

# Isaac's Story

From the Ontario Adult Autism Research and Support Network, 2001

*Isaac is an adult of nearly 40 who is quite severely handicapped by autism. He does not speak with his voice and finds it hard to show his feelings in ways others can easily understand. He tries, but cannot always control his movement disorders and sensory integration dysfunction. His life has been hard for him in various ways. But insights into how he experiences autism and the efforts of his parents and friends to help him get his life together have been succeeding.*

*Isaac allows his true story to be shared so it may inspire others. He hopes others will feel encouraged by knowing that he has taken several steps towards a better life. Isaac's story has messages for others who live with autism. But the combination of strategies that have worked for him would not work in exactly the same way for another person with autism.*

## **HOW ISAAC COMMUNICATES**

People who do not or cannot speak live with a very severe handicap. They have to learn to get attention and help in ways other than by using by their voices. But their disability is made worse by mistaken assumptions that they cannot hear or understand what other people say--even that they have no intelligence, thoughts or feelings.

Isaac understands most of what is said around him. He has also learned and uses several alternative ways of communicating needs, feelings and information. In the past, when he could not make himself understood, he might act out his frustration, thus communicating through his behaviour.

Isaac hardly ever uses his voice. He says it hurts to try. Occasionally, companions have heard him say something quite clearly. He will use his voice to protest when he is being urged or ordered to do something he is not ready for. At times when he is a bit excited, and less inhibited in his movements, he may hold a kind of discussion with himself, using two voices and accompanying gestures. He makes sounds that, if heard in the next room, sound like ordinary speech in which one can't quite make out the words. He gestures too, so it looks and sounds as if he is saying "On the one hand..." with a higher voice, then "But on the other hand..." with a lower voice. He uses his voice like this at times when his mood may be a bit volatile, perhaps when he is troubled or excited about something, but

sometimes too when his mood appears quite happy. He is more liable to move quickly, even break into a run at times when he has this kind of conversation with himself.

Isaac did speak as a small boy, at the age other children do. But he did not go through the usual stages of babbling. He said his words and phrases very clearly from the beginning. His first words were Car, Window, No, Bath, Book and Light. He did not say Mommy or Daddy and it was not till many years later that we knew he thought of us by our given names.

There were no services at all in the town where we lived when Isaac was little. So he spent about two years in a special autism program a 90-minute drive away. He stayed there for five days most weeks and we drove him back and forth for his weekends and holidays at home. As he sat in his seat in the back of the car, we used a simple way of communicating to check that all was well when he was quiet. We would click our tongue with an upward inflection, as in a question, and he would usually click his tongue with a downward inflection, in a reassuring response. We forget how we developed this very basic form of communication. But it's still useful. We may use it to check that he's OK at night, without turning on a light. It's one of several ways he uses to get our attention. He will also take us by the hand to whatever he wants to show us or to get our help with.

Isaac seemed lucky, compared with other young children with autism at the time, to get some formal service in the special residential program. The approach was intensive behaviour modification, with thousands of trials with rewards, to reinforce appropriate behaviours (including speech sounds) and extinguish inappropriate behaviours. Isaac disliked being away from home—but we did not know how

much until he told us much later with supported typing. At the time, he became sad-faced and thin and lost all his speech.

Isaac returned home to live when a class for children with autism was started in a nearby public school. With expert advice, he started to learn sign language—Signed English. From the age of 7, Isaac learned and has remembered hundreds of signs. He can still be a living sign dictionary for others. He will use signs with people who sign. It used to be thought that sign language would be the lingua franca in group settings for people with autism—as it is for hearing-impaired students at Gallaudet College in Washington DC. But for various reasons signing did not take hold in our region for children and adults with autism. As things have turned out since, most children and adults with autism do not go to school or live in such special settings. They are lucky if the speaking people in their lives learn to understand a few basic signs. Isaac finds that most people do not know or use signs, so he has too little practice, especially in stringing signed words together into signed phrases and sentences. But he does use and initiate well over a hundred signs for objects and activities of his everyday life. As well as the many formal signs he has learned, he has invented some of his own.

When Isaac was in his late teens, he was introduced to picture communication symbols. These were used to prompt him through a series of steps in self-help routines, such as dressing. Copies of commonly used symbols (with keywords), were also printed or photocopied and organized into a wallet, so that Isaac could pull it out and point to his need or choice. One idea was the sense that Isaac could cue himself better by visual aids, rather than by hearing people tell him (perhaps several times) what to do. Promotion of this system also recognized that other people—teachers, teaching assistants, support workers, family members—were not learning and using sign language, and that we could hardly expect people in the community to do so.

Isaac uses pictures and pictorial symbols today to cue him through new steps in learning skills, to understand and prepare for his day's activities, and to make choices. The American business that had marketed printed picture symbols developed a computer program so the stock symbols could be printed in colour and also adapted to suit individual needs. This is helpful, as the pictures can be made a bit more appropriate for Isaac's adult age and the unique features of his diet and way of life, and to express feelings. We've modified this approach to include photographs of Isaac actually doing his self-care routines or learning and practising other skills. As well, we've found that laminated cards with keywords also work, and that the pictures are not essential for him.

The other way Isaac communicates is the one he says is real and most reliable—supported typing previously known as facilitated communicating (FC). We discovered in 1991 that he is able, with some support, to type words and sentences about his feelings, needs and choices that he cannot express in any other way. He can open up more abstract subjects than he does with his other forms of communication. He expresses mature and responsible insights into his own life and the situations of other people. He uses precise and sophisticated words, and can turn a phrase that is distinctive, even poetic. He clearly expresses ideas and information that his facilitators did not know. He was fortunate to get the use of a device with text-to-speech output in 1992.

But, you say, wouldn't that mean that Isaac can read and spell? But he's never formally learned! And isn't FC discredited? It's really just the facilitator influencing the poor dumb person, isn't it?

All we can say is that supported typing works and is real for Isaac. We deplore the way so many professionals and administrators rushed to FC at the beginning, as if it were a cheap cure or treatment for everyone with autism or any other communication impairment. Its relevance to each individual should have been more closely studied, and facilitators should have been much more carefully trained. The severe backlash against FC is hard to understand, compared with reactions to other treatments and therapies that did not quite fulfill their first promises. An effective veto on the use of FC for all people, including a significant group for whom it was effective, was and still is a tragedy. Isaac was very upset about the loss of official support with his typing for several years. Fortunately he still had his computer-

*When Isaac was diagnosed with autism and when he lost his speech, we were devastated. Now we can look back on Isaac's life so far and respect him for his successful efforts to learn several alternative communication systems. We know that, though he does not speak, he definitely does have things to say.*

with-a-voice, and was able to keep going with his mother's support. In 2000, he reached professional help again and, since then, he has made notable progress. By using a mix of his various communication systems, we can be sure that he really means what he types. He continues to amaze us with his ideas and use of words.

### ***ISAAC'S DESIRE TO LEARN***

People with autism who are said to be “nonverbal” because they do not speak, are among the 75 per cent who are assumed to be mentally retarded. Our experience with Isaac makes us question the meaning of this statistic.

How do we measure intelligence in someone who does not speak? Or whose disabilities may have cut him off from the mainstream culture that is assumed in standardized tests? Or who will be very anxious in an unfamiliar testing experience with people he does not know for a purpose that has not been explained?

Beyond the questions of whether and how to test, there are further questions of “so what?” Do we simply categorize Isaac and all others who do not score well on verbal intelligence tests as “mentally retarded” and leave it at that? Should they be cut off from opportunities to learn? Because they do not learn in the “normal” way, should their time be occupied only in learning to tie shoelaces, or cleaning airline headsets, being shepherded on group outings, or even left alone? Why don't we try to understand each individual's different abilities, interests and ways of learning?

Isaac belongs to a generation of adults with autism who were observed as young children not to show good eye contact or to sit still in group situations. If a child could not speak by the age of six, he was assumed to be globally retarded and not worth the effort of being taught to read or use numbers. Children with such disabilities were considered fortunate to be in special small classes in which the emphasis was on functional life skills like dressing and walking to the supermarket. A few may have had dedicated teachers or assistants who saw and encouraged special abilities. But the age span in a special class (not uncommonly from 4 to 15 years) made it hard, if not impossible, for the teacher to stimulate real learning even for the children who could speak and considered higher-functioning.

Isaac was observed to have a remarkable memory, which he applied in learning so many signs. But no efforts were made with academics. He liked his teacher and coped fairly well during several years of living at home and attending the same special class. But most of the various ways he coped were dismissed as “cueing”—trying to read the intention and meaning of his teachers and assistants from their total body language, not just from their words. That seemed to us a promising skill rather than something to be dismissed as a sign of low IQ. When he had to go away to a special school as a teenager, he was less happy and developed some frustrated behaviour.

Only in the 1990s has it become clear that Isaac learned informally some skills he was never taught formally. With FC (facilitated communicating) he said in 1993 that he taught himself to read as a young child, before school, when his parents read him stories and he followed the printed words in the books. From the age of two, he loved to look through books in his home, especially reference works. The big Webster's dictionary was a favourite. We always noticed that he liked to listen to conversations in which irony played a part. He would show his appreciation with a chuckle, even when the irony was quite subtle and not signaled by the speaker's smiling or laughing. When he relaxes, he must have reading material and be able to listen to classical music. In what he expresses with supported typing, it is clear that he loves words, including long ones with precise shades of meaning. He surprises us with his choice of just the right expression. He also uses interesting images and turns of phrase.

*It seems to us that people with autism whose learning interests and capabilities were not detected or developed when they were children, and who show real interests as adults, deserve another chance.*

For the past few years, Isaac has told us that he wants to continue learning, including formal “subjects.” He is interested in all aspects of “the environment and how we can save it.” He also likes history and politics and has good grasp of current events. He has voted in elections at all levels from municipal to federal, and expresses remarkable insights into the issues. He has asked to learn about the brain so that he can understand what is different in people with autism. He wants to know more about people who

have done something worthwhile with their lives despite significant disabilities like autism. He is interested in music and art.

We have not yet been able to respond adequately to Isaac’s desire to continue learning. We have not managed to interest community literacy programs in his special interests and ways of learning. We know that others who have movement and communication differences like his (and even more severe), have developed their academic skills with the help of FC so well that they attend university and college. He says he would like to follow their example, but that he is also “practical” and sees that he must have “strategies” to prepare himself to do so.

Isaac knows the story of Helen Keller—how, with the persistence of Anne Sullivan and others, she learned to rise above her disabilities and contribute to society. We need to organize a process of learning so that various tutors and others who believe in Isaac’s abilities can support him consistently. We are searching for learning materials that are appropriate to Isaac’s age but also use various media to stimulate all his senses—in images, sounds, touch and real-life experiences, as well as the printed word.

### ***STRUCTURE IN ISAAC’S LIFE***

All his life we have observed, and now Isaac tells us too, that he must have a “regular structure” that is predictable. Resistance to change and attachment to routines and rituals are key diagnostic features of autism. We may also explain these traits in a more positive light. Structure is reassuring--something familiar to hold on to amid the turmoil of an unreliable sensory system and movement differences. Structure also gives him a framework of order and pattern of behaviour, so Isaac can try to conform to normal everyday life as much as possible. We understand that for him, regular structure has time, place and human aspects.

#### ***Time Structure.***

A regular timetable or schedule gives shape to the day and provides a balanced alternation of active and quiet activities. Isaac’s sensory diet fits into his total daily schedule. He has a large weekly timetable board that shows both the daily routines and the weekly events or activities. The timing of tasks and activities is helped by strip sequences of picture exchange communication symbols, especially when a new skill is being mastered or as cues when he is having a hard time integrating sensory information.

When Isaac finds transitions difficult, he is helped by advance reminders of what comes next. For example, as he returns home from a walk or travel in the car, we talk about the next activity so he can prepare himself. A “time-elapsed” clock can be set to guide him as to how long he has to get dressed, soak in the bath, or continue working at a part-time or volunteer task. Once a regular structure is in place, he can make transitions without direct prompts or commands if asked “What next?” in sign or words. He is much more likely to become less dependent on the constant reminders (even nagging) by others if he has a good sense of the regular structure of his life.

What happens when pieces of his regular schedule don’t happen? Isaac can be thrown off course when his day does not unfold as he expects. A few years ago, when he was very upset in the wake of his adverse reaction to drugs, it was hard to get going for the day. We found that a predictable sequence of getting dressed, breakfasting, doing personal hygiene, and then taking his dog for a long walk gave him a sense of purpose. Skipping the morning walk for any reason is not a good recipe for the day. Going to sleep without his long bath does not augur well for his night’s sleep. Long weekends and holiday periods, when regular structure may be suspended, can be hard. So can times when an expected tutor or friend does not arrive or when one of his parents is ill or away from home.

*Consistency at all times should not be expected of people with autism; nor should they be blamed (or made to feel at fault) when they are having difficulties. On the other hand, they are helped by consistent (and positive) approaches by the people who support them.*

#### ***Environmental Structure:***

New places are usually hard for people with autism. When families move house, a child with autism is very sensitive to the changes, not just in the layout of the home but also in the total neighbourhood, shopping centre and supermarket, play park, and of course school. Just

changing from one school to another is hard enough. An adult with autism is also very attached to familiar places. It's been said that a person with autism takes at least six months to get used to a new house or school or work setting, but for some it may take as long as three years.

More than we may imagine, the person with autism has made big efforts to learn the layout of his environment and will be very confused and angry at having to change. We can make the adjustment easier for a person of any age by composing a social story that explains what is happening and why, and that suggests strategies the person may use to get accustomed to the new place. When it's necessary to visit a new place, such as a medical building where a new specialist has her office, it's also wise to reconnoitre the place ahead and rehearse the visit.

The detailed environment of a person with autism should also be considered for its sensory content. While some of us like to have a lot of stimulating interest and colour in the decor of our homes, we should consider how colour and clutter may affect someone with an unreliable sensory system. Bright colours and juxtaposed objects and images may be impossibly "noisy" for them, like loud discordant music. Isaac likes a sense of space and lightness, and his favourite colours are green and blue. He likes the order and harmony of classical music and natural sounds.

Within a room or space, Isaac likes things to be in their proper places—or at least the way they were arranged when he first saw them. It's just as well if the arrangement was tidy then. His extreme sensitivity to detail may mean that he must get up from the table to close a drawer a millimetre more exactly, when anyone else would have thought it perfectly closed already. Or he can tell that someone has not switched off a light in another room (which he cannot see). Or he will concentrate on trying to remove minute wisps of hair or dust from a cloth surface. Sometimes Isaac's behaviour in trying to tidy his environment may irritate us. We may be concerned that others will be offended if he seems to want to enter their personal space. We would like to train him to refrain from touching other people's things or getting too close.

Isaac's passion for order can be channeled into useful habits. He does a great job of putting away clean dishes from the dishwasher and in drying and putting away dishes and flatware washed the old-fashioned way too. He remembers where everything is and can get needed tools and supplies from their storage places.

### ***Consistency of Support***

For Isaac, structure also extends to the way people relate to him and support him. To cope, he needs people around him to share basic understanding of the signs that he gives as to his intentions and needs. To grow, he needs his support people to share positive expectations of what he can do for himself.

Consistent understanding by the support people around him is all the more necessary as Isaac himself is not the same all the time. Indeed he can be very different indeed—from restless and hyperactive, through calm and balanced, to quiet and withdrawn. It's important to realize that when he is calm and balanced, his sensory and movement differences have not gone away. Through trying hard and consciously, he is just able to keep them under control. Nor is he being "good" when he seems calm and balanced and "bad" when he is either restless or extremely withdrawn.

We now know that discernment of sounds and stimuli is not constant for people with autism like Isaac. Sometimes things come together and are understood; sometimes not. Donna Williams, the Australian writer who has autism, has helped us to imagine what it is like to see or hear things differently, and how important it is for supporters and carers to be patient and provide encouragement and timely information.

It's important to Isaac that people show that they understand that it's hard for him to co-ordinate his senses and movements just about all the time. Having others affirm this understanding from time to time helps him to keep going. It also helps him to know that his friends and support people realize that he is more intelligent than he may seem when he cannot speak his thoughts and is sometimes delayed in interpreting and acting on sensory information.

New support people might react to Isaac's real challenges by feeling so sorry for him that they do too much for him that he can do for himself. He would accept such personal service rather than showing that he can manage by himself. Or, when he does not act immediately in routine situations, some people may

repeat commands to do this or that. He does better when given a little time or an encouraging sign to keep going with tasks that he knows very well.

As well as understanding Isaac's need for regular structure and trying to develop this positively in his life, we know that he needs help to become more flexible in accepting change, learning new skills, and facing new experiences.

### ***HOW ISAAC LEARNS NEW SKILLS***

Structure helps Isaac to cope with the turmoil of his sensory and movement differences by providing a framework of familiar routines for his daily life. But we must take care that he does not become trapped and isolated within an unchanging system of order. He needs respect for the importance of structure in his life. He also needs imaginative stimulation of his interests and abilities and patient encouragement of flexibility to learn new skills and face new experiences that will enhance his confidence and dignity.

From a practical point of view, we like the idea that Isaac could learn more life skills and thus become less dependent on others for personal support in repetitive daily routines. The benefits justify big efforts in encouraging him to become more self-sufficient. He has proved that he can learn new skills and there is scope for many more—caring for himself, his house, garden and dog, and working for pay and as a volunteer for the community. He also says that he really wants to have new experiences, especially in travel and learning.

To find effective strategies, we must understand the points of view of Isaac and the people who support him most directly. For Isaac, departures from familiar routines are very hard, especially if they are not explained. As for others with autism, it's difficult to take the initiative. This challenge is made greater by the long years of having others decide and do things for him. His first automatic reaction to a quick question or suggestion that he do something new for himself will almost certainly be negative. His first efforts may seem very slow and unpromising. The easiest, quickest and perhaps safest response is for parents and support workers to continue doing just about everything for him. But this won't help Isaac grow.

Isaac may fear that, if he does become more self-sufficient, the friends on whom he now depends will disappear from his life. That is a reasonable fear, as caregivers and their administrators focus on very basic forms of care. Isaac needs to know, and we have to ensure, that he will still have friends with whom to share activities that are more fulfilling and just as necessary for his mind and spirit as basic self-care routines are for his physical survival.

We also sense that, after years of having his life ruled or at least shaped by others, Isaac has certain areas in which he particularly resists change—as a way of asserting his control. These areas of resistance can get in the way of learning new skills and having new experiences. Isaac is most resistant to wearing a wider range of clothing that is appropriate to the season or the occasion. He may agree in social stories and FC that he really wants to be more flexible. But it may be virtually impossible for his emotions and sensory system to act on this understanding. We need ways to affirm that he can have self-determination and control in important and more positive ways so he can move on to become more flexible in such holdout areas.

### ***What strategies are useful?***

1. Suggesting a new skill or experience that is going to be useful, frequently repeated in everyday life, and personally fulfilling and enjoyable.
2. Thinking of the sensory implications: Will the movements and co-ordination be possible, not too strenuous or uncomfortable, and also positively good for sensory feedback?
3. Discussing the advantages and challenges of the new skill or experience well in advance, using social stories, asking for comments with FC, and considering the new activity from different points of view—preferably with several friends or support workers reinforcing the idea with their own perspectives and so building up his confidence.

4. Learning and practising the new skill in the appropriate location—rather than rehearsing it elsewhere first. If the location is new and strange, it's important that the supporter or companion be familiar and trusted and the environment be simple and quiet.
5. Planning the first learning and practice of the new skill on a day when Isaac is not having extreme difficulty with his sensory integration and movements, and is able to concentrate. Choosing times when he is able to co-ordinate everything sets up the experience for success. On the other hand, it is hard for Isaac if his companions and support people interpret his fairly rare times of difficulty as the norm and gear all his activities to a lower level of expectations.
6. Modeling the actions involved in the new skill, first showing him and then helping him to practise them with hand-over-hand guidance. We think it's wise to use hand tools because they are quiet and safer and allow Isaac to go at his own pace. If the actions are complex, consider teaching them in steps, with Isaac perhaps doing the last stage, then the last two, and so on backwards until he is handling the whole process.
7. Cutting words to a minimum and definitely not repeating commands if he seems slow and needs more time for processing. Signs and picture communication symbols help, as do photos and videos of Isaac actually doing the work. He responds much better to signs for "Keep going" and "What next?" than to direct spoken cues about what specific actions he should take. Avoid extravagant praise: it's better to express quiet confidence that of course you know he can do it.
8. Defining a quota of work to be done—in output or throughput or length of time to be spent—and understanding what will come next. "We'll shovel half the driveway, to this point. Then we'll take a break, and do the rest later." "When we've collated 150 packages, we'll go to the library." A special clock that shows elapsed time can visibly define the time to be spent on an activity.
9. Persevering if the first trial of a new skill does not go well. We find it can take four trials (with much patience and positive thinking) for Isaac to feel comfortable with a new work skill in a new location. But then the skill is never forgotten and will be done well even in the hard times.
10. Debriefing with FC, so he can comment on his experience in learning a new skill and to make suggestions and requests we might not have considered.

There are dozens of useful and necessary skills still to be learned. Shoveling snow is certainly useful and relevant. The actions of pushing and lifting with hand tools give Isaac a sense of his body as well as healthy exercise in the fresh air. He understands that it's necessary to clear the driveway so his visiting friends have space to park and so his parents can get out the car to drive him to community events. The visibility of the "white stuff" helps him to know what's been done already and where to shovel next. Learning to shovel snow can be extended into other sweeping actions—using a broom inside or out, a garden rake or a vacuum-cleaner.

Isaac's desire for new experiences, especially travel, calls for many complex skills. FC and social stories prepare him cognitively for what he must expect and needs to practise. He is approaching the experience of travel gradually, in stages from the most familiar. He walks his dog Missy quite independently around his home neighbourhood—a process that took three years and involved him in making decisions when something unexpected happens. The next stage is learning to use public transit, which has been a goal for even longer. He loves drives in the family car, especially to parkland destinations where he can walk with Missy, and he now accepts rides in the cars of other friends. But his favourite mode of transport is the train and he says he'd also like to fly to California. Clearly there's lots of scope for him to learn new skills and practise more flexibility and initiative!

### ***ISAAC'S SPECIAL DIET***

"We are what we eat." This old saying has special meaning for people who are allergic to or intolerant of particular foods. Many people with autism have been observed to be hyper-reactive to various foods and to have chronic gastrointestinal problems.

For nearly four years, Isaac has followed a diet that is completely gluten-free and casein-free. For some years before that, his diet used alternatives to wheat and cow's milk in any form or trace, and also

avoided any sugar, potatoes, tomatoes, yeast, coffee, alcohol, or chemical additives. For the past 18 months, following sensitivity tests, his diet has been further limited to exclude most fruit and fruit juice, corn and peanuts.

### ***Why change the diet of an adult with autism?***

Isaac has had gastrointestinal problems throughout his life. From infancy, he had alternating bouts of constipation and diarrhea—with resulting discomfort, shame and sleeplessness. Many features of “best practice” when he was a baby may have hurt rather than helped, including the early introduction of solid foods. Some autistic children of the same age in the late 1960s were diagnosed with celiac disease and the use of substitutes for gluten in their diets may have helped them. We restricted Isaac’s sugar intake when we could see a link with hyperactive behaviour. But through the 1970s and 1980s professionals did not see that gastrointestinal problems might be relevant to autism and parents’ observations were not taken seriously.

By his twenties, Isaac’s life seemed to have a 6-8 week cycle of moods and behaviour including gastrointestinal symptoms. When he was in the most distressed, sleepless and hyperactive phases of this cycle, some of his caregivers felt they had to administer anti-psychotic drugs so they could control him. The drugs always had contrary or paradoxical effects, winding him up to even more extreme distress, perpetual motion, and noisiness that could last several weeks. Isaac said that the drugs “scrambled his brains.” When medicated, he would also binge on foods that contained casein or gluten.

After one prolonged period of distress, we decided we had to act on our observations. We refused permission for any more drugs. Through a series of tests by allergists, naturopaths, and dieticians, we found that Isaac was intolerant of wheat, cow’s milk, sugar, potatoes and coffee—in any trace or form. His diet was immediately modified to use substitutes for all these, with menus and recipes that were appealing as well as nutritious. Tomatoes and yeast were later added to the list of forbidden substances. Isaac responded very well to the changes—in his health, physique, behaviour, and approving comments. His need for a special diet has been proved by what happens when it is occasionally “challenged.” Suspect foodstuffs have been deliberately re-introduced in “blind trials” to see the effects on moods, behaviour and sleep patterns. Isaac reacts sharply to these trials—in hyperactive and anxious behaviour, insomnia, food raiding and bingeing—as he does also after mistakes are sometimes made by his caregivers and companions.

Early in 2000, we read Karyn Seroussi’s book *Unraveling the Mystery of Autism: A mother’s search of research and recovery*. We learned of research findings and experiments that explained how people with autism could benefit from special diets.

According to the theory, some children may be born with a genetic predisposition to some dysfunction in their immune systems. If triggered by trauma, viral infection, multiple vaccines, or environmental toxins, the dysfunction may damage a child’s metabolism and neuroimmune system. The child may not be able to digest certain foods properly, especially those containing gluten (the protein in common grains including wheat, oats, rye, barley and spelt) or casein (the protein in all forms of dairy products). Peptides (breakdown products of proteins that are not properly digested) may enter the bloodstream and cross the blood-brain barrier; they are called opiates because they affect the nervous and sensory systems, moods and behaviour in ways that are like the effect of drugs. Prolonged exposure to such substances may mean that these effects seem to become ingrained. In addition to gluten and casein, a child may not tolerate or may react to other foodstuffs, such as sugar, yeast, potatoes, tomatoes, citrus, eggs, corn or soy.

We know that almost all the research and support around diet and autism is for young children. We dare not hope that Isaac’s autism can be cured when he has lived with it for so long. But all the efforts to support his special diet has been well worthwhile, to make him feel more comfortable and regular in his digestive system and sleep patterns, and for him to achieve a calmer balance in his moods and sensory system. We are encouraged to read of professional support for what we began on our own for our adult son. Stella Waterhouse, in *A Positive Approach to Autism*, for example, recommends that every child and adult with autism should be assessed professionally so that digestive problems, intestinal/bowel disease and/or food intolerances can either be eliminated or the necessary treatment implemented.

### ***Challenges of a special diet***

Shopping and food preparation require much more time and concentration. Practically everything has to be made from basic ingredients that have to be searched for in a greater variety of places than in the nearest supermarket. Even in health food stores, it's challenging to find packaged breakfast cereals or baked goods that are free of all gluten, casein, sugar and yeast. It can be hard to find dairy substitutes that are nutritious and do not contain gluten or sugar. We get a lot of practice reading lists of ingredients but occasionally make mistakes and buy things that contain forbidden substances. A special diet can also be more expensive. Substitutes for dairy, gluten and sugar can cost at least three times as much. Cooking with basic ingredients can be cheaper but involves more time and creative thought.

A special diet may seem to limit Isaac's and his companions' experiences. A typical adult consumes a significant part of his food in restaurants and fast food places. Isaac used to like snacks at Tim Hortons coffee shops while traveling, but none of the fare there is free of the substances he cannot tolerate. Restaurants that offer Isaac-friendly dishes are rare. Friends may feel inhibited in inviting Isaac to their homes for meals. But he is very happy to take his own snacks along and to join others in social gatherings.

Families contemplating a special diet for a child or adult with autism may also have to convince their health and other professionals. For laboratories that can test urine or blood, we usually have to go to the US. And once a diet has been followed for more than a couple of months, the tests may not be valid. It's possible to get a dietician's help in "challenging" a special diet once it has begun—systematically introducing the forbidden substances, one by one, and recording the effects.

Like other parents who have tried a GFCF diet, we would say that it has been completely validated by the improvements in Isaac's health, sleep patterns, digestive processes, and his more balanced moods and happier general outlook. Isaac's doctor was very supportive about his special diet; she liked the freedom from invasive drugs and expensive treatments. The diet has been checked by community dietitians who found that Isaac gets all the essential nutrients. They also said they found our information and experience helpful in their work with children who have autism.

Other families report that it can be very hard to implement a special diet because the child with autism may have a narrow range of preferred foods already and other family members may resist changes. Fortunately, we did not find this with Isaac, and our family accepted the changes with a very good grace. Our dinner meals are almost always made of ingredients that Isaac can eat. Breakfast and lunch may be more individually planned. We make meal times warm and welcoming. And we have been adventurous in trying out new ingredients and creating new recipes. We imagine we are in other parts of the world where the staple diets do not include gluten or casein.

### ***Sensory Integration: How Isaac Benefits from its Insights and Techniques***

Isaac now has a sensory diet as well as his nutritional diet. What is this? How does it help?

We wish with all our hearts that we'd had the knowledge and insight, more than 30 years ago, to see that Isaac's diet and sensory system really matter in helping him to cope with life. If he had been born 30 years later, prompt action with a gluten-free and casein-free diet might even have alleviated some of the worst symptoms of autism. We might have understood his unusual movements and rhythms and his reactions to all kinds of sensory stimuli as somehow associated with his biology, and with the effects of toxins and opiates on his nervous system. He might have been spared years of judgmental attitudes towards his "disruptive" and "odd" behaviours and some inappropriate and ineffective attempts to "manage" them.

Soon after Isaac was diagnosed with autism at the age of 4, we recorded our observations of ways in which his sensory reactions and behaviours were different from the norm. Responding to the questionnaire distributed by Dr Bernard Rimland of the Institute of Child Behaviour Research in California, we noted that Isaac did indeed seem to have unusual reactions to sensory stimuli of various kinds.

1. He seemed oblivious to some sounds (so we wondered if he was deaf) but hypersensitive to others. We found that classical music, lullabies, soft voices could soothe and calm him when he was most hyperactive and distressed.
2. He found it hard to be in crowded and noisy places or to accept change in his environment. He reacted in unusual ways to spaces and places. In any new environment, such as the hospital waiting areas where we had to spend too much time, he seemed to need to explore its outer boundaries and would move compulsively around the walls. When visiting familiar places, he wanted to restore everything to the way they had been the first time he saw them. He had a remarkable spatial memory. This meant both that he would insist on taking the same route to a particular destination and that, on his many explorations, he might seem to others to be lost but could usually find his way back.
3. While his fine motor skills were very good, he might “walk through” other people, as if unaware that his body was solid and would have an impact. Or sometimes he found it hard to walk in a straight line.
4. He did not typically walk on his tiptoes (“toe-walking” is noted in a significant number of children with autism) but at some times he did find it hard to walk on hard or shiny surfaces. So he might move about a room climbing and stepping from one item of furniture to the next.
5. He seemed unusually sensitive to heat and humidity. His body easily became over-heated and took ages to cool down.
6. He developed a habit of rocking rhythmically and very vigorously—either crouched on all fours and using his forehead as a battering ram on the headboard of his bed, or sitting on the floor and rocking hard with his head and shoulders against a wall.
7. He found that he could make all his joints crack—in his knuckles, wrist, ankles and neck—as if that relieved some pressure or cramped feeling.
8. He seemed to find vigorous and rhythmic exercise satisfying, and liked to swim, walk, run and cycle. He tended to be active, even hyperactive, almost all the time, and found it hard to sit still and concentrate. But sometimes, becoming too fast and vigorous with any of these seemed to wind him up more and he could lose control.
9. He reacted unusually to some foods based on their temperature and texture. A frozen dessert would give him a sharp headache, and he preferred crunchy or chewy foods.
10. As an infant, he was stiff and awkward to hold, and resisted touch by arching his back and holding his head back. Later, he could sometime seem to enjoy a bit of tickling and, during bedtime stories when he was weary and relaxed after a bath, he could be relaxed and almost “cuddly”.
11. He seemed unusually sensitive to the feel of clothing, disliking items with fleece linings or that fitted too snugly.
12. Isaac’s sensory reactions seemed most unusual and extreme when he had several stimuli together and/or when he was most sleepless and/or in new environmental settings. More extreme reactions seemed also to be correlated with ups and downs in his digestive system. At such times he was more likely to lose all control and have a full-scale “tantrum” as it was then called.

How did Isaac and all around him deal with what were then called his “bizarre mannerisms” when he was a child and teenager? We can now understand that some of Isaac’s unusual behaviours may have been efforts to cope with sensory stimuli that were confused and confusing. By rocking or running, he could feel his body and perhaps drown the confusing melange of other sensory signals. By cracking his joints, he could ease cramps or numbness. Other people, though, tended to view his unusual movements as aberrant and wilful behaviours that should be extinguished while reinforcing good and socially acceptable behaviours.

As Isaac grew bigger and physically stronger, and could no longer be held still, some of his caregivers felt that more drastic measures were essential to keep him quiet. Antipsychotic and antidepressant medication were both used, but without systematic records of dosages and reactions. The drugs tended to increase the hyperactivity and noise and what was seen as self-abuse and aggression. He could get so wound up that he would be in perpetual motion for several days until he crashed. If he were away from

home, his caregivers would administer more drugs, which had further contrary effects. The noisy hyperactive time would be prolonged. The meltdown would be more catastrophic and followed by a catatonic reaction of up to a week. He might be roughly treated at such times, and would be told he was “bad” in his behaviour.

It is only in the past few years that we have started to apply the theories of sensory integration dysfunction to help Isaac to cope with his sensory and movement differences. We looked at their books and listened to the taped presentations by Temple Grandin and Donna Williams, whose personal experiences have become known during the past 10 to 15 years. However, when we read about the Temple’s hug machine or deep pressure therapy, we assumed that Isaac’s hyper-reactivity to touch, texture and confined spaces would mean that he couldn’t bear even to try these. As Isaac was already an adult before these presentations, he was also beyond the professional resources that might be available to children with autism.

Several factors combined to make us take notice of the ideas and techniques of sensory integration. One was our decision to support Isaac to get his whole life together about seven years ago. He probably could not have benefited without his integrated way of life, consistency among the various caregivers, and opportunities for observing and recording his differences and difficulties and generally supporting him around the clock. Through his use of FC, we also became aware of the concept of movement differences as a way of understanding autism, first through reading the 1996 article by Martha Leary and David Hill in the journal *Mental Retardation*. It made sense to think Isaac, like others, had differences or difficulties with movements as a result of their unreliable sensory feedback, especially when starting, executing, continuing, stopping, combining and switching movements or actions. Isaac also began to have some occasional experience of relaxation therapy and said that it helped him to accept others touching him. We were also very keen to find ways to help overcome his extreme reluctance to wear new or varied clothing.

So we sought and found professional help in this field. These and other resources are listed at the end of this article. It was very helpful to understand the theory of sensory integration with special reference to three sensory systems--tactile (touch), vestibular (movement and gravity), and proprioceptive (awareness of body position). After consulting with several professionals, we introduced Isaac to the idea through some social stories and specific treatments. He has now had a full sensory diet for six months.

Throughout his day, Isaac has a planned and regular schedule, with a balance of active or quite strenuous physical movements alternating with quiet sedentary pursuits and phases of special kinds of rest and relaxation. Many of the activities are functional and their sensory value may be incidental to their other purposes. Some regular activities use techniques and equipment that have been specially designed for people with sensory integration dysfunction. Some techniques and equipment may be used mainly or more often when Isaac is having a particularly hard time.

1. First thing in the morning, before dressing and breakfast, Isaac goes through the “Wilbarger protocol” of deep-pressure brushing of his arms and hands, shoulders and back, legs and feet, followed by joint compression in the same areas. The routine takes about five minutes. When he began in early 1999, Isaac had this treatment every 90 minutes through his waking hours, but the intervals were decreased until the present maintenance level. Sometimes he has a second treatment in the early afternoon, or when he seems to have problems with his sensory system, or when he is preparing himself for a new experience.
2. At his meals, or when seated for reading, typing or working, he sits on a specially inflated cushion which effectively helps him to concentrate and stay on task.
3. He is usually able to concentrate on seated activities for quite long periods, but it’s best that he take regular “body breaks” at least every hour. A break may be informal, when he leaves what he is doing to walk about for a minute or two, and then returns on his own initiative. Or it may be planned and built into his schedule--reading books and magazines with music, or doing some breathing exercises, or 15 minutes of yoga. Or he may lie for five minutes under a special, weighted blanket on a daybed and listen to classical music for 5 to 10 minutes. He does this also to prepare himself for a new interaction or experience.

4. Some regular activities each day have sensory integration benefits. He walks around his neighbourhood several times a day with his companion dog. The physical exercise of walking, even without a dog, would help him. But holding on to Missy's leash and being pulled along by her seem also to pull his sensory system together. Walking with his dog helps him to walk in a straighter line, to keep to a path or track, and to cope better with changes in slope and terrain. His coats and jackets have weights in the pockets or sewn in the linings.
5. Cycling, horseback riding and using exercise equipment in a gym could also help, but are not regular parts of Isaac's schedule as they require special personal support and transportation. He is lucky to be able to swim regularly and benefits from the sensation of being surrounded by water as well as from the physical exercise.
6. Various kinds of physical work also have sensory as well as functional value. He sweeps and vacuums floors in his home, and uses hand tools like shovels, rakes, spades, shears and saws. He fills, pushes and empties a wheelbarrows and garden carts.
7. With any physical activity, as with everything else in his life, balance is the watchword. Having an extra long walk or very strenuous period of exercise, especially on a hot day, may wind him up so much that he cannot then relax.
8. Meal-times must be quiet and reassuring times. For other kinds of body breaks, he also likes to play cards and table games and do jigsaw puzzles with small groups of friends.
9. Last thing at night, every night, he has a long bath with Epsom salts added to the hot water. Though others might find it helpful, he usually chooses not to sleep under a significant weight of bed-coverings.
10. When he is having a hard time, when he cannot concentrate or is very restless and agitated, it's helpful to lie under the weighted blanket on his daybed more often and for longer. He also has weighted vests, and wrist and ankle weights, which he may wear to help him concentrate while walking or continuing active tasks. At times when he is very slow, and the muscle tone in his limbs seems weak, it may help to wear the wrist and ankle weights and for his hands to knead small exercise balls.

Now that Isaac and his companions have the insights and techniques of sensory integration, his moods and movements have become much more even. He feels a lot better now that others understand that he "can't help" his movements and that they support his efforts to "do my best." Being better able to control his movements and sensory reactions and to avoid the conditions that might lead to meltdowns, he is able to continue his learning and work activities more regularly.

### ***How Sleep Hygiene Helps Isaac***

Isaac has always had unusual sleep patterns and difficulties. As an infant, he was at his social best in the evening. Throughout his childhood, he found it hard to drop off until the early hours of the morning and would not always succeed then. He would try to lull himself to sleep by rocking his body, but the rocking could become so vigorous that he would wreck his bed and be more wideawake than ever. And so would everyone else in the household. Or a brief sleep would be broken by nightmares and he would scream in distress. He would get up during the night to read or explore or raid the fridge. We feared that he might slip out of the house.

During the day, Isaac's mood and behaviour might reflect his lack of sleep. One night's sleeplessness would not be balanced by a sound sleep the following night. More likely, lack of sleep would only predispose him to insomnia the next night, and so on.

From his early years, we noticed that there was some connection between his disturbed sleep patterns and signs of discomfort in his digestive system.

When and if he did sleep, he found it almost impossible to wake at a convenient time to be ready for the school bus or to fit anyone else's schedule. Letting him sleep in on a weekend morning, so others in the family could also catch up on some sleep, would also make him less sleepy the next night.

Family doctors could suggest only drugs to knock him out. "The medication won't help Isaac, but it might help you get some sleep so you can cope better during the day," we were told. But Isaac had

contrary and paradoxical reactions to drugs. A tranquilizer or antipsychotic drug only wound him up into more intense wakefulness and hyperactivity. Isaac did not get medication at home, but caregivers at his residential school or, when he was a young adult, his group home, insisted on the drugs at times when they felt they could not otherwise manage him.

A string of sleepless nights might be followed by a crash, a sensory and emotional meltdown after which Isaac collapsed into torpor and eventually woke numb, even catatonic. He would lose control of his bladder and bowels in such deep sleep, get out of sync with the daily timetable which gave some structure to his life, and regress with various self-care skills. He might be slow, even frozen, in his movements for up to a week after such a meltdown.

During the past five years, Isaac has at last been able to make us understand, with facilitated communicating, how the drugs made him feel, and about his nightmares. For most of this time, he has lived in the same house, with caregivers who observe him and support him in helpful ways that help.

First, we have done everything we can to help him relax and to allay his anxiety (without many medication). He has learned to tolerate, even welcome, various sensory integration strategies and has a sensory diet (described in another article in this series). Relaxing under his weighted blanket helps when he feels wound up and in danger of the restless hyperactivity which used to kill his sleep. He uses this aid proactively, as well. He has had very good experiences of relaxation therapy, yoga, therapeutic touch and reflexology. He finds that classical music calms him.

Second, we believe that Isaac's special gluten-free, casein-free diet has helped a great deal by easing cramps and pains in his digestive system and in reducing or eliminating the toxins that used to bombard his nervous system. He gets up in the night much less often to go to the bathroom.

Third, his home environment and daily schedule are designed to be calm, positive and reassuring. Earlier, we devised a schedule of activities so that Isaac felt there were good reasons to get up in the morning. Having his own dog to feed and walk after breakfast was one effective way. We also use social stories and other cognitive methods to allay his anxieties, and to help him to prepare for change and to understand and cope with disappointments.

Fourth, we do all we can directly to help Isaac to enjoy restful sleep. He avoids evening activities that are too exciting. Every night, before bedtime, he has a hot bath in which 500 grams of Epsom salts have been dissolved. After a shampoo, he lies in this relaxing solution for at least 30 minutes, and listening to classical music. His parents or other companions support him with affection through the routines of preparing for sleep, talking calmly about the day that is ending and looking forward to the next. He now seems to fall asleep much more easily and to have uninterrupted nights 98 per cent of the time. He sleeps much better if the air temperature of his room is cool. If he does not sleep immediately, he is usually able to lie quietly in his bed. If he has to visit the bathroom, he almost always returns to his bed and to sleep. Exceptional nights can be explained by emotional and other worries, by sudden changes in the weather or in his life, or by having consumed foods he cannot tolerate.

Fifth, we have found that Isaac needs more sleep than we had expected--at least ten hours a night. As he does not live with other people with disabilities or attend a group program during the day, we have been able to adapt his schedule to suit his biorhythms.

The best book we have found, for sleep disorders generally and autism in particular is: V. Mark Durand, *Sleep Better! Guide to Improving Sleep for Children with Special Needs*, Baltimore: Paul H. Brookes, 1998.

### ***ISAAC'S HOME***

Since he was a toddler, Isaac's family home has been the same middle-sized house in a middle-sized town. But he spent most weekdays away at special schools and adult programs from the age of 12. Only when he was in his late twenties could he tell us that he did not want to continue in group settings defined for people with disabilities.

First of all, he made it plain that he wanted to stop travelling away each week to his residential placement. Then he wanted to plan for a house of his own which he will share with friends he chooses

because he can tell that they are interested in him and want to support him to do the best he can with his life. This is a new and scary idea, and we are struggling with how to realize it.

When he was a teenager, we assumed and hoped that Isaac would spend his adult years in a good group home. We were associated with organizations that promised (or at least seemed to promise) lifetime care to the adults they accepted. Parents like us were urged to let go of our children with disabilities when they reached adulthood. After all, that's when normal children leave home, for university or college and then employment and marriage. Adults with special needs should follow the same pattern, we were told--even if they almost certainly won't have further education, a job, or a special relationship. And some day Isaac will have to do without you. So shouldn't we all get used to it now—when he is 18 or 21?

Isaac was on every possibly relevant waiting-list. We never heard again from most of the agencies but understood that each of them had dozens, if not hundreds, of applicants for any vacancy. We formed new organizations with other families and professionals and drew up plans for new adult programs. We met with government officials who could be enthusiastic about our creative ideas and plans but then were countermanded by their superiors. We might get promises of funds from one arm of government but not the complementary resources that would be needed from another department.

When Isaac was in his upper teens, we met with local social service people to see if we could patch together some skeletal support from “community resources” so he could continue to live in his home town. But nobody else came up with a plan for Isaac. We could find no pieces of support that would meet his needs and no way of co-ordinating them, if there had been any. When he turned 21 and his residential school would keep him no longer, we quickly turned to a good adult autism program across the border. But this became impossibly expensive for a non-resident and Isaac was unhappy that it was too far from home for him to return each weekend.

Isaac was then accepted by a group home program in Canada. It too was far from home; it was also very new. He tried to adjust to the new environment but his lack of speech meant that he received less attention than other residents who could express their needs and wants. Isaac suffered both depression and anxiety. The staff decided that he should be put on drugs for both conditions. The medication dramatically worsened his mood and behaviour. Staff could not cope with his upsets and meltdowns. So we decided that he should come home to recover. In all the time since, he has never wanted to talk about his experience at this group home. We were not told that he was forfeiting his government funding by our choice to take him away, but we still believe we did the right thing for him in bringing him home to live.

We tried again to set up a patchwork of local supports so that we could carry on with our own work and also support Isaac to live at home and recover. He managed to get funding for only 6 hours a week with a personal support worker at the lowest wage. But we made up the money to pay for a tutor for 25 hours a week for a couple of years, hoping that we might get some more resources. Local agency people, while very sympathetic, could offer no more real help. They advised us to seek a temporary placement in an institution while we continued to work for a regional program that would serve him as well as other adults with autism. We did not succeed in getting funds to realize any of these creative projects.

Through Isaac's facilitated communicating, we now know that he has a very good sense of how he wants to live. For the past few years, he has been centrally involved in making plans for his life. His clear desire to live close to us, in the familiar town that has been our home for almost his whole life, narrows the options a bit. He wants a place that will be his longterm home, shared with several people who believe in him and whom he chooses. His home needs to be spacious and to have a garden, and it should be in town, on a bus route, and close to open green space for long hikes with his dog Missy.

We share Isaac's dream because we see that having his own place will give him more dignity and sense of ownership. His friends can visit him without feeling they are intruding in our home. We can help him to have a good life with our resources and energy while we have both and not just defer everything until after our death. We have to play a large role because traditional agencies do not now guarantee to care for adults with disabilities forever. And for the past few years, governments have not offered social housing funds to subsidize housing for people with special needs.

Isaac's wish to live in his own home, not a group home and not shared with others who are defined by their disabilities, is a big challenge. There are all sorts of worries. Living the way he wants is a new idea

for the authorities and for friends who point out all the difficulties. How can he afford all the personal support he needs? What about his special diet and sensory integration? Or his need for regular structure and consistency, and for skilled and sensitive support with communication and learning? How can we vet the people who share his house to be sure of their motives and reliability? And what about the neighbours? We start to think that it's all too difficult. But then we remember that all these will be concerns wherever Isaac lives.

What inspires us to keep going that some others have already pioneered the path that Isaac wants. We think particularly of Catherine Schaefer of Winnipeg, whose story has been written by her mother Nicola in *Yes! She knows She's Here* (1997). The creation of Catherine's home, in a large house that she has shared with several others since 1986, seems the closest model for Isaac's home. Catherine has living space on the ground floor with one or two room-mates who provide part-time assistance in return for free rent and a stipend. Tenants of self-contained apartments on other levels of the house have their jobs or studies and pay rent, but value sharing in a very special household community. "Cath's the reason we're living here. She's the heart of the household." Their friends are always dropping in and expanding Catherine's own circle of friends. When a new person moves in, the existing household members have to approve. The property is owned and administered by a housing co-op but Cath's parents played a large part in acquiring and renovating the house and in continuing support.

Our dream and Isaac's is to achieve a home like that, shared with friends whom Isaac chooses.

## **ISAAC'S GARDEN**

Isaac wants a real garden and that is part of the plan for his own home. He needs a sense of space and likes quiet, beautiful places. The tasks of tending his garden with hand tools involve co-ordinating movements that give him sensory feedback. He can grow some of the vegetables and herbs that make his special diet nutritious and interesting. He can take a responsible part in making his home environment orderly and calming. He can give produce from his garden to friends, and some friends who share his interest in gardening can spend time with him in this activity. He can see through all stages of gardening--from planning the layout and ordering the seeds, through cultivating the soil, sowing seeds and setting out seedlings, mulching and watering, watching the plants grow, to harvesting and using the produce, and tidying and putting the garden to bed for winter. Looking after his garden fits his interests in the environment, sustainability and conservation.

Isaac's garden is scaled down from his dream to live on a farm. Working the land may be bred in his bones, as ancestors only three generations back on both sides of his family were part-time or full-time farmers. Traditional farming meant producing a wide range of plant and animal foods and using various kinds of equipment and skills. On a traditional farm, one had a good sense of the changing seasons and the natural environment, of cause and effect and the interrelatedness of things. Farming communities also used to have simpler and more direct social relationships than are typical in towns or cities. But real working farms in 2000 have changed a lot from our images of traditional family farms. They are larger, more specialized, mechanized and even automated, and often rather dangerous.

Some who plan good living and working environments for people with special needs say that life in a farm community is easier to understand and more fulfilling than in an anonymous urban area. Several remarkable organizations have established therapeutic farm and rural communities in Europe and North America. Isaac and we have visited some of them. Adults with various disabilities live in Camphill Villages, an international network of communities that includes Camphill Ontario near Barrie. Bittersweet Farms, near Toledo in northwest Ohio, is an inspiring model of a farm community designed for adults with autism. But the few farm-based programs that do exist have long waiting lists and few openings. For Isaac they are too far from his home town, though he says he would like to visit them again for short stays. Isaac's parents have dreamed of forming a new farm community in Ontario, based on the Bittersweet model. But this is going to take too long to help him.

So Isaac and his support group plan a more individualized good life with at least some of the idealized qualities of a farm community. He already practises some of these in his parents' garden. But the garden will be a central part of his life in his own home.

We are impressed with what Andrew, another man with autism, has been achieving with outdoor and indoor gardens at his home. Backyard garden space was created by filling in a large swimming pool. Andrew and his friends have built a greenhouse and a large raised and insulated bed for vegetables and herbs. Its design with interior access paths helps him to feel secure and to focus on his work. These food-growing features are set in a large garden that is both formally designed and has naturalized areas. There is a sunken garden with two small ponds connected by a waterfall; the sound of falling water is very calming and relaxing. A system of paths guides Andrew and friends to enjoy all the garden features. He has been involved in all the tasks of building and maintaining the garden. As every gardener knows, there is always something to be done! Andrew uses quiet and safe hand tools and organic methods. Indoors, he practises gardening under lights and with hydroponic methods, to provide his household with some fresh vegetables and herbs throughout the year.

Andrew and his support team have been consciously applying the ideas and methods of horticultural therapy to his quality of life—at the scale of an individual domestic garden. We see that Isaac and other adults with autism could benefit from these ideas. His garden will be a way of enhancing his sense of pride and responsibility and even of healing some of the hurts he has felt in earlier programs. He can be involved in choices and work tasks at every stage, with links to his communication, learning and social activities. He can visit the library and search the Internet to research options and make choices.

Gardening brings new vocabulary into use and applies some basic environmental science about weather, climate and the life cycle. He can visit plant nurseries and garden stores or order from catalogs to get seeds, plants and other materials. Plans can be typed on his computer and also expressed in graphic forms. All the practical chores in caring for his garden are worth learning as they will be used many times—from spring cleanup, digging, raking, filling and pushing wheelbarrows and garden carts, sowing seeds, mulching, watering, leaf-raking, to composting, harvesting, food preparation, and crafts using plant materials.

Isaac's garden will be an integral part of his structured pattern of life, giving him experience of controlled movement, expanded vocabulary, social and community connections, and meaningful work. It will also increase the variety of pleasurable and calming sensory elements in his environment.

### ***HOW ISAAC CONTRIBUTES TO HIS COMMUNITY***

“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 whether our paid work does much 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 particular aptitudes with computer tasks and systems generally.

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 copy-typing. 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 and to us. “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 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 Isaac’s 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 condition and of the courage and cheerful hope of many who live with disabilities.

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. Even for him, as it can be hard 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 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 help 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.

### **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.

### ***ISAAC'S FRIENDS AND NEIGHBOURS***

Isaac says that friends are his life support system. He defines friends as people who understand and believe in one another, share interests, and are kind and helpful to one another. As usual, Isaac is absolutely right. Friends and supportive social relationships are vital for us all. But most of us are able to call up our friends when we need them. Isaac's pervasive disabilities in making others understand him place special barriers in the way of ordinary friendships. His difficulties make it all the more important to have friends who understand and care about him. Special efforts may be needed to make and keep friends, now and for the future.

Wait a minute, you may say. An autistic person wanting friends? Autism means self-centred, doesn't it?—totally uninterested in other people? Difficulty with social relationships is one of the defining criteria of autism. We've been told that that people with autism cannot read faces or imagine what is going on in others' minds.... But we're learning that individuals with autism do want friendships and social relationships, and not just with staff or others who are defined by their disabilities. They can be very sad and anxious that it is so hard to make and keep friends. The greatest disability can be the social isolation that results from other people failing to understand how much autistic people want and need friends.

For parents and caregivers, autism is a very complex and challenging condition to live with. One of the hardest parts is the attitude of others—including neighbours, co-workers and even family members—who do not understand and may be afraid to get involved.

Parents of adults who are 30 or older may have been shunned by other people when their children were young. Back then, mothers especially were regarded as responsible for the autism and, in any case, as failures when their toddlers “acted up” in public. Ignorance and fear of contamination can have very isolating effects on the whole family of a child with a disability, especially autism. Neighbours who try to understand and help are precious.

For a few years after he was six, Isaac had good relationships with other children at his school. The principal and staff set a fine example, explaining to the school community that it was very fortunate to have been chosen to have a special class for children with autism. Isaac was very happy in these years. His experience supports the idea of promoting inclusion for the “differently-abled” among children from the earliest ages.

Isaac's need to leave his home town as a teenager and young adult raised another barrier to friendships in his neighbourhood and community. For more than half his life, he attended school and other programs at least 100 kilometres from his family home. Though he was usually home for weekends and holidays, there was no basis for friendly relationships in a shared school or work program. But we know that even teenagers and younger adults who more typically live at home may not be accepted because of their lack of conformity to norms and peer pressures.

When adults with autism are accepted, their different abilities are celebrated, and they are supported to do their best, they can cope remarkably well. They may do better in informal social relationships than when supported by paid staff. Like Andrew for example, a younger man with autism who enjoyed some wonderful travelling adventures around southern Ontario and nearby US states, supported only by his twin sister as his driver and companion and responding to her belief in his abilities.

Isaac would love to have such travelling adventures with positive companions. He dreams that, when he has his new home, friends and neighbours will understand and accept him as a real person beneath the facade of his autism. That when he walks his dog Missy through the streets around his home, people will say or sign “Hello” and wait a few seconds for his answering sign and smile. That when he rides on a bus

or train, people will calmly accept his presence and respect him enough to refrain from conjecturing what is wrong with him. That when he visits the library or a store, staff will not make a fuss or even call the police when he fails to answer them in words.

Isaac particularly needs friends and neighbours to understand and accept him now, so that they will be there for him in the longer term. He has no other family beyond his parents, and he knows he is vulnerable. Isaac and his parents have invited friends to form a personal support network that is in addition to any persons who are paid to be in his life. Friends in Isaac's personal support network spend time with him on shared interests and keep in touch with him and with one another. Thus they keep informed of his developing abilities and continuing needs. Some friends should live close enough that they can be a real part of Isaac's life and take a lead in his neighbourhood.

By starting now, Isaac's friends in his personal network can get to know him well while his parents are still alive and active. Together, we can all support him through various transitions -- from living in our family home to settling into a home of his own with companions he chooses; from dependence on us for many things to making more choices for himself and learning to depend on others; from a fairly narrow range of activities to a diversity of ways of contributing to and enjoying the community.

Isaac's network of friends makes all the difference between mere survival on the bare necessities of existence and having a good life. But a personal support network on the PLAN<sup>TM</sup> model can also secure his good life in the future after we have gone. His friends will know how to speak up for him and how to advise and support those who have formal responsibilities for his well-being.