

...offering
information &
inspiration
to individuals with
disabilities and
their families
as they direct their
own supports and
services



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Opening New Doors Sheila Schaffer In Real Life Choices

For Elizabeth Schaffer and her daughter Sheila, Real Life Choices (RLC) has meant a new lease on life. "Since becoming involved with Real Life Choices, I feel reborn," Elizabeth Schaffer told New Directions. "It was like 'open that door and let me out.'"

For Sheila, RLC has meant living in her own home and being deeply loved.

For years, Elizabeth has been the sole caregiver for Sheila, now 39, who has multiple disabilities including Down's syndrome and a congenital heart defect.

After she graduated from a special needs school nearly 20 years ago, Sheila went to a nearby day program. "She did ceramics, art and crafts and other things to just keep her busy," recalled Elizabeth. She was happy, active and had many friends.

But 10 years ago, Sheila developed an infection that spread through her body. "When she was released from the hospital," Elizabeth recalls, "it was like taking care of a baby again. I had to feed her, bathe her and she wore diapers."

Within a year, Sheila developed cataracts and her eyesight began to fail. Although her doctors believed that her cataracts were treatable with surgery, her heart condition made her a very poor candidate for anesthesia. In the end, Elizabeth decided it was too risky to operate. Sheila gradually went blind.

Soon there after, Sheila became depressed. She stopped talking and would not go to her day program. Her mom described how Sheila would curl into a fetal position and refuse to get off the couch. She tired easily, her muscles began to atrophy and she could no longer walk without assistance.

To make matters worse, Elizabeth was diagnosed with breast cancer. "Things were very bad for us then," she recalled.

With so many people coming into their home, Elizabeth says Sheila seems more responsive. "If I didn't have these people here, I couldn't do it. Sheila is coming out of her shell now."

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Sheila Schaffer in Real Life Choices, continued from the cover

“All of my doors were closed and all of a sudden, this one opened...”

Elizabeth isn't sure how it happened that Real Life Choices came into their lives. “I guess I was on waiting list,” she said. “One day, someone called me out of the blue. All my doors were closed and all of a sudden, this one opened for me. It was a God-send.”

Since getting involved with RLC, life has improved for the Schaffers. For starters, Sheila can now get outside. With funding from RLC, the Schaffers had a ramp installed so Elizabeth could get Sheila's wheelchair outside.

After she got the ramp installed, however, Elizabeth realized that Sheila could no longer get in and out of the car. “I had my grandson take the seats out of the car and Sheila would just lay in the back. I know it wasn't safe, but I had to get her places,” she said. With funding through RLC, the Schaffers were able to get a ‘companion seat’ for the car. Now Sheila can ride safely.

With RLC, Sheila has staff for roughly 5 hours a day. “Sometimes we need more time so I can get to my own doctor visits,” says Elizabeth.

The Schaffers have hired friends and staff from Sheila's former day program. With so many people coming into their home, Elizabeth says Sheila seems more responsive. “Even if its just playing with a ball or walking her to the bathroom, we get her up off the couch and moving. If I didn't have these people here, I couldn't do it,” said Elizabeth. “Sheila is coming out of her shell now.”

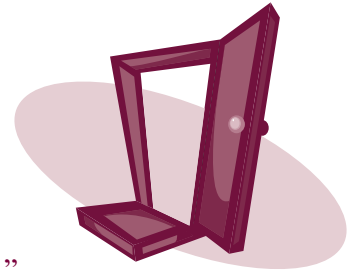
“Through Real Life Choices, I have been able to bring some joy to her.”

- Elizabeth Schaffer

Even with support from RLC, Elizabeth is still alone with Sheila all night. “I get up with her for the bathroom, and what ever she needs. I have broken sleep because I am up with her.” On some days, Elizabeth has to arrange for Sheila's support staff to come in just so she can rest.

There have been changes to Sheila's RLC plans since she

started last year. For example, Sheila was a ‘level one’ when she started, but now is a ‘level 4’. “There are so many things that she can't do now,” says her mom.



With funding through RLC, travel is now possible. “In the past, I never wanted to leave her,” admits Elizabeth, “but with my cancer, I was afraid I would die without traveling to see my great-grandkids. Now she can come with me.”

Next month, the Schaffers are planning to go to Florida. Elizabeth's lifelong friend, Carol, will join them to care for Sheila. “I can take Sheila on a trip because someone I know will be taking care of her. I know I can trust her alone with Sheila.” Elizabeth is even considering a trip to California to see her great-grand children.

Elizabeth does get to go out without Sheila, as well. With the trust she has in the staff she hired, Elizabeth can now go to the store or out to a movie without worrying.

Unfortunately, Sheila's health continues to decline. She is developing dementia, needs oxygen at times, and her asthma has gotten worse. Even still, Elizabeth sees RLC as a sustainable option. “The way I see it, Sheila is too sick for a group home. If we did not have help from RLC, she would need to go into a nursing home.” But that is not what Elizabeth wants. “They would never get her up and make her do the things I make her do,” she explained.

Often, Sheila and her mom will get in the car and set out for the beach. “The ‘boards (boardwalk) are good because she remembers it from when she was a child -we used to go all the time. She still wants to hold the cotton candy, even though she won't eat it,” says Elizabeth. Sheila also loves listening to music, especially the soundtrack to Grease, Annie, and Sound of Music.

With the loss of her eyesight and health, there is less and less that can make Sheila smile. Says Liz: “This program has let me bring some joy to her.”

GRIEVANCE & APPEAL RIGHTS IN THE MEDICAID MANAGED CARE SYSTEM

By: Valerie A. Powers Smith, Esq. & Herbert D. Hinkle, Esq.

If you are a Medicaid beneficiary in a managed care plan, you have several options to grieve or appeal a dispute with the Medicaid HMO.

First, you may file a grievance with your HMO regarding complaints about quality of care issues, denials, terminations, or reductions in your Medicaid benefits. In an emergency situation, you must receive a decision regarding your grievance within 24-48 hours (note, you must request an 'urgent review'). Otherwise, decisions must be made within 90 days of filing of your complaint.

Second, as with the Medicaid Fee-for-Service system, a Medicaid Managed Care Beneficiary may file for a Medicaid Fair Hearing whenever a covered health benefit has either been denied, terminated, or reduced. By law, you must receive written notice any time there is a proposed change to your Medicaid benefits or services. The written notice must:

- be timely (generally, at least 10 days before the proposed termination or reduction of services)
- explain how to obtain a Fair Hearing
- explain how and which benefits will continue pending the outcome of the Fair Hearing
- explain that you can be represented by legal counsel,

or have another person at the Fair Hearing to speak on your behalf.

Your request for a Fair Hearing must be filed in writing within 10 days of the notice; and should clearly state the reasons you are appealing the proposed action. Once a timely appeal is filed, all Medicaid services must stay "as is" (status quo) until the final disposition of the appeal.

Alternatively, as a Medicaid managed care beneficiary, you can also choose to follow the 3-stage appeal process (where covered health benefits have been denied, limited, or terminated):

Stage 1 - Informal Internal Appeal

Stage 2 - Formal Internal Appeal

Stage 3 - The External Appeal

The request for a Medicaid Fair Hearing may be made simultaneous to the 3-Stage appeal process. The Office of Administrative Law prefers that you proceed at least to the second level internal appeal before filing for a Medicaid Fair Hearing. If, however, you have problems getting the HMO to maintain your services during the appeal, others have found success in filing the Medicaid Fair Hearing appeal while indicating that the internal appeal process is also underway.

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Liz Obermayer, Advocate and Mentor, to Speak at Conference

"Nothing About Me Without Me"

Liz Obermayer sees living a self-determined life a bit like putting together the pieces of a jigsaw puzzle. Each piece interlocks and connects with the next to create a picture - a life - in the community. On April 16, Liz will speak at "Nothing About Me Without Me," the **4th Annual Gathering** for people involved in Self-Directed Supports, such as Real Life Choices and Self-Determination.

Here is what Liz had to say when she came to New Jersey last spring:

...When people with disabilities want to take a risk, the government, case managers and our parents have a meeting to decide if it is OK. But that is not OK. Why not let us make mistakes? ...I have taken plenty of risks by now, and let me tell you, my parents were freaking out. But I'm OK."

Hear more from Liz and 10 other workshop presenters as they discuss topics like Friendship, Creative Housing Options, Medicaid and Medicaid Waivers, Financial Planning and hiring staff.

Saturday, April 16, 2005 from 8:30 - 3:00
Double Tree Hotel, Somerset, NJ

for more information, go to www.umdj.edu/boggscenter
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