

Mutual Empowerment

The Mother of a Daughter with Disabilities

BY BRYDON GOMBAY

L'auteure examine les nombreux problèmes d'une mère qui élève une fille handicapée et commente sur cette relation qui renforce les liens qui les unissent.

There is a fundamental paradox in the idea of people empowering others. A relationship which has the capacity to give power undermines that received power by the very position of giving it (Gruber and Trickett). That paradox puts mothers in a double bind, since central to the task of mothering is to love and to let go (Hamilton). For mothers of young adults with disabilities, this double bind is accentuated, and problematically difficult to resolve. Their wish to foster independence is hedged about by fears concerning their children's vulnerability and their long-term future.

It is only when empowerment is mutual that I believe the concept to be truly illuminating. Otherwise a hierarchical relationship is established, in which one gives power while the other receives it: not a good recipe for a sense of power on the part of the recipient, while for the donor there is an implication of condescension which detracts from the very idea of empowerment. How then, can the mother of such a daughter untangle the strands of mutual dependency, encourage her daughter's independence, develop her own independence, and achieve peace of mind? It is only too easy for the mother to take on more prolonged responsibility for her daughter than is necessary or beneficial to either of them, seeing that mothering role

as central to the meaning of her life. By the same token, it is only too easy for the daughter to lean on her mother, and refrain from taking responsibility for herself. Such a behavioural pattern, once firmly established, can lead to a relationship from which neither is inclined to break free.

My intention in this article is to illustrate the ways in which one mother has resolved these issues, and helped her daughter to realize her full potential. The paper also addresses the contribution her daughter has made to her own growth and development. The mother's account of their lives together speaks to the problems they

have encountered in their interactions in the community, and with the medical, educational, and social support systems. As she struggled to surmount these problems, Kate developed a sense of her own power; Jennifer's parallel struggles led her in turn to achieve a level of independence and self-confidence which might have been unattainable in the absence of her mother's support.

This article is based on qualitative research I have conducted with mothers of young adults with disabilities, research which in this instance is based on three in-depth interviews, each lasting for about two hours. My research was participant-led, with mothers focussing on the areas of greatest concern to them. Interviews were unstructured and dialogic in nature, barring a few demographic questions. Participants chose their own code names to protect confidentiality; all received transcripts of our tape-recorded conversations, in order to confirm their accuracy.

Background

Kate has been a single mother for 17 years, when her alcoholic husband, who was largely an absentee father even before he left the marriage definitively, left her alone with her 16-year-old disabled daughter, Jennifer, and her younger son. Jennifer has developmental disabilities, both physical and cognitive, with perhaps some involvement of cerebral palsy. Her ex-husband provided little financial support thereafter, nor did Jennifer receive a disability pension until two years later. This forced Kate to give up her role as a stay-at-home mother who did volunteer work for the Learning Disabilities Association, and to become the family breadwinner. Now at 62 years of age, she is employed as a secretary for several churches, and a house cleaner for a friend. Jennifer, who is 33, attends classes and works at a nearby community centre for people with disabilities. Kate is also very active in working for people with disabilities, giving regular presentations about her life with her daughter to Special Education classes, early childhood educators, and groups of school principals.

Kate found little support for her situation within her community, or from medical, educational, and social services. She had to fight for Jennifer's rights in all these areas, fights which met with varying degrees of success. Even though some battles were lost, her sense of the meaning and purpose of her life deepened through them. Without Jennifer, she feels she would never have developed her present level of self-esteem, based as it is in that

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very ability to struggle on her daughter's behalf. Jennifer keeps her grounded, while she in turn has helped Jennifer to overcome obstacles placed in her path by those very services which purported to help her. In the absence of meaningful help from others, they learned how to support each other. From a position of isolation they moved together by empowering each other to their present situation, where each makes her own distinctive and valuable contribution to their community.

Community

Initially, help was not forthcoming from within their community. Kate felt very isolated when Jennifer was young, since her friends and neighbours avoided the topic of Jennifer's disabilities altogether. When she was still not walking at the age of three,

The people in the community were less than helpful, because they wouldn't come out and ask, you know, what was wrong with Jennifer. They would just say, "Oh my God, isn't she walking yet?"... I suppose it was just because they didn't know what to say. It's like going to look at a corpse. I mean, what do you say? "My, she looks lovely?"... I can remember taking her to church one Sunday, and taking her into the nursery, and she was standing up somewhere, and she wanted to go somewhere else, so she got down on her hands and knees and crawled. And everybody just stood, you know, looking aghast at her.

Those first years I was completely alone. Even my best friend, who was a psychologist, she was supportive, but we never talked about it.

Medical services

Dealing with the medical system presented other problems, mother-blame being not the least of these (Caplan).

Doctors silenced Kate, trivializing her questions and concerns. They were also unwilling to disclose their own concerns, denying her access to medical information. Having noticed there was a "jerkiness" in Jennifer's movements, Kate brought her to a pediatrician before she was a year old. As she recalls:

Unfortunately, we didn't click. I wasn't demanding, or aggressive, or any of the things that might have turned him off, but I had some questions, and he always just seemed to pooh-pooh them. And after a while, I felt as though he were treating me like a neurotic mother, and that I was being over-protec-

tive, and being silly. And I kept asking questions... Let me ask, why isn't she doing this? Or why isn't she doing that? And he would always come back with, "She'll do everything in her own time."

When Kate finally pushed him to make an unwilling referral to the Toronto Hospital for Sick Children, she discovered by sneaking a look at the file, that he was asking for a cerebral palsy search.

A referral to an orthopedic surgeon was a similarly negative experience. He said, "There isn't any reason why she can't walk... Goodbye, Mr. and Mrs. Watson." His cold, objective manner and lack of compassion were typical of Kate's encounters with the medical system.

Kate also took Jennifer to a psychologist, who left her with little hope and few options. In her opinion, "He should have been working with rats. He had absolutely no feeling for people at all. He treated us as though we were really interfering with his day, and he'd rather be doing anything else than seeing us." Some time after taking Jennifer away for a long battery of tests, he called her parents in for his verdict:

He sat behind his big desk, with two little [chairs] out here for us—and that told me a whole bunch about him—and he gave us just the blackest picture you could ever imagine. He... didn't explain what testing he had done, but he told us that she would never be independent; she would always be a drain on us, and on society, and she would never be able to be educated within the regular school system, and on, and on, and on. I don't know how I got out of there, but at any rate, it was then that I realized I was probably going to have to go through this exercise who knows how many more times, and that I was going to have to take what I could, and work with [that], and throw the rest of the garbage away.

Once again, Kate realized that she would have to rely on herself, though she had one positive experience with a medical practitioner at the Toronto Hospital for Sick Children, where she took Jennifer at the age of eleven months. "He told us they really didn't know what had happened, when it had happened, why it had happened, or what the prognosis was, but to take her home and treat her as though she were a normal child." Kate had been grateful that he had not suggested institutionalization.

Educational and social services

Although Kate sought help from both educational and social services, she found little there. Far from providing support, they placed further disempowering obstacles in her path. Educational barriers overlapped with medical ones soon after Kate took Jennifer out of a nursery school run by the Association for the Mentally Retarded. Kate describes this school as "a catch-all [for] autistic, aphasic, deaf, blind, and everything in between." During Kate's

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attempts to have her daughter admitted to the regular neighbourhood school, a public health nurse came to visit, and tried to persuade Kate to reconsider Jennifer's possible attendance at the school for the mentally retarded.

It completely took my breath away, because I had no idea that any of this had gone on behind my back.... And I said, "No. Jennifer isn't going to [that school]." And she got very, very angry. And told me in no uncertain terms that I was wasting the taxpayers' dollars. But I thought that Jennifer deserved, whatever anybody thought, I felt Jennifer deserved the chance to try it out in a regular situation. And when she left, she said something like, "We'll get her yet."

Thanks to Kate's insistence, Jennifer went to the neighbourhood school, where her teacher said she was "a delightful person to have in the classroom." However, after Jennifer had failed and repeated kindergarten, Kate was told that she must go into Special Education. As a result, Jennifer attended nine different schools thereafter, being forced to move every time the Special Education program was relocated. From then on, Kate struggled with educational authorities on behalf of her daughter for integrated schooling. This struggle culminated in her refusal to attend a segregated high school graduation ceremony for the Special Education class. After that, Jennifer spent a year at the local vocational high school, at the end of which Kate was told that she should seek another placement for her, "because she was taking up the room of someone who could learn better."

Educators also showed a tendency to belittle mothers, and to resent their intrusion. Observing one mother who "would just go in loaded for bear," Kate learned:

If you screamed and yelled and accused, you just got yourself a bad name.... You had to, first of all try and act as normal as you could be, and try and make as much sense as you could, even though that wasn't always very easy to do. And ... you had to be very careful not to set your child up so that he or she was going to be the brunt of whatever you were trying to do, because you're not in the classroom to ... suffer the consequences; they were.

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As a mother, Kate found this frustrating and unacceptable. Neither students nor their parents were being empowered by this system.

Asked if she had found any help from the social services, Kate replied,

Absolutely nothing! I found abso-

lutely nothing to be of any help ... there was a phenomenal lack of any referring to anybody. Everybody wanted to be the expert in their own field, and not yield to anybody else. It wasn't a helpful period.

Supports

However, when Jennifer was six or seven, Kate became involved in the Association for Children with Learning Disabilities (LDA), which she found out about through her own reading. That was a breakthrough, and the beginning of a sense of empowerment. In Kate's words:

We were a support group for one another, because so many times, until we got together, we didn't know that anyone else experienced feelings like we did. We thought that we were alone on our journeys, and that we were the oddballs, and that there was something wrong with us. And that's the group from which I got my support.

It was through membership in that group that Kate became involved in working for people with disabilities, an involvement which has led her into a life of disability-related public service. She has helped other parents negotiate their paths through the service systems, and learn how to confront professionals effectively. As well, she has embarked upon a career of public speaking about the issues discussed above, particularly with regard to the educational system. As well as being a support group, Kate believes that "the LDA was ... an avenue of acquiring knowledge of the challenges I would face, the solutions for some of them, and above all, a place where I could pay back and help others as a volunteer."

Further support came from her religious faith. Asked to describe herself in a few sentences, Kate's reply was, "a child of God." Her understanding of the life experience she has shared with her daughter is coloured by the spiritual values which are central to her life, values described by Carolyn Vash in terms of transcendence. For Vash, transcendence of disability is based on its acknowledgement and acceptance as part of an essentially whole self. She sees adversity as "a catalyst to psychospiritual growth".

Strategies of mutual empowerment

Based on both her positive and negative experiences, Kate developed strategies to empower her daughter's socialization, and to encourage her growth in self-expression and independence. From the outset, thanks to the supportive physician whom she only saw once, Kate realized that:

Jennifer was going to be able to be raised in the world as we knew it and ... from some of the things he told me, that I was going to have to guard against being overprotective; that I was going to have to be very dutiful in teaching Jennifer to do things, and to let her take

responsibility for doing them, or I was going to wind up with her being a basket case, and me as well.

My conversations with Kate have provided many examples of the ways in which she implemented this initial learning. When Jennifer was travelling on a school bus to Special Education classes, Kate discovered that another child on the bus was hitting her, apparently reacting to what was being done to him at home. Rather than call in the authorities, Kate sat down with Jennifer to discuss the ways in which she might avoid this boy. Some time after, three little boys rang her doorbell to tell her that Jennifer had told them to "fuck off" (25 years ago, this was unusual language).

I don't know how, but I had the presence of mind to say, "What did you say to her?" And of course they all looked really guilty, and hit the road... So we had to sit down and discuss where and when this was appropriate.

Letting Jennifer continue to travel on this bus was difficult for Kate. However, she resisted the urge to take charge, and deny Jennifer her independence.

I could have driven her, but I felt that that was even worse than that little step to independence of being on a bus ... and it was just absolutely terrible, because I wanted to do everything for her. I wanted to be in control, but something kept telling me that this was a gift that I had to give her.

Later, Kate helped Jennifer learn to travel alone on the city bus system, streetproofing her to the best of her abilities. Kate recalls:

I told her that if anybody ever wanted her to do anything that she knew was wrong, or that she didn't want to happen to her, that she [could] just scream. And we would run through the routine of how to manage herself. But I did a lot of praying during those days.

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An elegant woman herself, Kate allowed Jennifer to choose her own clothing, and to dress in ways which made her squirm, believing that others would see that as a reflection upon her parenting skills. Kate describes her frustrations:

Sometimes I was really sorry, because her choice of clothing was ... I mean, she'd have been fine today, when anything goes with anything, but back in those days, there were colour restrictions, and pattern restrictions, and because she

was awkward, she looked really worse in dresses than she did in slacks. And of course jeans weren't acceptable, and permopress had just come in, and the seams were sewn down the front of the pants, and invariably she'd put them on backwards. And there were many times that she went out to school, and I sat down and cried, hoping and praying that a teacher would be kind and say, "Your pants are on backwards; go and change them."

... And there were a lot of things that I should have changed, but I couldn't allow myself. I couldn't do them for her, because I guess I realized that if I did them, I'd be doing them when she was 40.

As well as encouraging Jennifer's autonomy to the best of her ability, Kate also gave her the freedom to express her feelings towards others, without trying to interfere. Jennifer's enthusiasm for people sometimes frightens them. One such occasion Kate witnessed was when Jennifer, aged about 12, ran to hug Arlo, the father of a boy with whom she was attending a summer camp run by a mental health facility. Kate recounts this event:

You could almost see him just wishing that he could go and jump in the lake, because the last thing in the world he wanted to do was let this strange child at him. And I was going to say something, and go after Jennifer, and something prevented me from doing it. And I just turned around. I didn't want to be involved any more than that, because I thought if it got too bad, I'd have to interfere, and I didn't want to do that. I made a decision, or had one made for me. And within a week, Arlo was running to Jennifer.

I decided then that Jennifer's relationships had absolutely nothing to do with me. I had to treat it as though it were an adult situation. I had no, absolutely no control over what two other people do, and how they interact. And I had made a decision then to stand back and let this happen. And it's very, very painful and awkward, sometimes... But as I say, if it works out, well, then it's beautiful, and if it doesn't, it's not my problem.

Recently, Jennifer became engaged to someone who works with her at Mainstream, the community centre where they both work and learn. When her fiancé began to talk to her about what they would do after they married, Jennifer's response was "No way!" As Kate explained, since Jennifer was happy to be engaged, but did not wish to marry,

Jennifer was faced with the fact that ... she was going to have to get unengaged without hurting Harry. And it was quite a maturing process for her. It didn't happen quickly. We talked about it, but I didn't do anything. I said, "You're going to have to tell him; I can't tell him." And eventually she did.

With respect to sexuality, Kate has been careful to educate Jennifer that intercourse may result in pregnancy, and has supported her decisions in that area. The courses she has taken at Mainstream appear to have reinforced "all of the things [she] feels on her own." Although she "enjoys people immensely," her mother says of her, "she doesn't seem to be a very sexual person." For Jennifer, the community centre has allowed her to experience many types of social interaction; for Kate, learning when to interfere and when to look away for the sake of Jennifer's personal empowerment have been skills that involvement with the community centre has supported.

Conclusion

Jennifer finds meaning in her work and learning at Mainstream. She travels about the city on her own, and is the mascot of the local baseball team. Her mother does not attempt to limit her freedom, with the exception of managing her money, an aspect of life which Jennifer's generosity might otherwise sabotage. Although at times she worries about Jennifer's safety, Kate explains: "... I can't be on her back like she's five years old; because she's 33, and she's an adult, and she values her independence, and I can't take it from her."

Kate now goes away for weekends, from time to time, leaving Jennifer at home alone to look after herself and the cat. She lives with the reassurance of knowing that when Jennifer wishes to spread her wings, Mainstream provides apartment living where she will have the necessary, but not too much, supervision. Jennifer is happy in her life, her work, her friends, and Kate has peace of mind with respect to the future, thanks to Mainstream.

Kate is convinced that the experience of being mother to Jennifer has empowered her to be a more passionate and involved person than she would otherwise have been, as well as an effective activist and problem-solver. Without Jennifer, Kate knows that:

"I had made a decision to stand back and let this happen. And it's very painful.... But as I say, if it works out, well, then it's beautiful, and if it doesn't, it's not my problem."

I probably would have taken a lot longer to accept anything as a challenge ... because I really was not motivated to do anything. I mean, I didn't have any great career ambitions; all I wanted to do was have children and be a mother and a wife.... I was pushed to do the kinds of things [I did] as a result of Jennifer's disability; I would never have accomplished anything like that. I certainly would never have been able to go to [speak at a university], and present to a group of people, or any of the other places that I've gone to....

In telling our story, over and over, it sort of clarified problems,

and how I dealt with them, and how we could continue to deal with them. It also helped my own personal self-esteem, and got me into many areas of life where I probably never would have entered, and [enabled me to become] affiliated and associated with people I never would have met: wonderful people.

I think that I've been very lucky ... Jennifer has been a gift.

It would be encouraging if we could believe that Kate's negative experiences with various systems and services reflected conditions which held true 20 years ago, but which were no longer relevant to parents of children with disabilities today. Unfortunately, that is not the case. Kate reveals that every time she describes her past experiences, members of the audience come up to her afterwards and tell her that she could have been talking about their experience today.

Her own experience has led Kate to a clearer understanding of how segregation continues to represent a significant limitation to the development of people with disabilities, as well as to the conscious understanding and sense of responsibility of other members of the community.

Most of all, Jennifer has taught Kate about humility, tenacity, and resourcefulness, as well as about the real value of mutual empowerment between community members, as well as between mother and daughter, to care for each other, to respect and learn from each other, and to know when to honour autonomy and diversity. Kate declares:

And having been involved with all the folks that I've been privileged to know through this experience, they're the real people. They're the people who know what life is all about. They know how to give. They know how to love. They know all the real stuff.

And whenever I think that I have arrived, that I'm really somebody, Jennifer just comes and kicks my ankle with some remark or some deed, and I'm very grateful, because I'm in the real world again.

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Brydon Gombay is a doctoral student of community psychology at the Ontario Institute for Studies in Education, University of Toronto. She is writing a thesis on the experience of disability in the lives of young adults with varying disabilities, and of mothers of such young adults.

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ELIZABETH JOHNSON

We Come Home

There was the hollowness of the apartment
as I stood alone, watching the silent newborn

and the fear as she stretched in the seat,
beginning to wake, to want.

I held my breath as her eyes opened,
lids peeling apart from each other,

fragile milky skin suffused
with her own incandescence.

There was my hand daringly placed on her chest,
the independent pumping of her heart,

the delicate throb of her body, a small sigh,
not sorrow, not pain, but knowledge of earth.

There was the stab in my groin
as a gaze held between us,

pull of my arms toward her squirm,
lift of my palms under her head and spine.

There was her flesh fragrant on my face,
her breath against my neck.

Elizabeth Johnson teaches writing and literature at the University of Minnesota. Her poetry appears in various journals.



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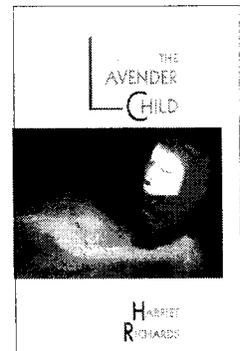
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