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Taking first steps toward aiding physically challenged children

Pathways helps put kids on road to a normal life

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Debbie Karl hoped she was just being neurotic, but after her son was born she began to fret over his inability to grab things with his left hand or roll over on his tummy when other infants his age began doing so.

Karl's pediatrician preached patience, cautioning that babies develop at different rates. But Karl went with her gut and insisted on tests to see if her son had medical problems.

Her gut was right. An MRI showed evidence of cerebral palsy. Doctors couldn't tell Karl whether her son would ever walk or talk.

But she took him at the age of 5 months to the Pathways Center for Children, a Glenview-based pioneer in outpatient therapies designed to minimize the long-term impact of early childhood disabilities.

Today at age 9, Karl's son still favors his right side and walks with a discernible limp. But he walks. And runs. And goes to school. And plays baseball. And lately he's been practicing how to cast for fish.

"Without Pathways, he probably would be just sitting all day, going through life doing nothing with his left side," Karl said. "He'd probably be stiff as a board."

Pathways has made headlines recently, not for success stories like the Karl boy but because of the disclosure that Maggie Daley, the wife of

Mayor Richard M. Daley, was paid \$75,000-a-year to run a sister not-for-profit agency called Pathways Awareness Foundation.

The foundation distributes videotapes and brochures across the nation preaching the benefits of early detection of movement disorders and early therapeutic intervention. It also promotes the mainstreaming of physically challenged children into religious services, recreational programs and school-related activities. It has worked closely with the Archdiocese of Chicago to further those goals.

Both Pathways programs were founded by Chicago insurance executive Patrick G. Ryan and his wife, Shirley, longtime friends of the Daleys' and the parents of a teenager born with cerebral palsy. Ryan's Aon Corp. holds competitively-bid contracts with the city, but a spokesman for the mayor said the foundation run by Maggie Daley has no financial ties to municipal government.

Pat Ryan was elected to the board of directors of Tribune Co. last May.

In an interview, Maggie Daley said she had worked as a volunteer for the foundation since its inception in 1989. She said her position was upgraded to a paid post two years ago to keep her from quitting and taking an offer of a full-time private sector job.

"This was taking a lot of my time,"

she said. "I was interested in working and had another opportunity. Shirley said, 'Stay.'"

Maggie Daley still does volunteer work in addition to her role with Pathways. She serves as the unpaid president of the Chicago Cultural Center Foundation. In 1995, the last year for which tax returns of the organization were available, the charity raised \$2.2 million for programs at the cultural center and elsewhere.

But it is Maggie Daley's paid position that has raised eyebrows among some administration critics. Still, the mayor's wife said she was proud of her role at the Awareness Foundation. "I do feel very privileged to be able to do this," she said. "I just hope my work speaks for itself."

Like the Ryans, the Daleys hold a close, personal connection to issues involving disabled children. A son, 2-year-old Kevin, died in 1981 from complications of spina bifida.

Experts in childhood disabilities say the goals of both Pathways programs are at once simple and important.

The reasons lie in the remarkable pliability of the brain, which in many cases can be trained in the early months and years of life to work around or minimize problems that impair movement, speech, hearing, learning and vision.

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"Early on in children's lives, there's a plasticity to the brain which decreases over time," said Meryl Lipton, a neurobehavioral specialist at Rush-Presbyterian-St. Luke's Hospital. "If you're able to provide interventions early enough so the brain can adjust, you can affect change which can benefit those children."

Indeed, according to Michael Cupoli, a pediatric specialist in chronic illness at Children's Memorial Hospital, research shows that early treatment can often revive normal reflexes impaired by brain damage.

"The brain tends to be a lot more flexible in the first few years of life than we once knew," Cupoli said. "We have good evidence that physical and occupational speech therapy can help children learn at the time when their brain is most receptive."

Because there's no rigid timetable for early childhood development, many pediatricians try not to be alarmist and tend to gloss over potential warning signs of problems in infants they see. To be sure, often youngsters who seem slow to raise their head or sit or crawl eventually perfect those skills. But in cases where they can't, delay in getting therapy can render impairments far more difficult to overcome.

The Pathways Foundation is a leader in attempting to raise public awareness about the issue. Its brochures, detailing for parents the early warning signs of developmental problems, are now distributed by officials in 22 states, according to

Shirley Ryan. They also are available by mail to anyone calling the foundation at 1-800-955-2445.

Videos on the subject produced by the group also appear periodically on WTTW-TV Channel 11 and other public television stations across the country.

In 1996, the foundation organized a conference with the archdiocese to promote the inclusion of people with disabilities in church activities and rituals. The inspiration for the meeting came when the late Cardinal Joseph Bernardin heard one of the older children from the Pathways Center say that he had longed to be an altar server at mass but was never asked to participate because of his disabilities.

"A lot of our churches were built in the '20s or '40s and have high steps," said Monsignor Kenneth Velo, Bernardin's longtime aide and friend. "It's hard for people in wheelchairs to come to mass. How can they get in? We need to sensitize people to problems like that."

Bernardin took part in the conference and also appeared on a video promoting inclusion, which has been distributed to parishes throughout the archdiocese. Pathways is sponsoring a similar interfaith conference next spring.

"If tomorrow, God forbid, you or one of your loved ones was in an accident and had to be in a wheelchair, you'd still be the same person but you'd be looked on very differently by others," said Maggie Daley. "We want to change people's attitudes about those who just happen to do

things differently."

Pathways Center opened in 1985 with only 12 patients, but that number grew to 80 within a year and now is more than double that. Children treated at the center range in age from a few months to 18 years.

Its treatment regimens are not unique but are more typically carried out in hospital settings rather than outpatient facilities.

A team of therapists works with each child, some to help them make more efficient use of their legs, arms, torso and neck, others to work on more precise skills like feeding, speaking and picking up objects with their fingers.

On a recent day, a therapist was taking one bright-eyed 4-year-old boy on a pretend picnic with plastic fruits and vegetables. The goal was to teach him to pick up the toys and toss them into baskets.

In another room, a 3-year-old patient who had suffered a severe head injury as an infant was being rolled around in a small version of the kiddie ball pits found in amusement parks. This exercise was designed to enhance his sensory perception.

The name Pathways was chosen deliberately, said Shirley Ryan.

"There's a connection in the brain that allows children to learn the language of movement," she said. "Physical therapy is the key to starting these new synapses or pathways."

Tribune staff writer Ray Gibson also contributed to this story.