



EXCEEDING Expectations

They told her to institutionalize her son. Instead, she helped change the system.

by michelle groleau engel '97

For years, children born with developmental disabilities were put in institutions and forgotten. When **Sylvia Kloc '59** gave birth to her second child, Steven, in 1966, that system was beginning to change, and Sylvia took an active role in helping the change along.

Steven was born with Down syndrome. Sylvia immediately knew something wasn't right. The other new mothers were holding their babies, but Steven, who was born a healthy 8.5 pounds, was not even being brought to her for feedings.

"I just didn't understand," Sylvia said. "I had seen him, and he looked very healthy to me."

The following weeks and months were a blur. The Klocs were told that Steven had mongoloid characteristics – genetic birth defects that are often related to mental retardation. They didn't know how serious Steven's developmental delays would be, but it became obvious that Steven wasn't developing like other babies.

"He was very, very small," explained Sylvia, "and months went by but he wasn't doing anything that would be considered typical – he didn't smile, or laugh, or cry. He would just

kind of look at you."

A specialist at Children's Hospital in Detroit finally diagnosed Steven with Down syndrome. The doctor told them he would never walk, talk, feed himself, or toilet train.

"He told us to put Steven in an institution and forget we'd ever had him – to go on with our lives. I'd like to have been able to take Steven back and show him that the only prediction that came true is that Steven never talked," said Sylvia.

When Steven was 2.5 years old and began to crawl, respond to his family, and respond to his name, the family's doctor referred them to Plymouth Center, a local in-

stitution for mentally disabled.

"There was never really a time we considered an institution," said Sylvia, "but I thought that someday he might have to end up in one."

Ironically, the Klocs got their first ray of hope at Plymouth Center. They learned that Michigan had started the process of deinstitutionalization, and routine admission into institutions was no longer recommended. Through Plymouth Center they found Northwest Communities ARC, which eventu-

"You cannot rely on the good intentions of people who are in power."

ally became ARC of Western Wayne County.

Sylvia noticed that Steven often lagged behind the other children she knew through ARC.

"Sometimes I feel like I just cried all those years," said Sylvia. "Various things would happen, and he was at the bottom of the totem pole. Here I was thinking he was doing great, and he wasn't."

As he got older, though, Steven continued to make progress toward independence.

"Over the years, he's constantly amazed me with how he's grown and developed, and how I've grown and developed along with him," said Sylvia.

The ARC of Western Wayne County has also grown and developed with Sylvia and Steven.

Sylvia began to volunteer with ARC. She helped with fundraising, advocating to government agencies, and publishing and distributing the group's newsletter. She served as president of the board of directors from 1976-1979,

and wrote the grant that made

their chapter of ARC a United Way agency. They were then able to hire an executive director, and Sylvia stepped into that role in 1984. She retired at the end of December.

As director of ARC, Sylvia has been responsible for fundraising, budgeting, volunteer development, advocacy, program development, day-to-day administration, United Way budgeting and reports, and grant writing. She has watched the agency grow from a staff of two employees working in a one-room school to a staff of five full-time employees and two part-time employees in a building owned free and clear by ARC.

Through her involvement with ARC, Sylvia was able to play an active role in the deinstitutionalization process.

"There's a perception that people with disabilities need to be served differently – that they need all of this stuff only professionals know how to do," said Sylvia. "What they really



When Steven was born in 1966, a specialist told Sylvia and her husband to forget he'd been born, and that he would never learn to walk, feed himself, or toilet train. The specialist was wrong.

Raising them Right

If Sylvia were talking to parents of children with developmental disabilities, here is what she would suggest:

- Get in touch with the local organization that deals with your child's disability.
- Work with the public school system. Every state is required to provide educational services to children with disabilities from ages 3 to 21. In Michigan, it begins at birth.
- Treat them like normal children. Many think that you have to treat a child differently because of a disability. In reality, children thrive when treated like other children.
- Expect the best your child can do; push the envelope. Accept that your child has a disability, but don't impose limitations because of that disability. Her son has done many things that experts said would never happen.
- Realize that we are always learning. There is always new research, and things that we considered true 20 years ago are proven wrong today.
- Love your child unconditionally.

need is appropriate support so they can do the same things as people without a disability."

Gradually, more community-based services for the disabled were developed. Small group homes opened for those being moved out of institutions. Eventually, a voucher program was developed allowing disabled people to live in groups of two or three and making apartment life possible. Later, families were able to take more control over how funds were spent to help their disabled children, and could not only choose where they would live, but also choose their own caregivers. Steven received many of the new services, and ARC became involved in administering some of them.

Today, ARC of Western Wayne County is considered to not only be one of the leaders within the Michigan ARC organization, but within the United States.

"I didn't do this by myself," said Sylvia. "It was with the help of a fabulous staff and with board members who were willing to listen and help.

"I feel very comfortable with retiring," she added. "I'm leaving the organization in good hands."

Sylvia and her husband will primarily be living in Florida now that she is retired, so she has worked hard to make sure she's leaving Steven in good hands. Their daughter, Beth, will step in to handle Steven's affairs, and their younger son Christopher will also stay involved in his care.

Now 38, Steven has worked at Dick's Sporting Goods for five years. He leases a vehicle, and with the help of his parents, purchased his own home. Both Steven and his roommate require assistance from full-time staff, but are contributing members of society.

"Nothing happened without us working for it," Sylvia said. "You cannot rely on the good intentions of people who are in power. You have to constantly remind people of why your son and daughter need these opportunities. What we have now are adults with disabilities who have jobs, are paying taxes and buying homes.

"I am amazed at the life Steven leads today," she added. "It's not a life I could even imagine in 1966. It has far exceeded what I considered vast expectations then."