

A Lot of Imagination Helps...

Highchair for the Handicapped

By Susan Swanberg

Trina Schneider, the daughter of Gail and Steve Schneider, has blue, kaleidoscope eyes, billowy blonde hair, a contagiously quick smile, a special love for her grandfather (and the country and western music he plays), an unusual highchair... and cerebral palsy.

Born October 2, 1976, Trina spent the first 10 days of her life motionless, except for strong, frequent seizures. After a blood transfusion, high doses of powerful medications, intravenous feedings and round-the-clock care by hospital personnel, Trina slowly began to recover from the trauma of her birth.

"They (Trina's doctors) told me on October 5 (1976), which is my birthday, that they didn't expect Trina to live. I even had her baptized in the hospital," Gail Schneider remembered as she bounced Trina on her lap. "To this day, her doctor calls her his miracle baby. He has a list of special children he prays for every day and Trina is on that list."

Accepting Trina's handicap was difficult for the Schneiders. And, Gail said candidly, "She's just about all I can handle. I don't think I could care for another child like Trina."

Caring for Trina is an almost constant task — one which prompted her mother to quit her three-day-a-week job. "I was always having to take time off from work to take Trina to the doctor," Gail said. Trina still has medical appointments at least twice each week.

The extent of Trina's vision is not yet known and doctors are currently plan-

ning a brain stem test, body scan and extensive hearing tests to determine, and hopefully correct, some of her many physical defects.

While Gail is enthusiastic and hopeful about these medical treatments and devices, she is especially excited about Trina's new highchair.

How can a highchair compare with sophisticated medical attention? Obviously it can't, but like Trina, her highchair is not ordinary.

The Schneiders acquired Trina's custom-built highchair from the newly-created Children's Adaptive Equipment Shop at the Hattie B. Munroe Pavilion, in cooperation with the Meyer Children's Rehabilitation Institute on the University of Nebraska Medical Center campus.

Trina had been receiving therapy at MCRI for almost two years when she and her mother paid the institute an unscheduled visit last April.

"I just stopped by the physical therapy department one day to say 'hi' to Duane (Duane Kliewer, Trina's physical therapist). I didn't even have an appointment with him. When I walked in, I saw this highchair and I just knew I had to have one for Trina. So that same day, we went over to the shop and they measured Trina and started building one just for her," her mother said.

To Gail Schneider, the new highchair means more than no longer holding Trina on her lap to feed her — it also means a lot of peace of mind.

"I know that feeding her on my lap isn't good. I'm really excited because now I'll have somewhere for her to sit where I can leave her alone for a short time. I can trust her to not fall out of this chair."

Because Trina can't sit in ordinary chairs, Gail often lays her on the floor. "I worry about laying her on the floor too much because it's not good for her back," she explained.

Kliewer began adapting equipment when the Children's Adaptive Equipment Shop was still just an idea.

"In those days we had to work with what we had," said Kliewer, referring to both materials and personnel. "I use a lot of duct tape. The reason is because of its strength and flexibility."

A wooden box chair lined with foam rubber, various walkers and other special chairs and equipment are among Kliewer's self-proclaimed "make-shift" adaptations.

"Physical therapists receive relatively little training in adapting equipment. I think necessity became the mother of invention in my case," he said. "So often parents come in and say they can't find anything commercially that will work for their child."

In these cases, Kliewer makes adaptations to better accommodate the child. For example, he said, "walkers need to give the child the opportunity to assume an upright position without constant handling by the parent. Par-



Photos by Tom Singarella

Gail Schneider helps daughter Trina, a cerebral palsy victim, try out a custom-built highchair.



McKinley Love and Chuck Pixler measure a wooden box chair in the Hattie B. Munroe Pavilion shop.

ents don't have 24 hours a day to totally care for the handicapped child, especially if they have other children at home."

The minor changes in a piece of equipment, which duct tape can accomplish, can be major ones if the child becomes more stable and better aligned as a result. "Anything that can be done to increase independence in sitting, assist standing, or the simple experience of being able to move is very important to both the child and the parents," Kliewer said.

Small changes in a chair, for example, can give the child more potential — better speech, vision, hearing and use of the hands. It's stressful for the child when lack of muscle control causes the body to involuntarily assume an uncomfortable position.

While adaptive equipment is designed to be therapeutic, the equipment needs to be enjoyable as well. "I made a walker for one little boy but he needed some motivation to use it, so I put Star Wars controls on it," said Kliewer. "He wouldn't use it until those controls were on there, then it was fun."

The fun and sense of freedom children derive from developing independence have played a part in the development of the Children's Adaptive Equipment Shop.

One parent, Jack Swaney, has been instrumental in the shop's development. His desire to find a tricycle his daughter Tiffany could ride prompted his interest.

Like Trina, Tiffany has cerebral palsy and she also receives therapy at MCRI. But cerebral palsy didn't squelch her desire to ride a tricycle. So her father, after "asking around and finding there was nothing available unless someone could build something," did just that — he found someone who could adapt a tricycle to suit his daughter's special needs.

That "someone" was Percy Roche — a New Zealand-born former aircraft engineer who adapted a trike especially for Tiffany. That first three-wheeler became the prototype for 10 modified versions Roche recently adapted for loan through the shop.

Roche's tricycle features a lowered middle bar (so the child can easily step into it), a back rest welded onto the seat and devices to keep the child's feet on the pedals.

The tricycles were purchased with money donated by the Variety Club of Nebraska Tent No. 16. Although Roche was paid, his charges were minimal.

"There were hundreds of things, so many things we need to do to help," said Roche. "But first we need to get over this attitude that they're (handicapped persons) 'poor little things.' They're not 'poor little things,' they can be a part of society, they can be productive."

Tiffany Swaney, now 6, is perhaps the personification of Roche's statement. When she received her special tricycle just a little more than a year ago, she couldn't walk or talk. Now she's doing both; and more — including attending school and taking ballet.

"When Tiffany first got her tricycle, we were going to attach a hook to the back for her crutches, but she decided she didn't need it because she was going to walk," said Swaney.



Percy Roche has modified 10 trikes for use by kids with special problems.

The Children's Adaptive Equipment Shop, the only one of its kind in Nebraska and Western Iowa, is not receiving any financial support from the University of Nebraska system.

Among several donors are the Rotary Club and Saunders County Office of Retardation. The Hattie B. Munroe board of directors found space—a former kitchen—for it in their building.

The rental truck that hauled remodeling materials was donated by the Ryder truck company, and materials were purchased "at a special rate," said Dave Rohe, MCRI physical therapy department director. Remodeling itself was done by parents, staff and local AFL-CIO volunteers. AFL-CIO member John Donaldson recruited his brothers and father to help with the shop's remodeling.

In addition to a fund for needy families, another future goal is to incorporate a recycling system through which parents could share equipment when their children outgrow or no longer need it.

Salaries for the Adaptive Equipment Shop employees are presently being paid by the Comprehensive Employment and Training Agency (CETA). CETA, however, will only pay the employees' first year salaries which means that the shop must pay its employees' salaries after this first year.

Shop carpenters Chuck Pixler and McKinley Love are enthused about their new jobs.

Already they've made a variety of chairs, desks, benches and tables. Pixler said: "I'm willing to tackle any project that comes through that door and if I can't build it, I'm going to find the guy who can."

Pixler says he enjoys the teamwork he shares with the MCRI staff. "The therapists know what they want but they don't know how to build it. I know how to build it and make the child more comfortable, but I might not know what's best for the child's health like the therapist does," he says.

Adapting equipment may not be an ordinary job and the future of an experimental project like the Children's Adaptive Equipment Shop may be an uncertain one, but for those involved there are some satisfying rewards.

Pixler explained: "When the lady (Gail Schneider) brought her little girl in to be measured for the high chair, and I saw how excited she was to be getting it, it was all the initiative I needed to think it's a pretty good job."