

Annie's Own Community



Age: Three months



Age: Fifteen months



Annie with sister

Dorothy Inglis

Annie est une fillette de 5 ans, paralytique cérébrale de naissance, qui habite à St John, au Nouveau-Brunswick: elle devint le sujet d'un programme intensif de "patterning", administré par huit volontaires de la communauté. Bien que tout pronostic pour le développement de Annie ait été négatif, ce programme communautaire bénévole de stimulation sensorielle et d'exercices a fait d'elle une enfant normale. Le point, dit l'auteure, c'est le processus – le fait que des gens ordinaires peuvent avoir un rôle dans le développement de la science.

Five years ago a baby, whom I will call Annie, was born in St. John's, Newfoundland, with severe brain damage. The prognosis for her development was not good. When Annie was a year old she did not react when people entered the room or respond if they spoke; her hands could not grasp; her limbs were limp and their movements were unco-ordinated.

Annie's parents, both of whom have scientific training, surveyed the possibilities, the bleakest of which was stated by one of the many doctors who examined the child: she would remain retarded in every aspect of her development and most likely be spastic in two limbs, if not all four.

The parents quickly became aware of the range of debate and controversy regarding the different approaches to rehabilitation of brain-damaged individuals, and after much thought they de-

cided to try what is perhaps the most controversial program, a method of intense sensory motor stimulation, known as patterning, devised by Glen Doman and Carl Delacato.

It was a massive undertaking. Annie was to be put through forty-five minutes of exercises, five times a day, seven days a week. Each session required three people to hold Annie, move her limbs, and provide stimulation. A family friend took on the task of organizing a roster of volunteers – eighty of them – and seeing that substitutes filled in when they were needed. Annie's mother instructed each group of volunteers in the exercise program.

The Doman Delacato method lays down a highly detailed series of exercises, and the keynote is repetition. In one early series, for example, Annie would lie on her stomach while her mother gently moved her head from side to side and two volunteers, one on each side, moved her legs and arms in a prescribed pattern to the rhythm of a seemingly endless succession of nursery rhymes in two languages. At first, not surprisingly, Annie did not like it very much. The volunteers could feel the rigidity of her limbs and the spastic contractions. Sometimes her tearful resistance would produce tears of sympathy in the adults, but soon they could feel a relaxation of her body and a growing plumpness in her muscles, and Annie came to enjoy the sessions. Tears of quite a different sort were shed on the day, several months after the

program began, when she was able for the first time to reach out and close her hand over a toy.

The program included a variety of kinds of sensory stimulation. Annie's hands were passed over dozens of materials of different textures. Lights were extinguished and flashlights used to assist in developing focus. Each stimulus was accompanied by talk and explanation: colours were repeatedly identified, shapes repeatedly demonstrated; concepts such as big and small were shown and spoken over and over. Progress was noted, and as stages were reached a new set of exercises began.

When Annie turned three, a magazine article quoted the family physician as saying that her

...development in cognitive areas such as speech and comprehension is close to that of any three-year-old. She's still behind in motor skills but [the doctor] says he's sure [she] will eventually learn to walk. "The achievements of this kid will be far ahead of any expectations that we had," he predicts.

That was two years ago. Today, Annie can not only walk, but run. She goes up and down stairs; she has a wide vocabulary and can make sentences. She operates a home-computer program and loves to see the images she has selected appear in response to her touch on the keys. She is learning to swim and can launch herself backward off the edge of the pool and come



Age: Two years, nine months



Annie today



Annie today



Annie today



Annie today



Annie today

up laughing in delight. When she is not copying her older sister at play, she is acting out with her dolls the care that her mother gives the new baby. She has been bowel trained for a year and has recently achieved bladder control.

For the past two years she has been attending a nursery school, at first for two mornings a week, and later for five. Her teacher says that although she was not walking when she first came to the centre, she was totally confident and at home from the first day:

She was a go-getter right from the first; she always asserts herself. She never feels she can't do something. Even the high steps to the slide didn't faze her. We used to hold her hand to paint; now she runs to get the paint and makes her own picture. When she pastes, she first decides where the pieces should go. Her social skills are far beyond those of the average five-year-old. She really makes your day with her cheery "hi" to each of the teachers.

It cannot be claimed that Annie, at five, is a completely normal child – whatever that may be. In many ways she is unique. She has a sly sense of humour and an infectious giggle all her own. She can be as demanding and manipulative as any healthy youngster her age. Her visual acuity is good, though she seems to have a smaller-than-normal field of vision. Her right hand is lower than her left, and the

sense of touch in both is less sharp than normal. It is not possible to predict how far her progress will go, but it is clear that she is progressing all the time.

For her parents and scores of friends and volunteers, of course, the primary point of Annie's story is Annie herself, and the success she has achieved. But there is a more general significance. It has nothing to do with the superiority of a particular program. Those debates will remain the subject of scientists for a long time to come.

The point is in the process. The program that Annie went through could not be replicated in a clinical or experimental setting without an immense expenditure of time and money; even then it would be impossible to duplicate the spontaneity, the sharing, and the sense of community developed by those scores of volunteers, and who can tell how important those were in the outcome? What Annie's story tells us is that ordinary people can have a role to play in the development of science, especially in the human and biological sciences. Instead of being passive consumers of discoveries made by an elite in the laboratories, they can be part of a process of experiment and study. As I have said, Annie's story by itself proves no neurological points. But a series of such stories, observed in a controlled manner by specialists, would be a source of data that could be gathered in no other way.

The benefits of the experiment in St.

John's were not confined to Annie and her family. The volunteers experienced a heightened sense of involvement and of community, and all of them learned to think in new ways about the workings of the human brain and body, about normality and difference, and a host of other topics. Clearly, a program like this is not the answer for every brain-damaged child. Indeed, Annie's doctor has stated that the only danger he can see in it is that it may hold too bright a hope to parents of children who could not achieve what Annie has. However, it does show us one way in which institutional science and ordinary people can come together to their mutual benefit. In times of fragmentation of community and alienation and distrust between scientific specialists and the general population, that could be an important lesson.

(I would like to acknowledge the assistance of "Annie's" parents and of my husband, Gordon Inglis.)

Further Reading:

Glen J. Doman. *What to Do About Your Brain-Injured Child, Etc.* Garden City, New York: Doubleday, 1974.

Dorothy Inglis, one of the volunteers for this program, is active in many community endeavours and is a vice-president of the National Action Committee on the Status of Women.