

ADULT AUTISM ISSUES IN WATERLOO-WELLINGTON

Newsletter No. 5, Winter 1999-2000

In this issue, we report in some detail on movements toward person-centred planning and individualized funding, as explained at GSA's AGM by Malcolm Jeffreys and Marlyn Shervill of Windsor. We also present reviews of two books--very different, but both important for understanding autism—and the report on a research project that was publicized through *wwasnews* in early 1998.

This is the time of year when supporters renew their memberships and make donations. The treasurers of WWAS and GSA will issue tax-creditable receipts for these amounts (see details on page 2).

AAIWW is mailed to many individuals and agencies connected in some way with human services in our region (as *wwasnews* was sent in the past). We are reviewing our mailing list. For some of you, an extra memo will be enclosed with this newsletter. Please reply as requested, to let us know whether *AAIWW* is still useful and if you want to continue receiving it.

We wish our families, friends, caregivers, and supporters all the best for the year 2000. May there be some gains in understanding, compassion and support for the people who live with autism.

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AUTISM IN THE NEWS

News media have reported the legal actions being brought against the Ontario Government for its failure to provide or fund effective treatment or therapy for young children diagnosed with autism. One family has been spending nearly \$88,000 a year for intensive intervention with its 4-year-old. It is argued that official recognition of autism as a neurological disorder (as it is regarded by a growing number of professionals and parents) would entitle affected people to be funded through Health. At present, perception of autism as a psychological disability means that services are not usually funded.

Notice of the legal actions prompted the Ministry of Community and Social Services (through the new Office of Integrated Services for Children) to announce an intensive intervention program for children with autism to begin in early 2000. Only children aged 5 and younger will be served. The new program is expected to cost \$5 million in its first year, rising to \$19 million a year.

In each of nine regions throughout Ontario, an agency or special consortium of agencies will be selected for its ability to deliver accessible and high-quality service. The OISC announces that "the regional programs will work with families to assess their children's needs, develop individualized service plans, provide intensive behavioural intervention, and work with other service providers to coordinate the right mix and level of services."

For the Wellington-Waterloo region, the Rotary Children's Centre (through Stephen Swatridge) and the Community Mental Health Centre (through Rick Finch) are proposing to deliver this program of early intensive intervention for young children with autism.

Families, friends and caregivers of older children and adults with autism--represented in WWAS and GSA--will rejoice that the needs of young children with autism are being recognized. We applaud the focus on each individual child in assessment and treatment plans. We should continue to press for the rights of all persons with autism and their frontline caregivers to access to the resources each needs for effective support.

BULLETIN BOARD

WWAS

- ◆ Continues its bursary program to encourage adults with autism/pdd to benefit from relevant therapies or develop their abilities, by providing one-time grants when funds are not otherwise available. Contact president Roger Hollingsworth at WWAS, 125 Union St, Waterloo ON, N2J 4E5; phone messages may be left at (519) 742-1414.
- ◆ Welcomes your support, as a member-donor and volunteer, for the causes of people with adults with autism/pdd and their families, friends and caregivers. Memberships or donations of \$25 or more qualify for official tax-creditable receipts. Members are invited to share concerns, ideas and hopes about autism issues, and are eligible to vote at general meetings and to be nominated and elected to serve on the WWAS Board. Send membership donations to: William Barnes (WWAS Treasurer), 26 Yellow Birch Drive, Kitchener, ON, N2M 2M2

GSA

- ◆ Can help adults with autism to live with dignity in their own homes and to make choices about their lives, by:
 - Financing and maintaining properties
 - Facilitating the roles of the support clusters or networks around each individual
 - Increasing community awareness of the abilities and needs of people with autism
- ◆ Board of directors elected for 1999-2000: Gerald Bloomfield (president), Henk Ensing (vice-president), Dave DeVidi (secretary, John Verhart (treasurer), Fred Dahms, Andrew Foster, and John Lord.
- ◆ Memberships or donations are welcomed by GSA; tax-creditable receipts are issued for amounts of \$10 or more. Please give to a director you know or mail: GSA Treasurer, Root Plaza Postal Outlet Box 23016, Guelph, ON, N1H.8H9. Phone messages may be left at (519) 821-7424 or 823-9232.

Review:

Building Bridges through Sensory Integration, by Ellen Yack, Shirley Sutton and Paula Aquilla, 1998. ISBN: 0-968-5375-0-2. Available for \$50 from 132 Queen's Drive, Weston, ON, M9N 2H6; phone (416) 785-7899.

This book is based on understanding autism as a neurological disorder that includes problems of perceptual and sensory processing and impaired motor skills. The authors are occupational therapists who work with children who have autism/pdd. They describe the abnormal perceptions of any sensory stimuli—sound, touch, light, smell, taste—and the responses expressed in “sensory defensive behaviours” as well as in high levels of anxiety and difficulties in attending to tasks, controlling impulses, tolerating frustration and balancing emotional reactions. Such behaviours are not consistent all the time or in different environments, and each individual has a unique combination. Children may actually seek some sensations to block out other sensations, or they may seem unresponsive because their nervous system “shuts down” to protect them from sensory overload. The theory of sensory integration is explained with special reference to three systems--tactile (touch), vestibular (movement and gravity), and proprioceptive (awareness of body position).

*Above all, **Building Bridges** is a very useful practical guide for professionals, parents, teachers and other caregivers. Its second part presents detailed assessment tools as well as consistent strategies for managing challenging behaviour. Successful sensory integration techniques include the Wilbarger Protocol for Sensory Defensiveness, the Sensory Diet, general calming and alerting strategies, and advice for a wide range of specific problems. Advice is offered on adapting home, school and childcare environments and routines to be more consistent and predictable. And there are creative suggestions for activities, equipment and resources.*

***Building Bridges** was written with young children in mind. But some of its insights and strategies can be applied and adapted for older children and adults. We are happy to report that young adults we know have responded well. We hope that, before too long, there will be a guide to sensory integration for teenagers and adults with autism/pdd, as part of an increased awareness of the continuing need for bridges between their worlds and ours.*

Book Review:

Shadow Syndromes, by John J. Ratey, M.D. and Catherine Johnson, Ph.D. (New York: Pantheon Books, 1997), 389 pp.

“Millions of people who attribute their daily life problems to bad parents or low self-esteem are in fact struggling with a shadow syndrome,” write the authors. Among these problems are mild forms of serious mental disorders that can affect the course of one’s life, such as chronic sadness, obsessiveness, outbursts of anger, inability to finish tasks, and discomfort in social situations.

Drs Ratey and Johnson say that such patterns of behavior have their origins in the “inherent structure and chemistry of the individual brain [and] that they are distinctly identifiable.” Knowing who we are biologically, as well as psychologically, is the key, they say, to living a free and full life. Both authors write from their own experiences.

In studying medicine, Ratey discovered his failure to free-associate, necessary for becoming a psychoanalyst. His brain was too active, too driven, too obsessed; its biology and basic neurophysiology interfered with his ability to do what he wanted to do. He learned that he suffered from ADD (attention disorder deficit) when he worked with patients who had similar problems.

Johnson found, a year after the birth of her son in 1987, that she was tired, sad, chronically worried, and unable to function. She was diagnosed with an “atypical” depression, mild as

depressions go. She tried Prozac and became one of that drug’s success stories, learning the fundamental lesson of this book—the importance of biology in a person’s capacity to function. Prozac, she says, did not change her history: it changed her biology and so her life.

Shadow Syndromes brings clarity to the biology behind personality, helping us to understand the real causes of the “treacherous moods and behavior that can hold us back” and providing guidance as to how to emerge from behavioral shadows towards a “positive and lasting change in ourselves and in those we love.”

Topics of chapters include masked depression, intermittent rage disorder, mild ADD, addiction, and anxiety. “Autistic Echoes” is our focus here. Here are a few echoes.

All shadow syndromes strike at the heart of social life. “The world of work is easier to negotiate than that of love and friendship.” Paid employment, not love, provides the main source of structure—with its schedules, routines and rhythms of work. “Shadow syndromes flourish in the open spaces of our private relationships. Mild depression, mild mania, mild ADD: all can sabotage the bonds of love and friendship. But in autism, full-blown and mild, social difficulties are the disorder.” There seems to be a genetic or hereditary factor in families affected by autism, as mild autistic tendencies may often

be noted in parents, siblings or other relatives.

The authors describe a mild form of autism that is compatible with marriage, parenting, satisfactory heterosexual-sexual performance, and gainful employment. “Who,” the authors ask, “is the person with a hidden or shadow form of autism?” The odd duck, the person (usually male) called a “geek” or “nerd” because he is socially awkward. Tech types recognize this quality in themselves. MIT offers a course in social skills to its students. There is a decided connection between autism and computerdom. Bill Gates reports such autistic qualities as rocking, jumping on trampolines, not making eye contact, lacking social skills to enter a group conversation.

So much more could be said. I appreciate immensely the message of this book, which is important for all of us, regardless of how we are “assembled as human individuals.” I wonder if the element of love is not given adequate attention. Yes, biology and chemistry are givens, and social difficulties are recognized, but love (from my perspective, a love of God in us) is what motivates understanding, caring, healing and the perseverance which is so much needed to help others and ourselves whenever difficulties “set us apart.”

*Reviewed by Lucie Milne of Newmarket, retired Presbyterian minister and author of **About Myself** (1998), the story of a Guelph adult with autism.*

PERSON-CENTRED PLANS AND INDIVIDUALIZED FUNDING: NEW DIRECTIONS IN SUPPORT FOR VULNERABLE PEOPLE

People who attended GSA's Annual General Meeting on 29 September 1999 were privileged to learn about the creative initiatives of social service agencies in the Windsor region during the 1990s. MALCOLM JEFFREYS, executive director of Windsor Community Living Support Services, and MARLYN SHERVILL, who is pioneering the role of personal services broker, explained the ideas of individualized planning and funding and how they are being put into practice.

GSA wants to support adults with autism and their families and friends as they move in these new directions towards better quality of life and choices while making the best possible use of community resources. Other people in Waterloo-Wellington have expressed interest in discussing these initiatives and how they may be realized in our region. Malcolm Jeffreys has kindly allowed GSA to make copies of the material he presented in overheads. Some is excerpted here. If you would like a full copy, contact GSA.

Windsor-Essex Community Planning Committee for Adult Development Services: Mission Statement (1 September 1999)

The primary mission ...is to plan, design, develop and coordinate processes that will improve opportunities for citizens who live with developmental disabilities to experience a secure and meaningful life as do all other citizens. It will ensure that:

- The system of services and supports mandated and funded by the Ontario government is organized and operated within guidelines that promote flexibility, responsiveness, efficiency, accountability and value to people who use services and to the taxpayers of Ontario.
- The processes of change will be guided by a sensitive and cooperative engagement and consideration of the various points of view that represent the whole spectrum of concerns, needs and interests. The contributions of individuals who use services, advocates, MCSS and funded service providers will merit equal value and influence.
- Access to resources (services and supports) will be based on the personal choices made by individuals and their families; and the system of funding adopted will empower people to protect their autonomy, direct their own lives and be supported to make the decisions that affect where they live, who they live with, and who they wish to be supported by.

Common Challenges faced by Service/Support Agencies in the New Environment

- *Shifting our ideals from models based on dependency to models of inclusion*
- *Addressing power imbalances between individual consumers and providers*
- *Encouraging collaboration between parents, professionals, self-advocates, consumer groups and governments*
- *Shifting from eligibility/ placement models of admission/demission towards personal futures planning and individualized supports directed by consumer interests*
- *Reallocation of funds to enable self-direction and self-administration*
- *Addressing competing pressures resulting from growth in demand, loss of financial resources and heightened expectations of accountability, i.e., shifting from a "just-in-case" philosophy of services to "just-in-time"*
- *Facing increasing competition within our service sectors without creating duplication*

Characteristics of Inclusion

- *We are all entitled to live in the community because that is where people belong*
- *Making this possible for some will require consideration of "under what conditions" and "with what support"*
- *All people have unique value and can contribute to the larger community*
- *All people benefit from shared lifestyle options offered by the larger community*
- *The life of all in the community is enriched and maintained by the participation of all its members in education, employment, home life, recreation and interpersonal interaction*
- *People associate with whom they wish, but also benefit from interaction with other people who share or do not share their characteristics and interests*
- *We are all members of our communities regardless of overt differences such as race or gender or hidden differences such as intelligence or personality*
- *Community membership can only be removed under legal authority and never as a convenience to society.*

INDIVIDUALIZED FUNDING

HOW IT WORKS:

- Each adult with disabilities and her/his family can have control over her/his life by ensuring that supports/services are provided in ways that s/he wants
- Funds are allocated to the person/family directly by the government, based on a **personal** plan (NOT a service plan)
- The plan is developed by the individual with her/his family and support network s/he chooses
- The \$ are approved by the government and sent to the agency of choice

WHAT YOU CAN DO WITH INDIVIDUALIZED FUNDING

A Personal Plan describes how an adult needs to live and be supported, for example:

- An agency-operated Group Home (24 hour care)
- Staffing support in a semi-independent living arrangement (e.g., apartment)
- A home operated by family or designate (with agency support if needed)
- Staffing support to live in parents' home
- Placement in a sheltered work setting (e.g., workshop)
- On-the-job training and support (e.g. job coach)
- Volunteer work and/or community activities
- 24-hour or less staffing support to be able to live with friends (other people with disabilities) in house owned or bequeathed by family
- Shared living arrangement with friends (non-disabled) with additional paid staffing support (i.e., homesharing)

Individualized Funding can also enable you to:

- Manage all aspects of the planning, service design and delivery
- Pick the agency you want, and elect to move your funds to another agency any time you choose.
- Purchase full service or only part of the service you need from one agency and part from another, or

- Purchase only accounting, payroll and administrative service if you want to hire your own staff, or
- Supervise the planning but have the agency help with the hiring, firing, supervision and accounting;
- Bank your funds with one agency and buy services from another under a purchase-of-service agreement.

WHAT IS A BROKER IN INDIVIDUALIZED FUNDING?

Someone who understands your needs and priorities, knows the social service system, and is “unencumbered” by other loyalties and responsibilities. A broker works for you, not for the service provider, and helps to keep you in the “driver’s seat.”

A broker can help by:

- *Providing information about available options*
- *Helping you to “shop around” to get the best possible support/service arrangement from agencies and other community resources*
- *Speaking on behalf of you (or your family) if asked, in approaching service providers and/or government*
- *Guiding/assisting in the preparation of a personal plan and its presentation to the government*
- *Helping to negotiate a contract with service providers(s) at a fair price.*

Research Report

Correlations between parental acceptance of autism/PDD during childhood, and adult outcome,

Susan T. Solursh (1999)

The purpose of this study was to assess whether there is a correlation between adult outcome and parental acceptance of a pervasive developmental disorder (PDD) during childhood. There were a total of 28 participants, 14 parents and 14 adults with pervasive developmental disorders. The participants with pervasive developmental disorders had a mean age of 32 years, while the parents had a mean age of 55 years. Six of the participants with pervasive developmental disorders were female and eight were male.

Level of education of the participants with PDD varied, with participants over the age of 21 years having attained an education ranging from eighth grade through third-year medical school. The educational attainment of the parents ranged from eighth grade through to M.Sc. and a postgraduate degree in law. Living environments of the participants with PDD also varied, from living with their families to living in independent settings.

It was found that a perception of acceptance during childhood (vs., that of repeated attempts to "cure" the child of the PDD) were perceived by the adults with PDD in a more positive way, and as having a positive influence on their outcome in adulthood. Females with PDD were found to have a higher mean score on the measure of Curative Attitude. The relationship between Curative Attitude and lower Affective Self Concept was explored. It was found that female individuals with lower Affective Self Concepts

exhibited a relationship between Curative Attitude and lower Affective Self Concept, whereas males alone did not exhibit this relationship. However, it should be noted that as a group, both males and females together displayed this relationship. Thus, the small sample size or some other factor may have influenced the results. It is may be that with a larger sample of males, similar findings to those with the females in this study would result.

Females also perceived their parents as having a significantly greater Curative Attitude than did males. No significant difference was found between the average female and male Affective Self Concept scores alone. Overall, it appears that females experience acceptance by their parents as more interconnected with their level of social competence.

It also appears that when individuals with autism/PDD feel more competent, they tend to perceive themselves as having greater social agility. This, in turn, may be associated with a healthier outcome and/or quality of life.

The findings in this study are important for two reasons. First, they show that acceptance may be particularly important and that there may be times when it is healthier to say no, both as parents and as adults with autism, when professionals or "professional advice givers" tell us we have to "repair" our children or ourselves. Second, these findings were based upon questions involving affective content. The adults in this study appeared able to answer these questions. Thus, it would appear that these adults do experience some awareness of affect, both in themselves and their parents.

Comparisons of parental and adult mean scores on questionnaires indicated that the two groups differed significantly only in regard to treatment and activities. Thus, there appeared to be some awareness by the individuals with PDD of their parents' affective experiences. Generally, the adults shared their parents' perceptions of the parental attitudes during childhood.

Overall, it appears that adults who felt that their parents had exhibited an accepting attitude regarding their special needs displayed higher Affective Self Concepts, leading to a healthier outcome. The results of this study also indicate the importance for both family members and clinicians to be aware of the possibility of difficulties with affective self concept in individuals with autism/PDD. Additionally, they suggest that the attitudes of parents correlate with Affective Self Concept and Outcome in persons with autism/PDD. These are relationships deserving of continued exploration due to their possible emotional and behavioural impact on the development, outcome and quality of life of persons with autism spectrum disorders. Ultimately, parents can effect positive growth and affective development in individuals with autism spectrum disorders.

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