

ADULT AUTISM ISSUES IN WATERLOO-WELLINGTON

Joint newsletter of Guelph Services for the Autistic (GSA) and Waterloo-Wellington Autism Services (WWAS)
Newsletter No 11, June 2001

“What will it take for people to start seeing us for who we are?”

The appalling situation of Hasit Khagram (31) and his mother Suniti Shah of Ontario’s Region of Niagara is in the news again. According to Margaret Philp’s front-page article in *The Globe and Mail* on Saturday, June 2, 2001, Hasit had been six months in solitary confinement and drugged in Bethesda Home, Vineland, in a “laboratory-rat existence without human touch or fresh air.” His mother and siblings are allowed to visit him only one hour a week. Before Bethesda, Hasit was confined for five months in the Hamilton Psychiatric Hospital in worse conditions. It is reported that Hasit and his mother are being punished by professionals and bureaucrats for his mother’s persistent advocacy on his behalf. Margaret Philp’s article may be found at <http://www.ont-autism.uoguelph.ca/item.PDF> and an earlier story at <http://www.newswire.ca/releases/October2000/17/c3980.html>

How much imagination and effort are still needed so that autistic adults can be listened to and respected by others and so they can use their abilities to contribute to their communities? Autism spectrum disorders are complex and pervasive and affect each person in a unique mix of ways. Those who are severely affected and who regress can be very challenging to support.

But there have been so many advances in understanding and helpful strategies during the 1990s, discussed in such books as Stella Waterhouse’s *A Positive Approach to Autism* (2000) and Gail Gillingham’s *Autism: A New Interpretation* (2000). Factors may include sensory integration dysfunction and sensory overload, anxiety and boredom, gastrointestinal problems, and extreme frustration at the inability to make others understand. Helpful strategies include augmentative communication, sensory integration, physical exercise, dietary intervention, intellectual stimulation, social interaction and, above all, respect and co-operation among all concerned.

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The Prologue to *Paid for the Privilege* (reviewed on page 8) quoted from one “silent voice of autism” has more meaning than ever:

“I sit here wondering what it will take for these people to start seeing us for who we are. I am a man with many qualities and I care about all those around me. Too much thinking with little or no talking is dangerous. And in our world, force seems to speak louder than words. I guess that is why we are in a scary place.

“It is hard to explain, but our brains may work somewhat differently from yours. We probably see, hear and feel things differently from you.

“We sit, rarely accomplishing much, and pretty much hide in our own world. It is lonely and wrong. Not many seem to think we know much, but we do and we want to know more. The time is coming when we no longer will have to feel detachment and isolation. We will belong, but we need your help.

“Wasting away is not what God has intended for us. A system with many misinformed people feels that enough is being done, and others feel that they have their hands tied by rules and regulations...”

ASPIRE: Autism Support Project: Information, Resources, Empowerment

Guelph Services for the Autistic (GSA), supported by Waterloo-Wellington Autism Services, proposes a new project to be accomplished in two stages over 2-3 years. If GSA receives funding for this project, ASPIRE will:

- a. Build knowledge of how adults experience autism spectrum disorders and the most effective strategies of supporting them to cope with their disabilities and achieve the best possible quality of life, and
- b. Model a facilitation service to inform and empower autistic individuals, with their families and friends, to plan and find resources for all the elements of a good life, including relationships with a personal support network, a home of one's own, ways to make choices and contribute to the community, and a safe and secure future.

1. In the first stage of ASPIRE, a survey is being taken of the status and needs of individuals with Autism who will be 17 years or older by the end of 2001 and who live in Guelph-Wellington County or the Region of Waterloo. A pilot version of the survey is posted on the OAARSN website at <http://www.ont-autism.uoguelph.ca/aans2001.shtml> and may be completed most efficiently online. If you would like to take part but lack computer access, leave a message at phone (519) 821-7424, requesting a paper copy.
2. In the second stage of the project, ASPIRE staff will work as facilitators with families to plan and set up effective strategies and to connect with resources for a good life and secure future for each individual. We expect to help two main groups: young people aged 18-20 who are leaving school-based services for adulthood; and older adults who still live with their parents and need to consider other options for the future. This phase will be concentrated in Guelph-Wellington to start with, but might be extended to the Region of Waterloo.

Activities planned in the second phase include:

- Studying responses to the survey to understand general patterns in living situations and needs;

- Following up leads provided by local support organizations to identify individuals and families who wish to take part in this project;
- Holding in-depth meetings with individuals and their families to clarify needs and expectations;
- Organizing small group meetings of individuals and families with similar needs;
- Providing training and orientation in best practices for supporting adults with Autism;
- Advising in the process of helping the adult with Autism to make a long term plan that outlines her or his goals and desires for living arrangements. This usually involves setting up ways to ensure that each person understands the process and is able to communicate her or his informed choices;
- Advising on the formation of a support network of friends and associates around the person with Autism, that will help the family ensure that the plan is implemented and be the mechanism by which the plan can extend beyond the life of the parents;
- Helping individuals and families to assess (and then access) the formal and informal resources which will be needed to implement the plans which are developed; and help them through the process of accessing resources which are available to them;
- For those who reach this stage, to advise in property acquisition, planning modifications to that property if appropriate, negotiating purchase, making legal agreements guaranteeing residency rights to the adult with Autism, and so on.

Both phases of the project will directly benefit adults with Autism and their families in our region. Both may also be extended to a larger area.

If you would like more information and/or to be involved in the ASPIRE project, leave a message at phone (519) 821-7424 or email a message to gbloomfi@uoguelph.ca

Announcing the Adult Autism Needs Survey 2001

<http://www.ont-autism.uoguelph.ca/aans2001.shtml>

Why this survey?

OAARSN is taking this survey to learn about how many people have autism and to understand their abilities and needs. This information will help various organizations that wish to provide the most useful support to adults with autism and their families. The last survey of Ontario adults with autism was taken in 1990 (and reported in *Our Most Vulnerable Citizens*, published by the Autism Society Ontario and posted on the OAARSN website at <http://www.ont-autism.uoguelph.ca/pdf/vulnerable.pdf>). A great deal has changed during the 1990s, but adults with autism are still among our most vulnerable citizens.

Taking part in this survey may help you--as an adult with autism or as a family member, friend or caregiver--to consider your current situation, various treatments and therapies, and how you are planning for the future. Please be assured that the results of this survey will be grouped, and your individual responses will not be revealed to anyone else without your permission.

You can ask us to send you a summary of the general findings of this survey, or to let you know of an autism services organization that may be able to offer relevant support and resources in your region. For example, Guelph Services for the Autistic and Waterloo-Wellington Autism Services are interested in responding to the needs revealed by this survey for the Region of Waterloo and Wellington County-Guelph.

Who should take part in this survey?

A person who has any form of autism spectrum disorders, and who was at least 16 years old by 31 December 2000. For this survey, autism spectrum disorders include classic autism, Kanner's syndrome, pervasive developmental disorder (PDD), Asperger's syndrome, autistic tendencies, autism in some form or degree combined with another diagnosis as well. We are particularly interested in the points of view of persons with autism themselves, so the survey questions are expressed in terms of "you" and "your." But you

(i.e., a person with autism) may be represented by a parent, sibling, other relative, trustee or caregiver who understands your circumstances, how you experience autism and any treatments, and your goals.

How to respond to this survey

We encourage you to complete this form electronically, on the OAARSN website by clicking the appropriate responses, and submitting it by e-mail. This is the most efficient and confidential way for us to store your information and also to analyze all the responses we receive. It is helpful to have your response even if you are completely satisfied with your present pattern of life and supports. Completing this survey takes about 30 minutes.

You may wish to print out the survey first, so that you can think about your responses, and then connect later to complete and submit them.

A printed version of the pilot survey may be requested by leaving a request message with your full name, address and phone number at (519) 821 7424 in Guelph-Wellington. If you prefer to use this or a printout of the electronic survey form, please mail your completed survey to Guelph Services for the Autistic, Box 23016, Root Plaza Postal Outlet, GUELPH, ON N1H 8H9.

The Adult Autism Needs Survey has six parts:

- 1: BASIC PERSONAL INFORMATION (7 questions)
- 2: UNDERSTANDING YOUR ABILITIES AND CHALLENGES (12)
- 3: YOUR PRESENT LIFE CIRCUMSTANCES (18)
- 4: TREATMENTS AND THERAPIES (3)
- 5: QUALITY OF LIFE (2)
- 6: PLANNING FOR THE FUTURE (14)

Super Sensory Reactions

In early May, Guelph Services for the Autistic and Ontario Adult Autism Research and Support Network arranged for two Super Sensory Workshops at the University of Guelph gave 38 participants the experience of being overloaded in four senses (sight, sound, smell and touch) while trying to concentrate and learn. For one hour, parents and other relatives, frontline workers with children and adults, and professionals in various fields could feel what it's like to live with sensory overload all the time. It was a chance to understand better and perhaps rethink ways to support and relate to their autistic child, adult, relative, friend or client.

The workshops were led by Gail and Clayton Wylie of Autism Consulting Service in Edmonton, Alberta.

Participants were asked to share their reactions to the experience and to respond to the following questions.

- *What did you learn from the workshop experience of sensory overload?*
 - *about yourself?*
 - *about the autistic people with whom you live or work?*
- *What differences does this understanding make in how you relate to and support the autistic child, adult, relative, friend or client in your life?*

Two participants, Heidi and Kirsty, have written up their reactions, also posted in the OAARSN Discussion Area at <http://www.uoguelph.ca/~gbloomfi/cgi-bin/Ultraboard/UltraBoard.pl>

Heidi's Response

When I realized how hot it was on the day of the workshop and heard that participants would be sitting in burlap tops next to their skin while subjected to a range of other sensory stimuli, I shuddered in horror. Anxious and fearful of my ability to cope under such anticipated conditions, my immediate gut response was: "Oh, my God, I hope I don't hit anyone!"

All kinds of questions began to surface:

- Do autistic people feel like this?
- How will I cope?
- How will others cope?
- Will I lash out at someone?

The only way to find my answers was to engage in Gail's workshop and ride out the dreaded experience.

My skin was immediately irritated by the scratchy burlap. I stiffened somewhat to minimize the scratching, then became entranced by the threads that needed unravelling. Not only my own top, but also those of my neighbours tempted me. This became my first focus of attention and kept me busy while I blocked out everything else around me.

Gail and Clayton firmly reminded me to bring my attention back to some task. I burst out laughing because I already had mine. Besides, the room was so stuffy and noisy I could not sense anything other than my own discomfort.

When a sheet of paper arrived with a prickly stick, I wondered what I was expected to do. I noticed a bottle of yellow paint sitting in front of me, so I opened it and dropped a few blobs on to my paper. Perhaps the stick was a paintbrush. I carefully picked it up, avoiding the barbs, and used it to spread yellow paint over my paper. My task complete, I continued with the loose threads which require my full attention.

I realized later when we all assembled that the paper we were given had questions on it. Well I didn't see them so they didn't exist for me. I also realized that we were to listen to a person on the video screen. The video did not engage my interest and the mumble jumble of words made no sense to me either. I could not be bothered engaging in what I perceived as ridiculous and therefore withdrew my attention. Somehow I blocked out everything in my immediate surroundings.

I realized that in order to cope with all the sensory stimuli I had to focus on my discomfort first and foremost. To my surprise I did not lash out at anyone. I was busily engaged surviving the ordeal in the only way I could. I withdrew my entire attention away from my

Heidi's Response, continued..

external surroundings and absorbed myself in my own tasks and coping mechanisms

Another participant, my neighbour, later told me I was bad. I thought the whole experience was not only bad, it was dreadful. A memory surfaced from my grade school years when I had endured similarly dreadful experiences—the long sits, the boredom, the demands that made no sense, my silliness—anything to inject some real life into the gloominess I felt. Let's not mention punishment—more long sits!

As past memories streamed in, new insights have also continued to surface, triggered by this workshop:

- How do we cope with demands and expectations?
- Do these match our current reality, whatever that is for us right now?
- Who has authority over our unique experiences?
- What causes us to comply?
- What nourishes and fosters our growth, and what diminishes us?

Yes, the questions keep coming.

I realize also that I always have looked for answers outside myself. Now I am learning to look inside—to feel, to sense my own experience. There is no other way I can relate to myself, or honour my autistic friend. Together we learn and share. Above all else, I'm valuing relationship to another human being who experiences life a bit differently from me. Perhaps he is my teacher. Listen to my body OK!! I'm trying my best! What is it that you are trying to tell me??

Kirsty's Thoughts

When I first heard about the workshop I jumped at the chance to participate. I thought it would be the best way to understand (or try to) how my friends who live with autism experience the world. However, as the day of the workshop drew near, I began to feel nervous. What were they going to do to me? But, as it turned out, my experience at the workshop was not as horrifying as I had expected. It was uncomfortable and insightful all at once. Here is what I felt.

The warm classroom, as well as the burlap against my skin, disturbed me the most. My coping mechanisms consisted of daydreaming and trying to sit as still as possible. These mechanisms worked for the first 15 minutes, but boredom quickly took over, which made me fidgety. By this time, I found that I could no longer filter out the auditory stimuli. I was slowly losing my temper and asking myself why couldn't someone open a window? It is too warm in here. Why do they have so much incense burning? Don't they realize that I am going to have a migraine? Just as I felt these emotions boiling to the surface, the hour ended and I was free!

As I look back on this experience I have one suggestion. Instead of having the sensory overload activities occur for one hour, it may be beneficial for the participants to experience them throughout the second hour as well (during the discussion). This would allow for further reactions and coping mechanisms to be experienced and observed.

Overall, I found the Super Sensory Workshop to be a great help to me. I have become more aware of my own and others' environments, focusing especially on the stimuli that cause individuals anxiety. However, my experience in the workshop has also helped me to focus on situations that enhance homeostasis and peace. It is my goal when working with others to try to maintain this feeling.

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WATERLOO-WELLINGTON AUTISM SERVICES

Information about WWAS may be found at <http://www.ont-autism.uoguelph.ca/wwasinfo.shtml>

Become a member with a donation of \$25 or more. Or subscribe to AAIWW for \$5 a year (to cover printing and postage costs).

Make cheques payable to WWAS and send with your name, full address and phone number, to William Barnes, 26 Yellow Birch Drive, Kitchener, N2N 2M2. For more information, call our answering machine at (519) 742 1414, leave your name, number and message.

GUELPH SERVICES FOR THE AUTISTIC functions as a housing trust, to help adults with autism to live happier and more fulfilling lives in homes of their own. See GSA pages on the OAARSN website:

http://www.ont-autism.uoguelph.ca/gsa/gsa_new.shtml

http://www.ont-autism.uoguelph.ca/gsa/gsafaq_new.shtml

Tax-creditable receipts are issued for donations of at least \$10. Please mail to Guelph Services for the Autistic, P.O. Box 23016, Root Plaza Postal Outlet, GUELPH, Ontario, N1H 8H9

How Isaac Contributes to his Community

This is one installment of Isaac's Story, posted in OAARSN's Unique Resource Documents at <http://www.ont-autism.uoguelph.ca/from.shtml#a>

“What nonsense!” might be our first reaction to the notion that someone who is disabled and dependent could contribute anything to other people or to society. A person with disabilities may be regarded as a burden that the rest of us must drag along--at worst, unworthy of recognition as a human being. Or, if we feel some compassion for those who are disabled through no fault of their own, we may think they should have treats to compensate for their misfortunes. People with disabilities are officially described as consumers rather than contributors, though they usually have few choices and their buying power is meagre.

We usually assume that contributing to the community means being employed for salary or wages and thus paying our share of the costs of government through our taxes. We may not consider what our paid work does for the common good. Or whether the amounts we are paid bear much relationship to the social value of what we do.

Ideals of normalization led advocates and policy-makers to create programs and opportunities for people with disabilities to work in paying jobs. This is good when all that prevents people from doing jobs for which they are well qualified are the misconceptions of others or the need for a little adaptive technology. People with autism have been found to make very good workers. They are punctual, reliable, orderly, thorough and conscientious,

especially in types of work that are more predictable and don't require having to cope with crowds of people, sensory overload, constant pressures, or unexpected changes. Some autistic adults have special aptitudes with computer tasks.

It's not so good when people with disabilities are made to work in any paying jobs, however menial and ill-paid, where their labour may be exploited. For those who cannot work without support and supervision, sheltered workshops take in consignments of work, usually from big corporations. One staple has been cleaning and re-assembling audio headsets for the airlines, for which the workers may be paid about 10 cents an hour, regardless of their productivity. Much of the time, there are problems with the flow of work, periods of rush work alternating with having nothing to do. Andrew, another autistic man who has a wry sense of humour, expresses his opinion that “boring work must be paid for!”

We would say that work, whether paid or not, should have meaning. Isaac and others should understand how their work helps others and society. Isaac has had experience of both sheltered workshops and of inactivity. He is keen to have “real work” by which he means work that is satisfying and useful. Isaac has volunteered for many years in collating paper reports, newsletters and mailings for worthwhile causes and community organizations. With his keen interest in the environment, he likes to be involved in spring

cleanup projects. He loves typing on his computer and is very accurate. He would prefer to work one hour a day for pay and six hours a day as a volunteer.

The following definition of work, from *A Good Life* by Al Etmanski (p. 161) appeals to Isaac:

Work means...

- *following one's passion*
- *earning a living*
- *increasing self esteem*
- *gaining job satisfaction*
- *being part of a team*
- *knowing your place in the world*
- *making choices*
- *meeting new people*
- *expressing yourself*
- *pursuing your dream*
- *being accountable*
- *making a contribution*
- *fulfilling your potential*
- *being valued and relied upon*
- *acquiring and improving skills*
- *earning respect*
- *pursuing a vocation*
- *enjoying social opportunities*

Isaac contributes by being in the community as well as by anything that he does. By walking his dog through his neighbourhood and along trails, by attending church, visiting stores and libraries, he is present for the rest of us. We all benefit by his presence, and the presence of others who have special needs and handicapping conditions. We need to be reminded of the diversity and vulnerability of the human.

....continued on page 7

condition and of the courage and cheerful hope of many who live with disabilities.

As the advocate Judith Snow notes: "By exiling obviously vulnerable people from daily community life and interaction, we create a situation where 'normal' people must hid their pain, or risk rejection. They deny the depths of both their wounds and their capacity to heal each other."

It might seem easier for everyone for Isaac to be invisible—in an isolated institutional setting or kept away from others in his family home or a group home. It is hard for him to go out in the community, to face the onslaught of sights, sounds, smells and touch and the confusion of strange people and unfamiliar environments—as well as the occasional taunts and slights.

Isaac really does want to contribute to the community. Because he shuttled between his family

Charter of Human Obligations

As part of my contribution to the vitality of my community, I am obliged:

- *to show up and be present*
- *to marvel at the ordinary*
- *to see beauty everywhere*
- *to listen with silent intensity*
- *to serve with gentleness and respect*
- *to nurture with kindness and curiosity*
- *to play with enthusiasm and humour*
- *to make the truth visible*
- *to accept my vulnerability and that of others*
- *to avoid idleness and to toil with love*
- *to embrace life with an open heart*
- *to sow seeds of tenderness*
- *to build a house of hospitality and affection*
- *to forgive gracefully*
- *to cherish a bold vision*
- *to care with compassion*
- *to perfect my life*

home and other places for more than half his life, he now has a strong attachment to the town he calls home. What if we, as people who do not live with severe disabilities, turn around some of our attitudes and assumptions about those who do? Thinking about what we do that gives meaning to our own lives, we may be able to understand Isaac's contributions and support him to feel satisfaction that he is giving as well as receiving?

In *A Good Life* (p.153) Al Etmanski proposes citizenship and human obligations as a basis for ideas about how we all, including people with disabilities, contribute to the common good. People with disabilities and their supporters and advocates sometimes stress the rights to which they are entitled as human beings. It is even more powerful to think about obligations and responsibilities.

BULLETIN BOARD



Autism Society Ontario's Annual General Meeting, June 22 & 23, 2001

Radisson Hotel-Toronto-Mississauga,

2501 Argentia Road, Mississauga, L5N 4G8 (905)

858-2424 or 1(800) 333-3333

Program includes presentations by *Dennis Debbault, Kathy Lear, Lindsay Moir, and Dr Jeanette Holden.* Note: All current ASO members are receiving full information by mail. All may vote by mail, fax or email for the five new ASO Provincial Board Members and for this year's recipients of the Gerry Bloomfield Award.

Workshop by Dr Simon Baron-Cohen of the University of Cambridge, England:

"Is Autism An Extreme Form of the Male Brain?" Hosted by Geneva Centre for Autism and North York General Hospital.

Time: July 12, 2001 Time: 9:30 - 11:30 a.m.

Place: North York General Hospital

Branson Auditorium, 555 Finch Avenue West
Toronto, Ontario

Books on the Autism Spectrum

Exiting Nirvana: A Daughter's Life with Autism. By Clara Claiborne Park. Little Brown and Company, 2001. ISBN: 0-316-69117-8. 240 pp. \$US 23.95. Reviewed for OAARSN by Lucie Milne

Exiting Nirvana is an account of the life of the author's autistic daughter. The story unfolds forty years of Jessy's life, starting from the almost mute eight-year-old she was in 1967. Jessy's first eight years are related in Clara Claiborne Park's first book, *The Siege: A Family's Journey into the World of an Autistic Child*. Neither book is a clinical account of an autistic person's development.

Each book is written from detailed records that Jessy's mother kept of every stage of her daughter's development: her language, her emotions, her interests and moods. Included is Jessy's social world and understanding /misunderstanding of other people, her capacities for logical and systematic thought and her strange obsessions. Oliver Sacks suggests that "there is more data on Jessy than on any other autistic human being who has ever lived."

Jessy's obsessions, or enthusiasms, as she calls them, have embraced numbers, colours, sounds and words to radio dials and heaters to roads and houses to elements of weather and astronomy. From her obsessions Jessy has constructed intricate systems of variables, all interconnected and correlated. Yet Jessy is blind to social meanings, facial expressions and intention in voices. Jessy's obsessions find form in her paintings that are detailed, accurate in line, and multicoloured with a brilliance that suggests surrealist art.

Jessy has had a privileged and highly stable life, with parents who were supportive and loving. Except for two stays in Europe with her family, Jessy has lived in one house. She has not experienced the changes and uncertainties of institutional or group home existence; she has attended local schools.

Her life has known the encouragement, interaction and attention of her three older siblings, as well as that given by caregivers and many young house mates/friends. Very likely Jessy's temperament or life mood has been generated by her family's intellectual and creative environment, her mother a teacher and writer, her father a theoretical physicist, and then there are her intellectually accomplished siblings.

Emotion and feeling in an individual, autistic or not autistic, develop with maturity, mainly out of pain, tragedy and suffering of living. *Exiting Nirvana* is not a sad story; it is upbeat. Jessy has certain feelings toward others, but they do not appear spontaneous. Her emotions and feelings have been taught to her, in a sense programmed into her. Her mother says it was important for Jessy to have manners, to look normal and to act accordingly. In order to learn responses to situations, Jessy was given role playing and she used cue cards to identify what her responses should be to questions and conversation directed to her.

I wonder about the title of this book. Nirvana is a Buddhist concept, a goal and state of having arrived at total Enlightenment. If an autistic individual lives in Nirvana, as the title suggests, they are already in a state of being enlightened. So how can or why would one exit into the enlightenment of a normal world? It is a strange oxymoron!

This book is for every reader, those who live with autism as well as those who do not. For the story demonstrates the meaning and need for our world and all its people to be the human beings we have been created to be, giving love and compassion, dedication and hope.

Paid for the Privilege: Hearing the Voices of Autism. By Dan Reed, 1996. A "Movin' On" book from DRI Press, PO 5202 Madison, WI 53705

A most engaging account of the author's experience as marketing director in a day center for about 100 adults labeled "severely and profoundly retarded and autistic" in the first half of the 1990s. All the early signs were against the job—so Dan on his first day thinks: "I want to run out of this place and never come back. I'll end up institutionalized if I continue working here." But he is struck when one of his new colleagues remarks: "Can you imagine growing up and spending your life—not around people that love you and want to be around you—but only with people who get paid to be with you? No free friends, only ones that are paid for the privilege."

The first few months were unpredictable, occasionally hilarious, always challenging and frustrating. Dan finds the largest stumbling block to finding jobs for the center's adults is communication. When he happens to see a TV program about a new technique called facilitated communicating (FC) he enthusiastically promotes its use. This book is a most readable story of how FC enabled adults with autism to express themselves, explain their dreams and fears, develop true friendships, and use their abilities. Experiences with sceptics and opponents of FC are recounted. A postscript presents a useful review of "New scientific approaches to challenge our assumptions about autism/ mental retardation" by Dr Anne Donnellan of the University of Wisconsin-Madison.

Five years after the publication of this book, everyone concerned with and for autistic adults could still learn from its messages

