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ABSTRACT

Data for this paper were taken from a study in progress on the life histories of women labeled mentally retarded and were derived from 25 hours of in-depth interviews with two women aged 32 and 19 who also have cerebral palsy. Both of these women experienced special education classes throughout their educational careers. Gender issues in the special education classroom, peer influence and relationships, and teacher student relationships were among areas covered in the interviews. A major difference between the two subjects was that one went to a school which was only for children with disabilities, while the other subject started school the year that Public Law 94-142 (Education for All Handicapped Children Act) was implemented. Both subjects felt that school did not prepare them for the real world; both were still struggling to adjust to the work world and to find appropriate employment. Study results suggest the importance of interaction of the disabled with nonhandicapped peers and point out the lack of strong role models for handicapped females. It is concluded that career opportunities, vocational experiences, and training should begin early and continue throughout the high school years and that parents, school personnel, and disabled consumers of services should work together to transition the student to the adult world of work or further education. (CB)

The Education of Disabled Girls:
Personal Experiences and Reflections

Symposium: Aspects of Involvement:
Women as Mothers, Students, Teachers, and
Graduates in Special Education

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Until very recently, women with disabilities were largely invisible to society. Meager demographic data describe a life that exists largely at the bottom rungs of society.

Women with disabilities, for example, are likely to be poor, divorced or never married, and unemployed. In one recent study, for example, only a small percentage of women had college degrees, while only 25% had jobs (Matthews, 1983).

Men and women with disabilities are found in the poverty statistics in disproportionate numbers and women with disabilities are among the poorest of the poor. For example, in a comparison of expected income, based on characteristics such as age, occupation, race and education, with actual income, disabled people were found to be 35% below expected levels (Luft, 1979). The mean earnings of all workers in 1981 revealed the following distribution, not unexpectedly, women with disabilities fall at the bottom: non-disabled men, $17,481; disabled men, $13,863; non-disabled women, $8,470; and disabled women, $5,835 (Asch, 1984). Furthermore, disabled women who are also heads of households experience the highest rate of poverty. Their median income in 1978 was $2,178 (Mudrick, 1983).

There are many causes of these discrepancies; discriminatory attitudes of society toward disabled women as employees (Asch, 1984); differential application of financial assistance programs and rehabilitation services (Bartholomew, 1982; Mudrick, 1983); and quite possibly, the vocational preparation received by girls with disabilities in the educational system.

Prior to the passage in 1975 of the federal law mandating the right of children with disabilities to a free and appropriate education, children with special educational needs were left to the whim of individual state laws. In most cases, even where appropriate state law existed, enforcement was non-existant, coverage spotty and quality atrocious. Most often those children with severe mental disabilities were excluded, while physically disabled children faced segregation in special, accessible schools for the handicapped. The programs available did little to prepare disabled students to reach their full potential.

The Education for all Handicapped Children Act (PL 94-142) had as its roots civil rights litigation. Brown vs. the Board of Education stated that all children, regardless of race had the right to a public education. Parents and disability advocates sought to extend this argument to children with disabilities through litigation which cumulated with the passage of PL 94-142. A decade after the passage of this legislation great strides have been taken to include disabled children in the educational mainstream, to train teachers and administrators, and to develop curricula to meet the needs of all children with disabilities. A decade later, however, the issues have become more complex. Improving the quality of integrative opportunities, involving parents, serving severely mentally and physically disabled students, providing functional educational and vocational opportunities, and transitioning disabled students to supported work environments instead of sheltered workshops--all of these, and more, face parents, teachers, and administrators today.

While grappling with many of these issues, it is perhaps an appropriate time to examine gender issues in special education. Gender issues abound in regular education, is it unrealistic to expect that they are absent from special education? Discriminatory treatment, attitudes, and lack of access may contribute to the grim statistics previously mentioned which describe the lives of women with disabilities.

One way of looking at this question is to examine the lives of women with disabilities who have experienced special education programs and to look at their experiences from their own personnal perspectives and reflections. This viewpoint suggests a methodology identified with qualitative research. This paradigm of research focuses on the way people construct their world and the meanings they attach to the interactions and events in their lives. It has its roots in phenomenology--the study of consciousness and the phenomena of everyday life (Husserl, 1913). Qualitative research also follows the tradition of symbolic interaction--the study of meanings or symbols people attach to the interactions in their lives (Mead, 1934). This paradigm, or way of looking at one's world, contrasts with a quantitative approach to research which would instead emphasize establishing theories or hypotheses about the variables under examination, then proceed to test these theories and use statistical techniques to describe the relationships between variables.

In qualitative research indepth interviewing consists of "face-to-face encounters between the researcher and informant directed toward understanding informants' perspectives on their lives, experiences or situations as expressed in their own words" (Taylor & Bogdan, 1984). Although non-qualitative research uses very structured interview formats or questionnaires, this type of interview assumes knowledge of the informants' perspectives. It assumes, for example that the questions asked are relevant and meaningful to the subject, that the subject will respond with appropriate answers, and that the choices given as possible answers are not excluding the "real" answers (Schwartz & Jacobs, 1979). This contrasts with a qualitative approach to interviewing which does not assume the "right" questions or answers. The questions or issues instead emerge from the interview, reflecting the subject's own meanings and constructs.

The data for this brief paper on the special education experiences of disabled girls are taken from a study in progress on the life histories of women labelled mentally retarded. Extensive, in-depth interviews have thus far been conducted with two women, totaling 25 hours of taped interview data. Both women experienced special education classes throughout their educational careers. Their perspectives are particularly interesting as one of the women received services prior to the passage of the Education for All Handicapped Children Act, while the other postdates this legislation.

A brief introduction to these two women, Linda and Ann, will help us understand their experiences. Linda is 32 years old. Cerebral palsy gives her a slightly awkward, unsteady walk and mildly slurred speech. A hearing impairment causes her to wear two hearing aides. Even with these aides she depends on lip reading for understanding most communication. Severe allergies, particularly to various foods result in her eating a very rigid and restrictive diet, which may explain her extreme thinness.

Linda went to the public schools in the community where she grew up. First she went to a segregated school--one only for children with disabilities. By the middle school grades, she was enrolled in regular schools, but still in self-contained segregated classrooms. After graduating from high school with a certificate of attendance instead of a diploma, Linda dropped in and out of a large sheltered workshop for approximately ten years. She found assembly work boring and the people unpleasant. She tried, at various times, volunteer work in a nursery school, cleaning jobs in a nursery school and dish washing in a large nursing home. For the past ten years she's been trying to earn a GED by attending classes in a variety of adult education programs. She's also looking for another job, perhaps in food service. She dreams of eventually going to college.

Ann is 19 years old. She has cerebral palsy, and uses a wheel chair. Over the past several years she has had numerous operations to correct her legs and feet so that some day she may walk with braces or a walker. She also has slightly slurred speech and a mild accent. She was born in Guyana, South America and came to this country at age ten with her mother and eight brothers and sisters.

Ann started her education when she came to this country in 1976, the same year PL 94-142 was implemented. She attended a segregated school for physically and mentally disabled children. It is the same elementary school that Linda attended ten years earlier. Ann attended this school until she went to high school where she attended special education and a few regular classes. Ann's vocational rehabilitation counselor wanted her to attend a sheltered workshop after high school. She refused and after leaving school, enrolled in the local community college's pre-placement program for disadvantaged youths.

Although she had to drop out of her first semester due to surgery, she has had special tutoring to maintain her skills. Presently she has enrolled again, and with a lot of one-to-one help she may finish. Eventually she wants to earn a degree in human services so that she can work with the families of children with disabilities. Ann lives at home with her mother and several of her brothers and sisters.

Two major topics seem to run through the special education experiences of both Ann and Linda: classmates and teachers.

Classmates: "Mostly, I didn't want no boys in my classes."

Both Ann and Linda characterize their relationships with other students in special education as problematic. Interestingly, neither had much to say about typical students not in special education. Ann, however, makes distinctions between special education students who used wheelchairs and those that did not.

Ann's first exposure to special education was quite a shock:

> I was not use to seeing what I saw. The students would misbehave, you know, because they couldn't help it or something. Throw their papers around in the classroom and make noise and beat up on the other kids and everything like that. That really threw me... I wasn't use to that kind of thing. They would chew up their homework or put their homework in their mouth. In fact, they were even beating up on me because I was very bright. Most of the things they were now learning, I had learned already.

Ann's experience was compounded by the fact that she is dark complexioned and at the time spoke with a thick accent. She was harrassed by other children in her special school, both those using wheelchairs and others she characterized as "slow."

Escape was Ann's first reaction to this turbulent world of special education. She often went home from school early saying she was sick. Her mother caught on, however, and told her, "You'd better learn to deal with it. I'm not going to be there to help you all the time."

Next, Ann tried to fit in, to be like the other students. In her words:

> I would just fling my hands up in the air. I wouldn't listen to people, be sassy and everything... I came home and I wouldn't talk in a normal voice, I would just stutter all the time. Just go ah, ah, and not say a word...
>
> I guess at that time, the message I was getting from the students was, "You act like us." I use to speak as well as I can, but they didn't understand why I was not more like them. You know what I'm saying?

Ann got through this period with her mother's help:

> My mother didn't like it. She said, "I didn't bring you up like that, what do you think you're doing? Don't you dare get like that."...It took her months and months just to teach me how to be Ann again. I looked like Ann, but I was becoming a whole different person...
>
> When people were around, it got worse. So she'd wait till everybody left and work on me and teach me. She'd have this mirror and say a word to say, just so we could start speaking my regular way...She said, "I don't want to see you like that." She really pushed. She was really terrific. She didn't say, "Well, this is alright, she's handicapped anyway, she can act like this." She went like, "Oh no you don't!"

Linda also experienced difficult relationships with the other children in special education:

> I really didn't like going to, probably the word for it is, I didn't want no boys in my classes at all. They were really bad... I didn't like the kids. Most were always teasing me...Because they were always getting me into trouble. Like in junior high school. As they got older, they learned how to tease me.

Like Ann, Linda's experiences also were not easily resolved. She experienced difficult relationships with both handicapped and non-handicapped peers in all of her work settings. She remains very sensitive to her speech impairment and uses other people, especially her mother, to initially interact with agencies and professionals on her behalf.

Teachers: "She really believed in me."

To the extent that Ann and Linda talk about their teachers in special education, they talk about the ones who, in their eyes, believed in them and encouraged them to develop their potential. In Ann's words:

> In my final year, I had the most hard teacher, that's why I loved her so much...She really showed me that I had the chance to do whatever I could...
>
> She said,"Nobody out there is going to be rooting for you. You might as well root for yourself. Nobody ever said that...
>
> She said, "I'm not going to hand you anything because you're handicapped. People think you're good for only a few things. You better start proving to yourself right now, how good you are."
>
> This teacher was not only realistic, she was tough:
>
> All the kids never wanted to go to her class. Because she was really hard...She wasn't just patting me on the back and letting me pass. When I got to her class I had to shape up...
>
> And she had a lot of students in her class, it was like ten students to a room. Sometimes I wasn't so smart because the kids never liked me. Because they saw how smart I was. She would say, "What do think is going to happen to you when you get out there? People are going to be able to handle you like they handle clay."

In Linda's eyes, the good teachers not only believed in her, they protected her from the other kids, while bad teachers allowed other kids to tease her or teased her themselves:

> I got switched again to my first teacher. That was really great. She helped me along better than anything else...
>
> Because she knew what to expect and stuff like that. I got mostly A's in 7th and 8th grade...
>
> She taught all three subjects, then none of the other kids did not tease me so often. Because they were watched more then by her. That helped me a lot.

An Overall Look at Special Education: "It's not like the real world."

Linda summarizes her special education classes rather quickly, perhaps not much differently than some of us would look back on those days:

> First grade came along, two years in that, and then another, uh, second grade was almost three years, that was too much...We learned math. My teachers got me, uh, into telling the times of the clock. Easy, real easy stuff. Then I went to school at R., in special ed. classes.
>
> Then on to Blank Middle School. I didn't like the way that one of my teachers always teased me too much. There were other kids in my class that were really bad. Things like that...I was learning about the American history and stuff like that. And, uh, I was learning mostly thing that every classroom were. Mostly things like that.
>
> Ninth, 10th, 11th, and 12th grades were at the High School...I learned to sew...I was in special education all my life.

The relationships with the other children and with teachers, particularly involving teasing, occupy most of Linda's reflections about school.

Ann, whose school experiences were much more recent, had much more to say about school. Here she is describing progressing from class to class in the segregated school. The "regular" kids she refers to were special education students who did not use wheelchairs:

Ann: This school was like a flat school, basically for people who were disabled or who had some sort of mental handicap. They had about five or six rooms on this one floor. There wasn't no elevators or anything like that. We had the one floor and the regular other kids had the upstairs. You were like in grade one, you started like in kindergarten with toy blocks. Play with toys or anything. Depending on how smart you were, you stayed there for about three years.

Int: How old were people who played with blocks?

Oh my goodness, between twelve and thirteen. Some of them were older. I only stayed in there for three weeks. There would also be other classes that you had to go to, but basically, that room was it. That was the room you went to for class and that was the room where you stayed.

If you wanted to have therapy or something, like most of the handicapped students, you go to the therapy room at a certain time. They had a swimming pool and a gym.

> Down from there was another room where the basic reading skills and the math skills started. O.K.? Some of the teachers teach you reading themselves, but some of them, they had a reading teacher and we would go to her room. Then you spend a few years there. A lot of students they couldn't teach all of us at the same time, there would only be one teacher. We each had different needs. Then we got to the third class where you really start to get into like reading, they had to teach you that because people would come in there and say, "You're not doing your job."

Int: You think that's why they have classes?

Ann: Yes!

The theme of going to the large, sheltered workshop in this community surfaces often in Ann's reflections about school. Ann asserts that special education only prepares students for sheltered workshops in the next passage where she discusses the last classes at this school:

> To the last two classes is where you really had to succeed. You would know whether you were going to the workshop or not. Other classes you would just pass, you know? Nothing really gained, you just passed. So, the last two classes were always the hardest...
>
> and also in the last class, we use to call it the big room, because after you were finished with that class you got out of that school.

Ann summarizes her school experiences with strong words:

> Like, what I'm saying is that when you're in junior high school, you're taught one thing. When you get to high school, it's still the same thing. You go in circles, it is not anything that you are really taught. Because of the system, they have The Workshop or OVR. (Office of Vocational Rehabilitation)...
>
> But when you get there (junior high school), you already know OVR is coming...So you just go around doing this and that, it's like, being in prison and just serving out your sentence. <u>It's not like the real world</u>.

The real world. Neither Ann nor Linda received adequate preparation for it. Ann eloquently expresses an awareness of the inadequacies of her skills to continue with an education and a career. She articulates it as a deficiency in the educational system to prepare people with disabilities for anything but the safe world of programs for the handicapped where people are treated as handicapped: "the only thing some of them don't do is breathe for us."

Linda does not articulate this insight into school programs and services for people with disabilities, but her life is an example of someone struggling to overcome educational shortcomings. Her search for meaningful work and the many years spent trying to earn a GED--without financial assistance from the vocational rehabilitation agency--testify to a spirit that refuses to be molded into societal expectations for the handicapped. One is struck by the similarities in the experiences of these two women. This, in spite of the fact that their educational experiences occurred back to back and Ann's education occurred after the passage of PL 94-142 which revolutionized special education. Perhaps it was too soon in the revolution for Ann.

Conclusion

Gender issues are not readily observable in the personal reflections of these two women. One cannot assume, however, that they do not exist. I am struck, for example, by the similarity between the female experience of being raised in a safe world with no expectations, so aptly described by Friedan (1963), and other feminist writers, and the safe world described by Ann:

> Because it's like as soon as you're finished (with school). that's your ready-made world. It's a world all ready for you...I just wanted to be out of there. Because I didn't like that world. Because I was in a wheelchair, my world was to be ready made. I'm not going to have some superman or something move all the earth for me. That's what they want to do to you. Protect you. Send you here or there.
>
> ...especially the handicapped person, because we are handicapped. We're not taught to take care of ourselves, but people are taught how to take care of us. Sort of like robots, you know.
>
> If I was brought up differently, maybe then I would have loved being in that safe world. You know sometimes we all want to escape to a safe world. All of us. But then you have to get back to reality and there's no superman to take all your worries away and save you.

Ann describes the sterotypic attitudes held by society toward the disabled: helpless, passive, dependent, objects of pity and charity, incapable of surviving in the real world of work. Unfortunately, society also views women as helpless, passive, and dependent. The similarity in these two sets of stereotypes leaves women with disabilities with few role models. At least men with disabilities can aspire to overcome the stereotypes of the disabled by achieving typical male characteristics: e.g. assertive, independent, forceful. Women, on the other hand, are assigned to "rolelessness" (Fine and Asch, 1981). As another disabled woman writes:

> We can't become adults, because with few exceptions (success stories) disabled people, especially disabled women, don't grow up. We can't be women because "true women" are able-bodied. The most prevalent social message is that we stay home, nicely protected, the eternal child. I long ago tired of being treated as a child. My place is in the world with everyone else. (O'Toole, 1979)

There is a striking similarity between the experiences of disabled girls and that of black girls. Lightfoot (1980), for example, describes the latter as an "ignored and invisible" population. She asserts that there is little written about their experiences in social science research because of a cultural orientation that devalues black women. As with disabled girls, young black girls have few role models. Black women are stereotyped as the enduring mother, caretaker of white children and white families, or, conversely, as the sexy, liberated, aggressive siren. One wonders how self-identities are formed for both groups of women, both of whom deal with two characteristics devalued by society: the dual stigma of being female and black or being female and disabled.

Does special education contribute to this state of rolelessness by encouraging passivity and helplessness, as Ann argues? The preliminary information from these two women suggests more in-depth probing into such areas as feelings about self-worth, independence, social relationships with non-disabled peers, and future career goals. There are several implications for the educational system, however, which can be derived even from this preliminary examination of the experiences of Ann and Linda:

1. The importance of interaction with non-disabled peers cannot be overestimated. Peer acceptance and understanding contributes to the self-confidence of young girls with disabilities.
2. Career opportunities, vocational experiences and training should begin early and continue throughout the high school years to enable students and to begin planning and considering options.
3. Parents, school personnel, and disabled consumers of services should work together to transition the student to the adult world of work or further education.
4. Parents and disabled consumers of services need to advocate for more meaningful work experiences as alternatives to sheltered workshops.
5. Young girls with disabilities should be encouraged to become assertive and as independent as possible, by being provided with positive role models.

As more women with disabilities tell their own stories, they will contribute to our understanding of what it means to be both a woman and disabled in our society. Their contributions and participation will enhance the analyses of issues facing special education today.

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