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**Nancy Salzer, 56 years young,
living a full life with Morquio Type A**

I thought our Support Group Newsletter readers might be interested in some reminiscences by an adult who has Morquio. In this article I will describe my childhood, concentrating on my education, and in later articles I'll discuss my efforts to go to college and find employment, and the importance of the disability rights movement for me.

Born in 1945, in a suburb of Rochester, New York, I'm an only child; my father was a skilled factory worker, my mother a homemaker. In my very early childhood, my parents noticed that I had difficulty beginning to walk, and that most of my joints had a limited range of motion. At age two I was admitted to the teaching hospital affiliated with University of Rochester and diagnosed with Morquio. Since, in 1947, there were no genetic tests, I do not know how the diagnosis was reached. I believe I have a relatively mild form.

I am of short stature, 4' 6", and have the flat-bridged nose typical of Morquio. All of my joints have limited range of motion. Although, I never had pain in any of them until the onset of osteoarthritis in my early 40's. Compared to most children with congenital disabilities, my childhood was relatively free of hospital stays. I had no health problems, and only two orthopedic surgeries, when, at age nine, I had surgery on my knees to enable both to straighten properly. Afterward, I began to walk with crutches, and had greatly improved leg strength and mobility. The range of motion limitation in my other joints, such as my hands and fingers, was significant, but I compensated easily, again, until the onset of arthritis.

It seems I was a fairly happy child, although quite shy, and not particularly adventurous about trying to do new things. My father was quite overprotective of me, my mother less so, and I was content to let my mother help me with daily activities like dressing far longer than necessary. I have always traced my early timidity to the fact that during my hospitalization to diagnose my disability, my

parents were not permitted to visit me. Apparently, in those days, medical "experts" had the strange theory that a two-year-old would not be upset by having her parents disappear for more than a week! This had to have had an impact.

I had some neighborhood playmates who were very accepting of my physical limitations, but for the most part played alone, watched television and read a good deal. When I played, alone or with my friends, I loved tomboy games like cowboys, perhaps pretending to be more daring in play than I was in reality.

When I was five years old, my mother took me to our local school to register me for kindergarten, where the school refused to accept me because of my disability. In the 1950's, my parents had to fight for my education without the protection of laws like IDEA or the support of any parent organizations. I was apparently the first child with a disability ever to seek an education at my school, and administrators were not sure what to do with me. They also assumed that since I had a physical disability I might also have impaired intelligence, and insisted that I have IQ tests. The tests showed above-average learning ability (I have since earned a bachelor's degree and two master's degrees!), and the school, though refusing to admit me for kindergarten, did agree to accept me for first grade.

I spent first, second and third grades there at my neighborhood grammar school. None of my teachers had special training in educating disabled children. The first two were, however, experienced and talented, and made an effort to help me fit in. I always did well academically but had increasing mobility problems and was often the "odd child out" at school, particularly in third grade, when I had a teacher who was far less interested in me. My mother, waiting for me one day while my class came out of school, saw another child imitating the way I walked (before the knee surgery), bent forward, pressing one hand on a knee for balance, although I have no memory of seeing that myself. Whenever my class walked from one part of the building to another for an activity, I could not keep up my classmates. One day I fell in the cafeteria but was not injured.

During my third grade year, my parents learned of a "special Ed" program in the nearby Rochester city school system. I think that they learned of it from the newly appointed principal of my school, but it's possible that they learned of it at the hospital Orthopedic Clinic to which Mom took me periodically. In any event the principal recommended it and even took my mother to visit there one day. This was, of course, an easy way for the school to pass off to someone else its obligation to educate me, but in fact the change in schools was a positive one for me. My school district arranged to pay for my transportation on the half-hour ride to the city every day.

One might think that I would have vivid memories of my first Days as a fourth-grader at the "Orthopedic Unit" of Rochester's School Number Five, an environment far different from my old school, but I do not. Of course, I'd seen other children with disabilities before, at the Clinic, so perhaps I wasn't surprised at the sight of a classroom full of children who used crutches or wheelchairs, and who had a wide variety of disabilities such as cerebral palsy, muscular dystrophy, spina bifida, polio, and other, more uncommon "birth defects."

At Number Five I had a "total immersion" in a disability Community, no longer the only disabled child, now among children who accepted one another's disabilities as "normal," helping one another when necessary, forming friendships and cliques, joking and arguing. I had a wonderful socialization experience, but a poor academic education. There is a debate in the disability community now about

the good and bad aspects of mainstreaming. The failure of special Ed in those days was that educators tended not to expect much of us academically. Instead of challenging us, they protected us and did not prepare us for the real world. We never even had homework assignments. Yet, this school did provide a community, a place to be ourselves and be comfortable, to accept ourselves and not bother about what the able-bodied thought of us. We grew up with a sense of solidarity with one another.

There were so few children at Number Five (about eighty, I think), ranging from kindergarteners to seventh graders, that each classroom of about twenty children usually covered two or three grades. Thus my classes had a one-room-schoolhouse atmosphere. Even in one class, often only two or three children were studying the same subject at the same time, and many of my classmates were behind on some subjects because of many absences for surgeries or illness.

As I've said, I got a poor education at Number Five. But my Parents encouraged me to read at home. I did watch television, but Also read and played and exercise my imagination and intellect. When I began seventh grade, a new teacher tried to remedy the poor education we were getting. I moved along more quickly, but never did even start seventh grade math. My father bought a copy of the textbook and, that summer; he and I spent every evening after supper working on my math skills.

After seventh-grade graduation from Number Five, I like most Special Ed students, moved on to a city high school, Jefferson High, At Number Five our Orthopedic Unit was completely segregated from all the other students in the school, separate on the third floor of the Building, but at Jefferson we attended classes with all the other students. We rode on the freight elevator, operated by one of the school custodians, to move up and down the building's three floors, and were allowed to leave class five minutes before the class bell rang so we could get to the next class on time. That, and the presence of a not-always helpful "counselor" were the only accommodations for our disabilities.

Some Number Five students had difficulty with being thrust into A normal high school routine, expected to keep up with the class and do Homework assignments. However, after a slow start, I thrived. I was fascinated by all that there was to learn, the sciences, literature, History (my favorite), algebra (with my father's help), even Latin. My Classmates were all friendly and accepting. Although there were other Disabled students in the school, as I recall I was the only disabled Child in any of my classes.

In 9th grade I began to be bothered by the fact that attending A city high school, rather than the same high school attended by the others in my neighborhood, was preventing me from having a full high school life. I could not stay for after school activities. At home I had no contact other than phone calls with my schoolmates, yet neither did I have much contact with other neighborhood high schoolers. My district had just built a new high school, Eastridge. While it was in no sense designed for accessibility, it was a single story building in which I would have little difficulty moving around as long as I was given extra time between classes. Eastridge already had an excellent academic reputation, and some of my teachers had been telling me that I was "college material" and should attend a better quality school. My parents let me make this choice on my own. I was happy at Jefferson, but the lack of a social life, and some desire to challenge myself, made me decide to transfer at the end of my freshman year. More to follow about my later years!