As she reached her first birthday, Sami Humphreys had a sweet disposition, but she was a quiet child. Too quiet. “She didn’t talk at all. She was silent,” said Heather Humphreys, Sami’s mom. Two of Humphreys’ three older daughters had received services from the Up to 3 early intervention program at Utah State University’s Center for Persons with Disabilities, so she was familiar with the program.

By the time Sami was 14 months old and still not talking, Humphreys called Up to 3 to request a free developmental assessment. “They listened to me and let me ask a million questions,” she said. “They gave me information and let me make the decisions. Doctors are not going to take that time.”

They were referred to the CPD’s interdisciplinary Autism Spectrum Disorder (ASD) Evaluation Clinic and Sami began receiving speech therapy and occupational therapy services just before she turned 18 months old. She was also referred to the ABC preschool class for children with autism. “Up to 3 was a major blessing, because at 21 months she completely tanked,” Humphreys said. Sami’s behavior regressed and turned self-destructive. “Because of the OT help and ABC and her speech-language pathologist, she’s a totally different person than she had started to become,” Humphreys said.

The goal of early intervention

Sami is only one of the more than 400 children and their families who received services from Up to 3 from July to December 2012. The majority of those children have moderate developmental delays, mainly in speech and language, said Sue Olsen, director of the exemplary services division of the CPD.

“The goal of early intervention is to have kids kindergarten-ready so they won’t need specialized services from the school district, and that equates to saving tax dollars,” Olsen said. Children who have developmental delays and do not receive early intervention services start preschool in their local school districts at age 3, or kindergarten at age 5, with virtually no preparation.

“Our primary mission is to have children who have significant developmental delays leave the program with skills closer to their age group peers, and those with moderate delays to be functioning within their normal developmental range,” Olsen said.

According to Marla Nef, program coordinator for Up to 3, more than a third of the children who receive early intervention services are not eligible for services—meaning they are within their normal developmental range—by the time they start school.

“Early intervention is so important because children make so much progress when they’re young,” Nef said. “Any help they can receive at that age can decrease their struggles in the future. It also decreases the parents’ frustration and provides a toolbox for them to use in the future.”
Nef said most referrals to the program come from well-child checks performed by local physicians, but anyone can refer anyone who might need the free developmental evaluation. Her staff members use a variety of ways to find children who need services.

“We had one mom who had picked up a brochure at the WIC booth at the Homecoming parade in Hyrum,” Nef said. Parents who are already in the system may call because they have another child they’re concerned about.

“We don’t turn a child away,” Nef said. If, after the evaluation, the child is referred for services, the family pays a flat monthly fee, no matter how many services are required. “We won’t deny services based on an inability to pay,” she said.

Services vary from child to child and family to family. Staff members talk to the parents about their concerns and then determine the child’s needs.

“Whatever their needs look like, we’ll put together a team and go to the home,” Nef said. “If they’re worried about language, we’ll send a speech therapist. If they’re worried about behavior, we have grad students in psychology who deal with behavior. If they’re not eating well or having trouble sleeping or having problems with sensory integration or fine motor skills, we’ll send an occupational therapist.”

The Up to 3 staff includes seven service coordinators (case managers). One of the service coordinators also is a nutritionist, and one also is an autism specialist. Two nurses are on staff to determine or rule out any other medical need. There also are five speech therapists, three occupational therapists, three vision specialists, two behavioral specialists, one physical therapist and one physical therapy assistant. An office in Brigham City is staffed by a speech therapist and a physical therapy assistant.

Funding for Up to 3 comes from Baby Watch, a program of the Utah Health and Human Services department. The current session of the state legislature is considering a building block grant for Baby Watch to fund growth in early intervention programs across the state.

To aid in that effort, Nef is seeking parents of children who are currently receiving services or have received services in the past, who would be willing to share their early intervention stories and successes with legislators.

“We need to show them how important it is,” she said. Parents can call or e-mail Nef using the contact information below.

Pieces of a puzzle

Occupational therapist Amy Henningson works with children who have feeding aversions, sensory processing impairments and problems with fine motor skills.

“In feeding aversions, you have to look at what is causing the problem,” Henningson said. “Is it reflux? Do they have a sensory impairment where different food textures make them gag? Is it a motor problem where they can’t move their tongue or mouth correctly to suck, swallow and breathe?

“Being a therapist is like putting a puzzle together,” she said. “You have to figure out the underlying cause, and what you can do to facilitate the response you want.”

Children on the autism spectrum often have difficulties in sensory regulation, Henningson said.

“Kids who are more hypersensitive to external stimuli are the ones who are more prone to meltdowns,” she said.

Techniques such as deep-pressure full-body hugs and massage, as well as items like weighted vests and blankets, are just some of the things parents can use to help a child with sensory difficulties.

“It’s tough enough to deal with everyday issues,” Henningson said. “It’s especially difficult when you have a child you can’t take to family activities because there’s too much stimulation and there will be a meltdown, or you can’t take them to the store because people look at you and say why can’t you handle your kid? It’s not a behavioral issue, it’s a neurophysiological response to something in the environment.”

Fine motor skills include being able to hold an object in each hand, transferring an object from one hand to the other and pointing to objects. Parents can encourage activities that can improve those skills, Nef said, because they can do it much more often during the course of the family’s daily life, even simply by playing with them.

“If you’re changing his diaper, hold a toy and see if he’ll reach across his body to get it,” she said. “Put him on all fours and set up a row of toys to encourage him to move toward them.”
Parents of children with disabilities often think they have to be doing things just right, Nef said, and sometimes it’s a struggle.

“There’s a lot of pressure there,” she said. “There may be grief over the loss of what might have been. There may be marriage troubles or frustration from trying to find resources.”

Jeanie Peck is a licensed clinical social worker and offers mental health counseling to family members if another therapist or service coordinator identifies a need.

“I work with them on whatever issue they have,” Peck said. “It’s guided by the parents’ need.”

She doesn’t work with every family in the Up to 3 program, and the time in which she’s involved varies with each family. She has worked with as many as 20 families at one time, and is currently seeing 11.

**TechnoTots provides assistive technology**

If the occupational therapists, physical therapists or speech-language pathologists who evaluate the child feel she would benefit from assistive technology, the child goes to TechnoTots, a program run by Henningson and speech-language consultant Stacey Sessions.

Located next door to the Assistive Technology Lab in the Janet Quinney Lawson building, TechnoTots custom-fits positioning and mobility devices for children with more severe developmental disabilities. Henningson and Sessions, with the help of the AT Lab, find, adapt or make devices that can be used for adaptive play, communication, positioning, literacy, mobility or computer access.

“Sometimes they’re trapped in their little bodies and they don’t learn cause and effect,” Sessions said. “We can hook up switches that they can hit with whatever part of their body they can control. If they hit the switch, the toy moves or makes a sound. They start to learn that their body movement can cause things to happen—cause and effect.”

Communication devices can be as simple as pictures or symbols on a card to sophisticated high-tech dynamic displays. Pictures of food choices, for example, allow a child to communicate whether he wants cheerios or toast or chocolate milk for breakfast, which helps to decrease his frustration with his inability to express himself.

Sessions said iPads are huge now, and apps are improving. The Humphreys family bought an iPad with a grant from Autism Gives, but so far have only used it for Sami’s visual schedule.

“TechnoTots is going to help us use it to try to develop expressive language, which she does not have,” Humphreys said. “She doesn’t ask for help, she doesn’t try to pull anyone else in. Hopefully this way she can say I’m tired, I don’t feel good, I’m cold, I want to play.”

Sessions said iPads have a long way to go, but they will only get better as more apps are developed. They are also much less expensive than specialized communication devices that can cost upward of $7,000, she said. Insurance will cover much of that expense if they can prove that the child’s speech has not improved during the time the child has received services. That usually means the child has to be closer to three years old.

A typical 3-year-old speaks in three-word phrases, Sessions said. Communication devices are not easy things to learn, so she is happy if the children in the program are using one- to two-word phrases before they get to school.

“Without the communication devices it puts them that much further behind,” she said.

**Home visits and field trips**

Occupational therapist JoHanna Keller Eggleston recently visited Tara Stevens and her 2-year-old daughter, Natalie, at their home in Nibley. Natalie has Turner Syndrome, a condition caused by the absence of an X chromosome. Natalie exhibits some autistic tendencies and behaviors, as well as some sensory processing issues, so Stevens called Up to 3 for an evaluation. She, like Heather Humphreys, was acquainted with the program because her 4-year-old son had received services, although her 8-year-old daughter did not.

“I knew Natalie was delayed,” Stevens said. “I knew what things to look for, and I knew she probably needed speech and other things.”
Now, Eggleston is working with the Stevens family to help Natalie cope with having other people in her space. Going to church, eating out at a restaurant, even family gatherings offer too much sensory stimulation, and she reacts with a meltdown.

One of the goals they are working on now is for Natalie to be able to tolerate going out to eat at a restaurant with her family. Eggleston suggested taking her to restaurants during off-peak times, and to ask for a corner booth, which can be a little quieter. Actually eating at the restaurant is optional.

“You can work into the eating part,” she said. “If she doesn’t eat there, it’s not a failure. She’s there.”

“A lot of times, with a child with disabilities, what you expect is what you get,” Eggleston said. “Having expectations in the future will help shape how she deals with the world. She can’t live in your house by herself forever. She has to learn to be in the world.”

Eggleston tells Stevens about an upcoming community event for families in the Up to 3 program—a princess party—and encourages her to take Natalie.

“There will be lots of kids and all kinds of trials for her,” Eggleston said, noting that Natalie is not the only child in the program who struggles with crowds and people. It’s also a place to meet other parents and ask them what works for them.

Nef said gymnastics classes were already being provided in the community by Altius gym in Logan, PEAK in Brigham City and Tanglewood in Bothwell/Tremonton.

“They’ve been great to work with,” Nef said. “We just pay a flat fee. Our physical therapists teach balance and motor skills and the kids love it.”

Humphreys is enthusiastic about the community events.

“The field trips are the coolest things,” she said. The group has gone bowling and ice skating and to the soft play area of the Cache Valley Fun Park in North Logan. Humphreys compared a trip to the fun park with Sami before she entered the Up to 3 program and a recent trip with her ABC class.

“We went by ourselves when she was 20 months old,” Humphreys said. “She just kept her hands on the mesh and screamed her little guts out.”

When all the Up to 3 kids went, Sami was really tentative, Humphreys said, but her therapy people were there and it was OK. On the last field trip with ABC she just took off, almost like a little neurotypical child.

“Field trips are so valuable,” Humphreys said. “It gives them new experiences and helps them be able to handle it. We just love Up to 3! I cannot imagine life without them in my village.”

As children get closer to age 3 and are about to enter the local school district’s preschool, they are able to attend Lil’ Aggies, a preschool for any child in the program, or ABC, which is for children on the autism spectrum. Children on the autism spectrum who are ages 3 to 5 may also attend the ASSERT program in addition to their local school district’s preschool.

Li’ Aggies and ABC help children gain the skills they will need to be able to function in a public school setting, like sitting still and following directions. The classes also help children who have separation anxiety issues.

“I’m kind of nervous for her to go to preschool,” Stevens said of Natalie. “It was good for my son, but Natalie is a little more extreme.”

Sami Humphreys attends Li’ Aggies twice a week.

“It will help her transition to the school district preschool, which I think is brilliant,” said Heather Humphreys.

More than early intervention

While the Exemplary Services Division’s Up to 3 program is far-reaching, it is not the only service offered to the community.

Clinical Services runs the ASD evaluation clinic, serves as the clinical training site for students and is the practicum training site for doctoral-level psychology students at USU. Clinical Services also provides consultation services to community agencies.
**TOP Sports** is a parent-run program offering sports and other activities for children with developmental disabilities.

Local school districts provide services from age 3 to 22. After that, there is the Developmental Skills Laboratory (DSL). Director Drake Rasmussen said the DSL impacts participants in many ways.

“It gives them the opportunity to be part of a group, and it helps them integrate into the community and sometimes access services they otherwise wouldn’t get,” he said, including speech and music therapy.

Rasmussen said if the participants weren’t at DSL, some of them might be able to attend the Cache Employment and Training Center, but that facility offers more work site-based activities.

“The majority of our participants come here because we’re more activity based,” he said. “We take them on a lot of tours, we take them to movies and bowling. We help them become independent in daily living skills.”

Heidi Hill is a long-time DSL participant and writes a monthly guest post for the CPD blog which details the fun things she does with her “buds.”

Average daily attendance is about 14, Rasmussen said, with seven staff members. A summer program for people under the age of 22 increases the daily participation to more than 25, with about 15 staff members.

Participants get a lot of interaction with USU students, staff members and volunteers as they walk to the TSC or the bookstore.

“The social aspect and building of friendships is huge,” Rasmussen said. “If our program wasn’t here, they’d be sitting at home doing nothing.”

DSL’s program is a benefit to the participants’ families as well, he said, because it allows family members to keep a job and have a place for their loved one to stay during the day.

“Community integration and social skills—that’s a huge benefit from our program,” Rasmussen said. “They get to know lots of people and become friends with lots of people.”

For a free developmental assessment for a child under the age of 3, or to share early intervention experiences and successes in the Up to 3 program, contact program coordinator Marla Nef at (435) 797-2043 or by e-mail.

For more information on the Up to 3 program, click here.

For more information on Clinical Services, click here.

For more information on the Autism Spectrum Disorder Evaluation Clinic, click here.

For more information on TOP Sports, click here.

For more information on the Developmental Skills Lab, click here.

To read Heidi’s Happenings, visit the CPD Blog here and type “Heidi” in the search box.