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# It's Time We Learned

*Why Should A Disabled Woman Who Has To Worry  
About Getting Attendant Care, Housing,  
Accessible Transportation, Family Support, A Job  
And A Vacation Learn To Read And Write?*

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omen with disabilities face a unique struggle in acquiring literacy skills. Not only do they need to improve their education level to manage competently in a highly technical society, but they struggle with the double burden of being disabled and female in a society which for so long has been dominated by men in an able-bodied culture. All three areas of vulnerability need to be presented here to clearly illustrate the additional difficulties encountered by disabled women who do not have the literacy skills to function fully in Canadian society.

Women in Canada lobbied to acquire the vote, to become pilots of their own fates and owners of their own property (including their very persons). Conversely, women who were disabled have been segregated, often institutionalized and rejected by society as a whole. Only radicals believed that disabled women could contribute to society for, if one was disabled, she ought not to jeopardize the gene pool by producing "defective" offspring, or if producing classically healthy children, she could not raise them herself, and so she had no role in society. While the women's liberation movement and equal rights efforts should have emancipated all women, those with disabilities were still safe targets for old-fashioned views and lowered expectations.

The champions of the Civil Rights movement did not advocate an "integration" that permitted black-only schools, or black-only classes within neighbourhood schools. Integration meant that students of both races were *interspersed*, integrated within the fabric of the school. To do otherwise would have served to

perpetuate the sub-standard education offered to the black minority group. Arguments ensued that white students would reject peers of the visible minority, that white families would protest and haul their children out of schools where they feared the standards would be reduced. But these assumptions ultimately were proved false, and in the interim, were not accepted as reasonable arguments against integration. Indeed, integration within the schools set the tone and example for civil and social integration at that time.

How ironic that for people with disabilities, these assumptions remain as valid arguments for segregation outside of the mainstream whether in school, housing, or social spheres.

Rosa Parks caused an uproar when she refused to relinquish her seat to a white man on the bus. Disabled women are not even allowed *on* the bus! Instead, if any transportation is available in their communities at all, they ride in separate vehicles, segregated from the mainstream of society.

The issue of integration is central to an examination of the problems disabled women face when their handicaps are compounded by weak literacy skills. The fact that women had not been *expected* to integrate in any socially relevant way has been one of the underlying assumptions in developing educational and service policies for children and adults with disabilities. Along with the assumption that disabled people could not contribute to society came service structures and mechanisms which underlined this deficit, and, eventually, contributed to the perpetuation

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of its own false assumption.

Following are two concrete examples illustrating the profound implications of these structures on the lives of people with disabilities:

Sarah, age two, is too uncoordinated to perform the typical tasks that two-year-olds can perform, and so her parents seek medical help. The doctor refers Sarah to the local medical center for an assessment, where it is discovered that Sarah has cerebral palsy, which is disrupting her motor development.

The staff at the center have assessed many children like Sarah before, and using the best of their training and experience, recommend to Sarah's family that she should be institutionalized.

"It is too difficult for you to do this alone," they explain. "You really should put her away and have another." Her parents have already started to feel the impact of looking after Sarah. After all, by now she should be getting more independent, but what they foresee is the additional time and effort required to assist Sarah to master basic tasks. Won't all this extra attention to Sarah undermine their relationship with their other children?

"She'll be better cared for in an institution," the staff add, consolingly. "They are better trained than you are to care for these children."

Even with the rationalizations, the decision to place Sarah in an institution doesn't *feel* right to her parents, so they ask for time to think it over. A few days later, against the better judgement of the medical professionals, they decline to send their child away.

By deciding to keep Sarah at home rather than have her institutionalized, her parents have opted for a new life of research, planning and advocacy. They will have to fight hard for the services Sarah is presumably entitled, if not in court then in libraries, social service offices and school rooms. Wherever there are gaps in services, they will write proposals, analyze services and assess Sarah's needs themselves in order to articulate her needs clearly within the arena of services. If they are successful, they will gain a reputation for being demanding, for thwarting the system and for rejecting assistance when it was offered during Sarah's initial assessment.

So Sarah lives at home, but she is rele-

gated to a segregated class in her neighbourhood school, because her parents lost the fight to have her integrated with an aide in a typical class. Her teachers have special training and experience. At eight years of age, Sarah's teachers determine that her inability to speak will inhibit academic pursuits and it will seriously restrict the contribution she can make to society. Sarah's curriculum, therefore, is designed around "life skills" and recreational activities.

Sarah grows up, and her family celebrates the welcome changes together. However, these changes mean that her service needs changes, and these changes must be documented and justified in every new service request. They win many battles, but with each passing year, the gap between Sarah's scholastic achievements and those of her peers widens.

At twenty-four, Sarah has graduated from high school as part of an "exceptional student" program. Her school work was primarily non-academic and she was ungraded. As an adult, she understands that her lack of academic skills will render her unemployable, so she approaches her local literacy program. Sarah is ready to fight her own battles: she wants to read and write.

What is it about our educational and social systems that allow early verdicts to young children about their adult potential? Why should a handicapping condition be used as a rationale for slanting the curriculum away from academic subjects? Why do we spend less time teaching those who need the most time to learn?

Literacy programs, whether community-based or classroom style, need to serve members of their community who have handicapping conditions. The immediate fear literacy practitioners express is inadequate "specialized" training. And yet, the competencies they have already acquired will be useful with students who have disabilities. Teachers during the Civil Rights movement had to teach all their students — black or white — and were no longer permitted to discriminate. Why should teaching people with disabilities be any different?

Educators must understand that the burden learners with disabilities face is not their disability *per se*; more it is the attitude of others who have continued to slough them off to experts faithful that they know better.

Human needs are universal: we all need food, shelter, and people in our lives who matter to us; we all need mobility, transportation, dignity and a sense that we are safe from threats. These needs do not change because a person has a disability.

Typically, a woman in this society will meet her needs for food and shelter by earning money to purchase food and shelter. Typically, she has transportation to work and shop, and she has the personal mobility required to get herself up in the morning and look after her personal needs throughout the day. With these basic needs met, she can nurture new friendships and maintain old ones. The difficult pieces are finding the right job at reasonable pay, and finding the right accommodation at reasonable rent.

Now, comes the twist: imagine this same "typical" woman — call her Vivian — who now has a disability which severely limits her personal mobility. How does she get her needs met? How are her difficulties compounded beyond that of the woman described above?

First of all, she uses a wheelchair for mobility — a power wheelchair because she lacks the strength to push a manual chair. These cost \$6,000 and she is not yet working, so she must investigate the financial assistance programs available for such purchases. Until very recently, reliance on the benevolence of service clubs was her only possibility. To them, she would describe her plight in graphic detail, trading off dignity for practicality. Now, in Ontario, Vivian also has the option of applying for government funding through the Vocational Rehabilitation Program or through the Ministry of Health's Assistive Devices Program.

Since Vivian can read and write very well, she can read the program titles, document her need and complete the appropriate forms. The service providers will evaluate her request to determine whether she requires this device, and is therefore eligible. This is the process which is necessary for her to meet her mobility needs.

Because of Vivian's mobility limitations, she requires assistance in activities of daily living, such as taking a shower, preparing meals and using the washroom. She realizes she can not depend upon her parents for this assistance much longer and investigates her housing/attendant care choices. She completes a 20-page

application for attendant care in a wheelchair-accessible apartment in the community. Until recently, she would have had to fill in a different version of this lengthy form for each housing project to which she applied, but now there is a centralized system, so she just has to do it once. Since she can read and write very well, Vivian completes the form with no difficulty. It takes her four hours.

She reads newspapers and has memberships at a number of consumer-based organizations which deal with disability issues, and so she is painfully aware that very few projects exist which offer housing and attendant care. She knows she is not eligible for Outreach, because she needs help more than three times per day.

Because the turnover and subsequent vacancy rates for attendant care are slow, Vivian will have to seriously think about organizing a new project were she would have a better chance of getting in. It only takes three or four years to develop a project, because many of the documents each group has to create can now be built upon those of existing groups. Personnel policies, bylaws, job descriptions, flow charts, program plans, hiring plans, land allocations, contracts with housing companies, rental subsidies, selection of staff and tenants all take time. Vivian is optimistic that she could accomplish this before her parents retire.

In terms of looking for a job, she will require alternate transportation until the Wheel-Trans service has an available place. Wheel-Trans has become computerized, resulting in a more efficient system, so she might wait only two weeks. The odds against Vivian getting Wheel-Trans decrease if the job site is far from home, and if it falls outside the travel path of existing runs. She has no way of finding out the Wheel-Trans runs before job hunting, but she is an adventurous spirit and goes ahead anyway, letting the dice fall where they may. This is, after all, an improvement from ten years ago, before there was even such a thing as Wheel-Trans. She is thankful for all the hours she invested to lobby for at least a demonstration project. Before Wheel-Trans, Vivian could not have gone out anywhere on her own, and now that the hours have been extended to week-ends and 11:00 p.m., she has the possibility of a job where she might be required to work evenings or weekends.

The fact that sometimes the vans have been known to catch on fire, or, more often, a passenger falls when a hydraulic lift cracks at the seams, is not really on her mind as she books her rides.

Because Vivian can read and write, she was able to do the lobbying, address questionnaire envelopes, send letters to her MPs and MPPs, write the newspapers and finally, fill in the form to register for the service, which her doctor and one other health professional co-signed, as required, to assure Wheel-Trans that she was not pretending to be disabled.

With her basic mobility needs met, Vivian can continue to look for a job. With her good education and communication skills, she will find appropriate employment with reasonable pay. Without her education, she would not be able to work at all. Jobs which rely upon physical strength are out of reach: she can not work with a construction crew, arrange goods in a shop, work a cash register or paint houses. Even for a non-disabled person, these options are fading if one lacks the basic literacy skills essential for learning computerized cash machines, reading paint labels or operating manuals and completing invoices.

It was crucial for Vivian to receive a good education. It pays off now as she scans the want ads, looking for employers who announce the job is an "equal opportunity" position, so she can have at least minimal assurance that they won't be daunted by the fact that she brings her own chair to the interview.

Vivian is extraverted, so she has always made friends easily and has the social skills to make her friendships blossom. She looks forward to being married someday, and perhaps even raising children, but she'll wait until she has the energy. Oh, the energy isn't for raising the kids, it's for doing the advocacy necessary to develop housing where she can receive attendant care services in a family situation, for encouraging and shaping governmental policies to permit additional assistance to her raising her children, and for educating her doctor, maternity nurses and attendants of her right to have her child if she wishes, despite her disability. Her writing skills will serve her well as she writes letters, proposals, conducts research and develops surveys to document the need.

And now we're full circle: let's look at

how these problems are compounded if the disabled woman who has been the focus of this discussion could not read and write.

Like Sarah, Vivian would have been educated in a segregated system, where the expectations were lowered and her handicapping condition was considered insurmountable. The professional advising on her curriculum would have assumed Vivian was not educable or, if she was, teaching her would take skills beyond the expertise of her teachers.

Vivian hasn't had to devote the time or energy to developing services, where none previously existed, but she has helped to discover what services might assist her, with the advice of someone who understands the systems well. This person must present Vivian's case wisely to ensure Vivian receives transportation and attendant care services.

Vivian has to rely on the meager income provided through the disability pension, because she does not have any skills to bring to the market place. Depending upon the philosophy of her social worker, she might be "encouraged" to spend all her days in a sheltered workshop. Her social worker shares the view of many social service professionals who believe it is better to have clients relegated to workshops to "earn" their benefits, although this means exclusive association with other people who share the same label, and the workshops tend to reinforce isolation from the mainstream of society. To refuse might jeopardize her benefits.

Without an income, Vivian can not be accepted into an attendant care project. Once her parents could no longer care for her at home, Vivian could only live in a chronic care institution, a fate her parents initially wished to avoid.

Vivian's experiences would primarily be within a segregated context: she would have had disabled classmates, disabled workmates, and eventually, disabled roommates. Her social circle would be very narrow and she would be quite lucky indeed if, over the years, relationships were sustained where she mattered to anyone. Most of the people with whom she would be in contact would be paid to spend time with her. A relationship, marriage and children would be out of the question. Her chances of being sterilized socially, if not physically, would be rather high if she lived in an institution. On top

of all this, to learn to exist within these limitations, she would have to learn how to be a "happy disabled woman:" passive, submissive and accepting, not daring to show how unhappy she was for fear of making things worse.

Vivian's inability to read and write would have sentenced her to a homogeneous life, a life without challenges, with lowered expectations. Vivian would end up being the victim of those who would control her life, rather than being empowered to make changes for its improvement.

Literacy is vital for survival in an industrialized society like Canada, even for the general population. For a disabled woman, literacy creates the opportunity

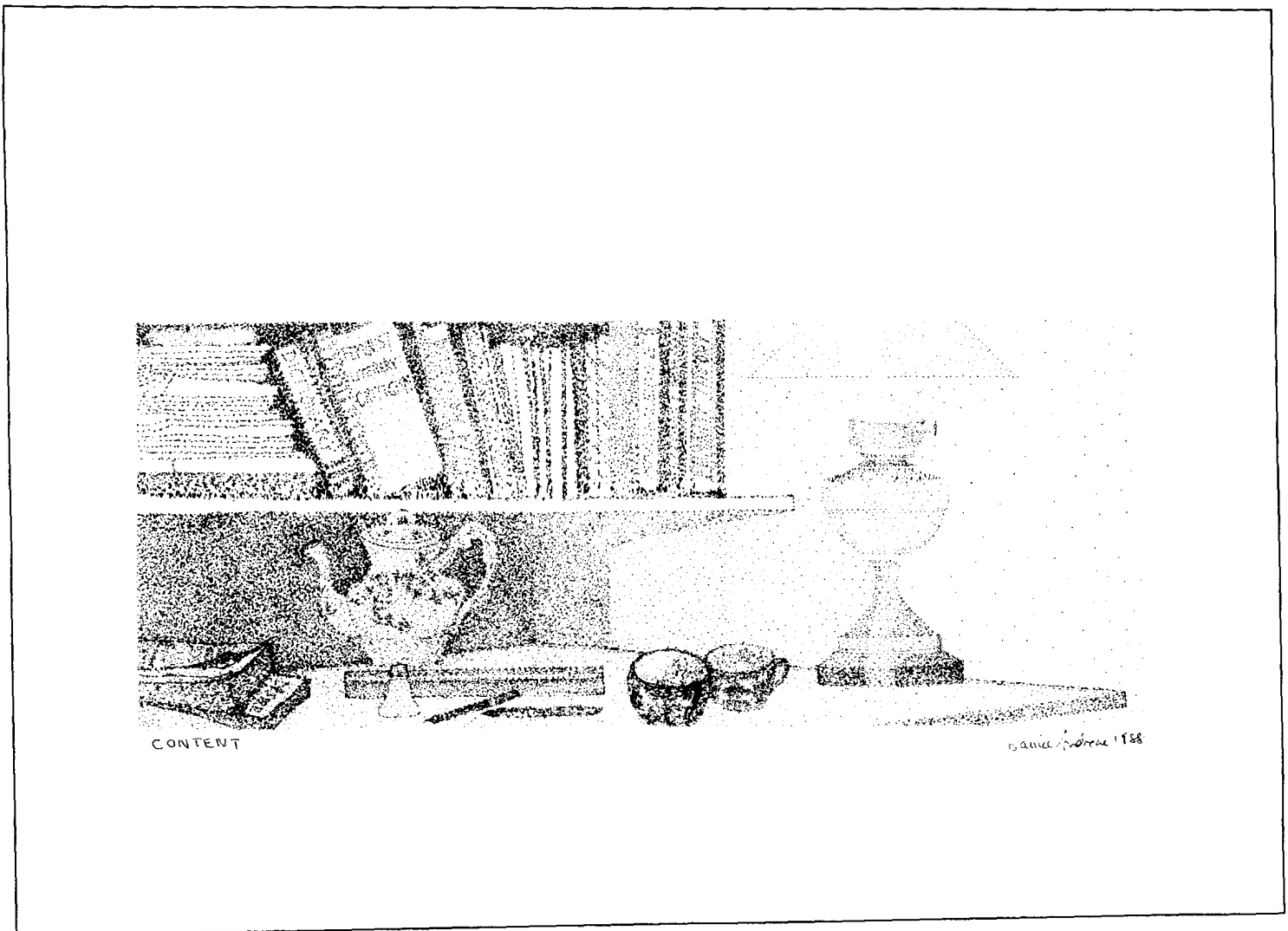
for a life approaching normal rather than one condemned to exile. The only thing worse than having to do all the form-filling, lobbying and advocacy for very basic services is not having the skills or the assistance to perform these essential tasks at all.

If educators understood the kind of impact that literacy instruction could have for a disabled person, they would not ask, "Why should I include this person in my program?" Instead they would work out *how*.

And just as women needed to be educated about the possibilities which would become open to them after liberation, so too, do disabled women need to be educated about their possibilities — possi-

bilities created and increased through literacy.

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