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**Abstract**

This article discusses the obstacles to full participation in the classroom for students with disabilities now that inclusion is more common. The article suggests that inclusion is happening on a physical level but not on a mental/emotional level. The article covers the strategies used by parents and teachers to facilitate peer acceptance and friendship development for children with disabilities. Many such attempts have been successful but it is stressed that such relationships need careful nurturing and that attitudes take time to change. **Keywords: Attitudes, Friendship, Inclusion, School Age, Education**

# Rising Expectations: Relationships and children with disabilities in the regular school system

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It is a classroom scene that is becoming more common: children with mental handicaps and disabilities sitting elbow to elbow with their peers. *Changing Canadian Schools: Perspective's on Disability and Inclusion*, published by The Roeher Institute, states: "Participation in regular classrooms gives students who have a disability the opportunity to escape the cycle of segregation. They break the cycle in three ways: they acquire skills which make their participation more meaningful; they develop relationships which foster true membership in the community; and their presence teaches other people how to accommodate the surrounding environment to their differences."

With integration a reality in many Canadian schools now, there is an opportunity to explore children's relationships. Do children with disabilities meet with friends during recess and after school? Do they get together with the gang at baseball games, go to MacDonald's for french fries and a Coke, or just hang out?

The Roeher Institute met with a group of Extend-A-Family (EAF) coordinators, many of whom are parents. They talked about the experiences of their sons and daughters connecting with other children in integrated settings. They were asked what barriers they have encountered and how they have tried to overcome them. EAF was begun 13 years ago by a group of Toronto parents to help their children and others to meet people and participate in the community. EAF now has 18 programs across Canada, most of them in Ontario.

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\*All names have been changed.

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## School of hard knocks

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Cathy Anderson's nine-year-old daughter Maggie\* has been in a regular classroom for two years. Several factors came together in the right combination for her daughter: "Maggie has had a very positive experience in her school in terms of friendship. [The school is] small enough that there is one class per grade and the kids she's in with this year are the same kids as last year. They'll go right up to Grade 8 knowing each other so they can establish a relationship one year and not lose it. She had a super teacher and a super aide last year so those relationships really melded. All the kids except two or three like her. They want to be with her; they see it as a privilege even to be with her."

Many other parents, however, have had less than positive experiences: "In our naivete," said Sandra Maclean, "some years ago we thought that if we could just get our kids in [the neighbourhood schools] where everyone else is, things would happen. With Alison, she was in the neighbourhood elementary school but the high schools where her friends were going wouldn't accept her. She ended up in a high school in another neighbourhood with a new group of people. There are significant cultural differences that keep her socially isolated. So now we're at Grade 11 and we're still fighting. The reality is that there are very few if any situations where it happens."

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## Constant parental input needed

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The parents say the situation requires a great deal of their input. Friendships with

their son or daughter seem to need constant nurturing to continue. The parents spoke of spending a great deal of time and effort in the schools trying to provide that nurturing themselves. They also spent time educating the teacher in how to build relationships with their children.

"Things go well for a while and then somebody loses track of our goals," says Cathy Anderson. "Maggie was mainstreamed in this community school last year for the first time and her teacher was fabulous. She understood what was going on and was a wonderful facilitator of friendships within the class.

"She had a chart of a buddy system where kids could sign up on their own to be Maggie's buddy for a day. Two of them would sign up each day. It was something the kids did independently. And those kids helped Maggie; they included her in whatever they were doing, whether it was at recess time, lunch time. The chart itself was a real hodge podge, a mess, because the kids were writing it themselves and crossing names off. It wasn't particularly attractive but it was meaningful.

"The teacher this year has a very hard time understanding the whole concept. He thinks he understands now but I hear of situations where he's an actual barrier to a relationship. Kids want to help but he feels it is interrupting something else. He doesn't mean to be cruel, but he's physically excluding Maggie. The kids are good; outside the class they just take over, knowing what to do from last year, but in the class it's difficult. He caught on to this buddy idea and liked it but he put up a really nice neat board. He writes down the names and he says what days the kids are going to do it."

"They have guidelines which are very difficult to change," says Beth Downing. "The [teachers] believe they understand but they don't really. You try to bring them farther and certain resentment develops. It is a long, long road for people. I asked a

teacher, "Can you encourage the girls in the gym class to participate with Cynthia outside gym class?" It's not appropriate for Mom to go into gym class and say, "Hey do you guys want to come visit Cynthia after school?" Finally the teacher went into gym class and said, "Cynthia, when she goes home from school, is by herself. She doesn't do anything after school. Would anybody here think of spending time with her after school?" And that's good.

"But when we come to the next part of encouraging that interaction with Cynthia to continue - and there has to be a person within the school who encourages it - that's it, the teacher has done her bit. I have to actually go into the school and speak to these kids. But I can't do it every day and it has to be done every day."

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### **The pitfalls of liability**

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In identifying the various reasons why students like Alison and Cynthia remain isolated, the rigidity of the school system came up more than once. "One barrier I find in the school system," said Cathy Anderson, "is the liability rules and regulations. Often you hear 'You can't let that happen, what if they fall and hurt themselves, who is going to sue who?' "

Particularly with students who appear fragile or different physically, the school system's rules seem to hinder the natural progress of friendships. "My daughter, because she's diabetic, gets very hungry at certain times and eats quickly and doesn't chew," Beth Downing explained. "She has choked in the past but she doesn't choke every day. However, they sat her in the front of the cafeteria because they said they had to get to her in case she choked. She has never choked at school.

"We had a whole group of students who were quite happy to eat lunch with Cynthia but there was no way they were going to sit in the front of the cafeteria because that's where the cafeteria monitor stands. He or she sees everything they're doing; they

can't even sneak a kiss. They said, 'We have other friends; that's an important part of the day to socialize.' But it was Cynthia's time too, it was her opportunity to share and do what she could do."

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### **Isolating through overprotection**

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Teacher assistants and aides can isolate a student within the regular classroom when the aide works exclusively with that child. People see the child as having all the support he or she needs and tend to stay away. In *Changing Canadian Schools*, a case study of a student named Sue notes this effect: "In an attempt to help her cope, Sue was given an aide. She was often seen with her aide, studying during class time or playing solitary games during recess or lunch. Someone was always close by keeping an eye on her. Sue was being looked after but rarely was there any interaction between herself and her teacher or her neighbouring peers."

"Having an aide for Sue was a mixed blessing. Over the short term, the aide was helping to deal with immediate concerns such as Sue's tutoring, general welfare and behaviour. But over the long term, the aide's presence seemed to further distance Sue from those around her."

For most teachers, having a student with a disability in the classroom is a new experience. Many teachers have a great deal to learn about including students with disabilities and about new methods of teaching which address different learning styles and abilities. They also need information about supporting relationships and interaction in the classroom. Teachers require support at every level, from the school board, from school administration, and from in-school resource personnel and fellow educators.

Advocates of integrated education envision a more cooperative approach to teaching, which is very different from the traditional autonomous model of a teacher alone in charge of a classroom. In short,

integration often calls for a major shift away from many traditional aspects of the education system. When there is no support to achieve these shifts - support from the school administration, and additional time, training and personnel - students with disabilities are often not truly integrated. They are merely physically present in the classroom. "It is also important to realize," reminds parent David Jory in *Changing Canadian Schools*, "that our society asks the impossible of teachers and school administrators. We expect them to resolve all our social problems and have all kinds of programs such as AIDS and anti-racism education and propaganda from the nuclear industry. Integration means appropriate educations for all pupils and is best accomplished when teachers are not over-stressed."

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### **Experience Required**

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Like all relationships, friendships require skill and hard work at the best of times. Without early life experiences in making and keeping friends, children with disabilities are disadvantaged from the outset and have difficulties developing these skills as they get older. "Our children do not know how to socialize. They haven't had the experience," said Heather Arneault.

"They are impoverished," said Marilyn Shaw, "in terms of their social experience and opportunities, as illustrated by Tommy's story:

*All the kids loved to make fun of Tommy. He was the butt of all the jokes. One game the kids loved to play was to call Tommy over, saying, 'Hey Tommy, I've got something for you' and show him a nickle and a dime. 'You can have one of these. Which one do you want?' And Tommy would choose and all the kids would laugh.*

*One day a teacher overheard a couple of students pull the nickle and dime routine*

on Tommy. The teacher called Tommy over. 'Tommy, don't you know that the smaller coin is worth more than the large one?'

'Oh sure,' Tommy said, 'I know that.'

'Well then, why do you let them fool you like that?'

Tommy smiled, 'Because the first time I pick up the dime, they'll stop playing with me.' "

(from *Reflections on Inclusive Education* by Patrick Macken)

They pointed to the stigma that is still attached to people with differences. They find it can discourage children, particularly teenagers, who experience a great deal of peer pressure. "We have to think of the pressure that students within the school who choose to be with our sons and daughters are subjected to by their peers," pointed out Beth Downing.

"In high school there may be a student who wants to reach out to my daughter without any support and without any facilitating but peers are watching. There is a lot of pressure on that student," Sandra Maclean agreed.

"I think many kids are uncomfortable and awkward about relating to someone who can't talk back to them or who can't move around the same way or who can't do things that they do," explained Michael Griffith. "There's nothing wrong with being handicapped but people don't know how to relate to it. Also, with kids, anything that's an issue for adults, even with the best intentions, is suspicious. [Interacting with children with disabilities] is often premised on an 'ought' or a 'should' and that doesn't always work for kids. So if we lay a heavy on a kid, 'You should take Sally out after school', why should they? You wish people would respond more kindly, but they don't."

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## Diplomacy versus anger

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So often the task of initiating and nurturing relationships for their children in the school falls to parents, particularly mothers. But does that mean that the child's experience in the school depends on her mother or father's approach or attitude? Does the child of a polite, diplomatic mom have a better experience than the child of an angry, aggressive mom? Does the parent walk a fine line between being nice and being assertive enough to open doors for her child? Her presence in the school is already unusual. As the parents pointed out, by the time kids reach high school, most parents only see the teacher or principal when there is a problem. Few parents are there on the doorstep every other day.

"In Maggie's school," said Cathy Anderson, "there are two children who are physically disabled. The other mom and I are totally different in terms of how we handle situations. The [school] system looks upon that other mom as nasty and uncooperative, uninvolved, always complaining. They see me as a person who is involved in the school, supportive, pulling up the slack, on the PTA - the system's ideal of 'a nice little mom'. The other mom is really upset because she sees Maggie getting so much in the school, having friends, etc., and she looks upon it as, 'how come I can't get those things for my kid just because I'm not so-called nice'. I realize how much diplomacy, being nice and cooperative makes a difference for your child."

In being "nice" and attempting to open doors for their child, the parents often have to become involved to an unusual degree in the school and its staff. "I have tried to develop a personal interest in each person," said Beth Downing. "So that while I'm attempting to put something in place for Cynthia I try to keep in mind that the person I'm communicating with has needs and things they're dealing with as well. I feel I need to listen to them, which

means spending a lot more time in school than a normal high school mom."

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## Ongoing work

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Despite their involvement, they were all simply trying to bring their child's experience as close as possible to the experience of other children. They are wondering why they aren't getting there. "Is it because we're using the wrong words?" asked Heather Arneault. "Is it natural to go around saying I'm looking for a friend or I want a friend? We don't talk like that."

The pressure on artificially constructed friendships also prevents people from connecting with isolated individuals. In more natural settings, friendships begin and end, friends come and go, people let each other down. "I think in talking about long term relationships we frighten many people off," said Heather.

"It's impossible to expect one person to be someone's only friend," Leslie Eastman added. "I don't have one friend. None of us do and we have friends for different reasons but [with a friend who has a handicap] it's so focused, you're their whole life. I've heard that as [non-handicapped] kids get older, [they resent] the constant calling [from their friend with a handicap]; they say, sure I want to be your friend but I don't want to be your life.' "

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## ***Parents are developing the skills to encourage and nurture relationships among their children and other children.***

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"Because there aren't many people in Peter's life he thinks that [his friend] Tim walks on water and the expectation is heavy," said Marilyn Shaw. "Because they have so few relationships there's an awful weight put on the ones they do have." And after all their efforts, there is very little

continuity created. When their children leave high school, they say, the connections usually end and they have to begin again.

Many strategies have been developed to bring people together and foster relationships. While they take the form of "programs" and require outside support and facilitating, often a friendship blossoms from within the structure and takes on a life of its own. *Making Friends: Developing Relationships Between People with a Disability and Other Members of the Community*, published by The Roeher Institute, describes four such strategies across Canada. They include a University of Alberta one-on-one strategy for linking people; a British Columbia group called Rights Now, a group of self-advocates helping educate the general population about the importance of friendships for people with disabilities; and examples of creating informal and formal support networks.

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## Finding a dream that works

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The parents said that, in their roles as EAF coordinators, they are continuing to break down important barriers and are seeing many friendships and connections developing. They are helping change parents' expectations for their children. Parents are beginning to recognize the importance of friendships for their children. More and more, parents want to get away from programmed relationships; they want natural friendships for their sons and daughters. EAF coordinators across Canada have been active helping parents develop the skills to encourage and nurture relationships among their children and other children.

"We may not find the ideal connections, the long term connections," said Sandra Maclean. "There are problems in finding what people dream of; but if we can build in the family and in the individual an expectation of friends, it may carry over even into adulthood. Even if they live in a

group home, there may be an expectation that there's more to life than the group home or the workshop. They've had a sense of relationships, of doing other things and being connected in other places. We begin to build an expectation that they don't have to settle for a group home and workshop and nothing else."

Progress will continue at the insistence of parents and people such as the EAF coordinators. They will continue to break new ground for their children and spend hours educating parents, the school system, the community. They will work hard to show people how to be friends with their children and how to support

relationships with their child. In our fragmented communities, the kind of continuity Maggie enjoys is difficult to achieve. But inroads are being made and victories are visible. "I've been to [school] football games," said Marilyn Shaw, "and have seen the kids with disabilities with all the other students, and their faces are painted in school colours. They're having a hell of a time and so are all the kids around them."

*Changing Canadian Schools and Making Friends* can be purchased by contacting The Roeher Institute, Kinsmen Building, York University, 4700 Keele Street, North York, Ontario, M3J 1P3 (416) 661-9611.