more serious.

² See for example, Jacobson, J.W., Mulick J.A., Green, G., 1998: "Cost-benefit Estimates for Early Intensive Behavioral Intervention for Young Children with Autism-General Model and Single State Case", **Behavioral Interventions**. Vol. 13, 201-206.

This is similar to telling a child cancer patient that it is too bad that he or she has only mild leukemia or a small orthopedic cancerous tumor, because this year the government is only providing funding to treat severe cancer and large metastatic tumors. This warped way of thinking does not express the values of a universal health service. Nor does it demonstrate special caring and high value for families or our country's children.

Further while the Ontario government purports that the new program provides intensive intervention services to children with **moderate degrees of autism**, in practice, local programs are concentrating on the most severe cases and are neglecting to treat equally, children with devastatingly moderate levels of autism.

This is not all. The Ontario government, quite arbitrarily, has taken the position that when a child reaches more than six years of age they will no longer receive medically necessary treatment for autism. This makes no sense. What will happen if therapy is stopped is well known and well researched. When needed therapy stops at 7 years of age the child's progress will stop, and the disability will continue or get worse.

To avoid responsibility and the cost of treating all younger children the Ontario government wants to pretend that a neurological brain disorder that obviously affects learning should become mainly an educational problem after the age of six. This new provincial program that offers intensive therapy to autistic children is refusing to admit children for therapy if they are older than 6 years of age. And the plan is to kick out children from the program when they reach 7 years of age even if the therapy is clearly beneficial. The Ontario government now denies medically necessary therapy services to autistic children because of age.

This not only violates the Canada Health Act and the age discrimination section of Canada's constitution, it probably violates the province's new child welfare law and if so constitutes a form of child neglect.

Imagine ceasing to give children the medical and health services they need because it is their seventh birthday. This is nonsense and it's age discrimination. Would it be acceptable if the government decided that it would no longer pay for heart surgery for all persons over 6 years of age?

Education budgets should not have to replace health care budgets. Teachers should not be asked to replace therapists. Children who attend school should not be denied health services outside school.

There is also a huge problem in the City of Toronto, Ontario.

It is understood that the Toronto Preschool Autism Service has a totally inadequate budget. It is months behind in its ability to tell families that they will be accepted for service and when, let alone actually start treatment.

- The Toronto service has received over 356 applications for children 6 years of age and under.
- The current budget of between \$3.4 to \$4 Million for Toronto will restrict service to about 168 children. The program is so far behind that it will take months to even begin to provide service to many of these children.
- The totally inadequately lack of funds means that if no other applications are received (likely an unrealistic assumption) about 188 young children will not receive urgently needed treatment for months or years, if ever.
- The majority of the 356 children need 35 to 40 hours of treatment a week for the next two to four years.
- The Toronto Autism Service alone needs a fast cash infusion to bring its approved budget to at least \$16 or \$18 Million. And the rest of the local area budgets across the province need huge and immediate additions to their funding. And if the rate of applications continues to increase the necessary funding should match the rate of increase.
- The Toronto Autism Service (and all other local area services across the province) should expand and provide treatment to young children on the basis of need and stop determining eligibility on the basis of age. The absence of continuous service imperils the future of children with autism and is unjustly discriminatory.
- Just from the pool of existing applicants, the Toronto service is leaving hundreds of moderate to severely autistic children at risk of remaining permanently and seriously disabled for the rest of their lives through neglect of the government to quickly implement, urgently needed and medically necessary intensive behavior intervention program. **This is a national tragedy and a national disgrace.**

The Honorable Paul Martin and the Government of Canada's Economic Statement.

The Government of Canada's pamphlet of October 18, 2000 called **Economic Statement and Budget Update – Overview**, includes the following points:

Canada enters the 21st century with greater resources and more choices than it has had in decades. The choices we make will mirror our values as a society and our obligations to each other as citizens.

With a strong economy and budgetary surpluses, the Government has been able to cut taxes and invest in Canadian's key priorities of health and education.

The government makes a commitment to deliver the \$21.1 billion in federal funding to strengthen Canada's treasured system of universal health care as agreed by the Prime Minister and premiers in September [2000]

[The federal government is committed to] providing \$2.2 billion to the provinces and territories for services to the youngest of our children;

How can the level of miserliness in funding universal health care for children with autism by the provinces continue given that \$21.1 Billion for universal health care was promised to the provinces in September 2000 by the government of Canada?

Just over a month ago the federal government also promised the provinces and territories \$2.2 Billion "for services to the youngest of our children". Young children with autism are amongst the youngest of our children and they are being denied medically necessary treatment and hung out to dry by the Ontario government.

A Question of Parents with Autistic Children

One of the questions parents of autistic children are asking is ... "When will our society's obligations to children who suffer the most severe developmental disorder of childhood become evident by fully including these children in Canada's treasured system of health care and providing intensive behavioral intervention, which is the only scientifically proven treatment that works?"

A Question for Prime Minister Jean Chretien and Health Minister Allan Rock

Will Mr. Chretien and Mr. Rock make a visible commitment to the families of autistic children across Canada to use the considerable resources of the federal government to guarantee that no autistic child in need shall be without universal, accessible, comprehensive, portable and publicly administered specialty autism treatment, including the medically necessary and only scientifically validated program of intensive behavioral treatment for correcting and reversing autism, Applied Behavioral Analysis or Intensive Behavior Intervention.

Two Questions for Candidates for Office as a Member of the Canadian Parliament.

1. How many candidates running for office as a member of parliament and which parties are prepared to make a commitment to solve this huge gap in medically necessary services for autistic children?
2. Will you support government allocation an adequate portion of the billions of new dollars the federal government plans to transfer to the provinces, to ensure

that Canada's children with autism can reach their maximum health and remediate to the fullest degree possible their profoundly handicapping disability?

Politicians from all parties should work to guarantee that "medically necessary" intensive behavior therapy services are provided to young autistic children at developmentally critical periods in their life cycle.

**Prepared by:
Friends of Children with Autism (FCWA), Toronto, Ontario ***

Contacts for this Brief.

Dana Vrooman, Toronto, Ontario, Mother of a 4 year old daughter with autism and no public treatment for the condition. tel: 416-494-0041

Paul Vrooman, M.S.W., Toronto, Ontario, Grandfather of Dana's 4 year old daughter with autism and no public treatment. tel: 416-406-1933 Cell tel: 416-299-1755

Suzanne Wetzel, Ph.D., Sault Ste Marie, Ontario, Mother of a 6 year old son with autism and no public treatment for the condition. tel: 705-742-6552

Huguette Boisvert, Ottawa, Ontario, Grandmother of a 4 year old boy with autism and no public treatment for the condition. tel: 613-722-5068

Simon Wynberg, Toronto, Ontario, Father of two twin boys with autism and no public treatment for the condition. tel: 613-961-5546

* Friends of Children with Autism (Ontario) FCWA is a group of families whose goal is to get medically necessary treatment, education, social services and financial supports for their own young children and those of other Ontario families in order to ameliorate the devastating effects of a serious neurological disorder of the brain called autism spectrum disorder or pervasive development disorder.

FCWA is challenging the government's continuing refusal to provide essential levels of universal, accessible, portable, comprehensive and publicly administered health care to all children with autism spectrum disorder including the medically necessary and only scientifically validated program of intensive therapy for correcting and reversing autism, Applied Behavior Analysis or Intensive Behavioral Intervention.

One of the activities of FCWA has been to retain the services of Toronto lawyer David Corbett to launch a legal action against the Government of Ontario for its failure to provide adequate health care, educational services and funding for children with autism in Ontario.

FCWA is challenging the continuing failure by the Province to recognize the most basic rights of children in Ontario: the rights to necessary medical care and an education.