

Letters from Fellow Parents and Caregivers

I am woman!

Ro Vargo,

Syracuse, NY

When the little yellow school bus stopped coming - actually, a whole year before the little yellow school bus stopped coming, we admitted to ourselves that we needed help - in providing Ro with an active, happy, safe and stimulating lifestyle beyond her school years.

We had lots of ideas. Ro had lots of ideas. So, we invited about 25 people we knew through church, work, school contacts, family and friends to come be a part of Ro's Circle of Support. About a dozen people responded to our potluck supper and we began looking at Ro -- what she really liked to do, what she was really good at, and most importantly, we began offering her choices of activities that other typical adults her age might want to do. The life plan that took shape, while tentative and fragile in terms of providing the necessary day-to-day support, turned out to be a perfect model for Ro. Ro is taking a course at Syracuse University entitled, "Understanding Music II." The class meets for lecture on Mondays and in the Multi-Media Lab on Wednesday and Friday mornings. On Monday nights, she attends our church's folk group practice, of which she is a member. She is responsible for bringing the refreshments. Every week, Ro decides what to bring and either cooks it during the day after class or goes to the store to buy something. On Tuesday, she volunteers for two hours at our neighborhood Day Care Center in the 4-year old room. She supervises the water table activities and shares snack and circle time. On Wednesday, she spends her lunch with the Baptist prayer group on campus. She swims once a week in an Aquatics Program. On Thursday, she does her homework and reading at the Library on campus and eats lunch with the Multicultural students at Hendrick's Chapel. On Fridays, after her computer lab work has been completed, she spends one hour of fitness time with three physical therapy students who are attending Upstate Medical Center University. Lunch on Fridays usually takes her to Marshall Street, the campus hub. Ro also holds season tickets to the Syracuse Symphony. She has two seats so that she can invite another person to go with her.

Ro's days are supported by family and friends, paid and unpaid personnel, as well as peers/students on campus. Ro can decide if she wants to change or adjust anything in her schedule, depending on her stamina or weather conditions. Nonetheless, Ro is happy and very content and for now, that makes it all worthwhile.

Amber

Donalee Echols,

Fort Worth, TX

"When Amber turned 22, a doctor called to see if he could examine her for the purpose of determining if she fit the diagnosis of Rett syndrome. It was hope! Amber and I went, and found out that she does, indeed, have Rett syndrome. We finally had a name.

Today at 31, it is hard for her to keep her balance due to scoliosis, so she must be supported while walking, getting in and out of the tub, chair, etc. She loves to go on outings, eat in restaurants, swim, take short walks and have someone pay attention to her. She beams from ear to ear when I tell her that I am proud of her and that I know she understands. I feel so fortunate to have Amber, to know pure love and to witness the courage of one who lives in a trapped body."

Darleen Melissa Sherman

Priscilla Sherman,
Boynton Beach,FL

We first met Darleen Melissa Sherman at the age of 11, when she came to live in the institution where my husband, Ron and I, worked. It was Darleen's beautiful smile, her gentle nature and twinkling eyes that reached into our hearts and that very day, Darleen had a new home with us. Thirty years have passed since that day, and Darleen is now 41 years old. She has faced many trials including multiple orthopedic surgeries, spinal fusion, pneumonia and ovarian cancer. Just this past year, she spent more than fifty days in the hospital with pneumonia and severe sepsis. She has lost the ability of assisted walking, the ability to swallow and the ability to vocalize. Through it all, she has never lost her ability to enjoy all that life offers. In her younger years, she participated in many activities such as motorcycling, snowmobile riding, ice skating parties, gardening, travel (especially to Florida), boating and even mountain climbing on her Mom's hip. She has touched the lives of countless people and showed them the meaning of true courage and unquestioning love and trust.

Darleen attended excellent programs from age 14 to 21. After school, she attended an adult training program at a local UCP program. When we moved to south Florida in 1986, there were no day programs for individuals with severe disabilities. Darleen accompanied me to workshops and IEP training meetings, making friends wherever she went. We also went fishing and swimming in the ocean. After seven years of waiting, Darleen was among the first group of adults to benefit from the Medicaid Waiver Program and attended a newly developed Adult Day Training Program run by the local ARC. She was diagnosed with RS after we found an article about the syndrome quite by accident.

Today, Darleen no longer attends a Day Training program. Her health is fragile and the long days and travel time is too much for her. A personal care aid/companion comes to the home five days a week to bathe and dress her and take her out into the community. The pace is determined by what Darleen is able to do. She still travels extensively with us, and spent this Christmas at Disney. She may be more fragile than in her youth, and the salt and pepper in her hair gives away her age, but the twinkle in her eye remains, as does the strong and loving spirit of this beautiful angel.

Stacy Ruble

Sharon Nanninga,
Springfield,MO

Stacy Ruble, 25, lives with her mom, step-dad and ten-year old brother, Levi. She likes to go fishing and to the zoo. She loves parades and clowns are her favorite. She likes shopping, especially at Walmart, and going to visit Grandma and Grandpa. Stacy loves clothes and animated toys. She dearly loves her dog, Lucy, and the only time she will bend over is to give him a kiss. They have a great bond; she slips the hot dogs she doesn't like under the table to Lucy.

Stacy got her school Certificate of Completion at the age of 21, and stays at home now. We go out in the community a lot! We have learned to take one day at a time and to try to keep our sense of humor. It can be hard sometimes when I see Stacy having more trouble with her motor skills as she gets older.

Stacy is the light of my life; she always has a smile on her face and a twinkle in her eyes. She is a very good-natured young lady, and she loves to be around people. Her Aunt Michelle watches her sometimes so I can get a break. We don't know what we would do without her. She is Stacy's guardian angel. Both my kids are my pride and joy.

Erika Robin Gladstone

Irene Gladstone,
Needham,MA

Erika Robin Gladstone, 23, is quite short, only about 4'5" and weighs about 90 lbs. We think she is very cute with her red hair, freckles and almost constant smile. She is currently living at home in Needham, Massachusetts, with her Mom and Dad and attending a day habilitation program. Erika is always happy to see her older brother, Andrew, 25, when he comes home for visits.

Erika's day program is run by our local Association for Retarded Citizens (ARC). The MA Department of Mental Retardation (DMR) and Medicaid provide funding for the program and provide transportation. There is a DMR case manager to serve as a liaison between the ARC and DMR. The program Erika attends is housed in a beautiful new building which opened the week before Erika started, and it is only about two miles from our home. Her program runs from 9 to 3 daily and provides her with physical therapy, speech therapy, music therapy, and occupational therapy.

She shares a direct care provider with another young woman with Rett syndrome. Erika and Jess have been in school together since they were three years old. One of the biggest problems with the local day programs is finding adequate staffing. Attempts are being made to increase the staffing in Erika's program. When this is accomplished, we are hopeful that Erika will be able to take more community trips. In her previous school program, Erika went out into the community almost daily. Once a week she worked as a volunteer in the cafeteria of a local hospital where, with the help of her teacher's aide, Erika cleared and cleaned cafeteria tables and "earned" her lunch. She also went bowling and to movies, restaurants, performances, museums, parks, and many other locations with her classmates. We would like to see this variety and quantity of community involvement in her adult program. Right now she does get out for walks and weekly shopping trips. Erika requires one-on-one assistance for all activities and therefore adequate staffing is essential for all outings and for activities within the building. We feel that Erika's quality of life as well as her alertness and physical well-being are greatly enhanced by activities outside the program's walls.

Erika loves to be active. She is presently walking, but needs someone by her side and physically holding her arm as she walks about in public. At home, she does walk without assistance and wanders around the house. The quality of her walking is poor and she is bent forward at the waist, but as Doctor Rett advised us when he diagnosed Erika in Baltimore when she was six we "keep her walking." We use a Convaid Cruiser for Erika when we need to move fast or will be covering large distances. Erika does receive additional physical therapy outside of her day program and we attempt to stretch her at home.

Erika is in excellent health and does not have seizures. We are fortunate that at present she is not on any medication. She did have scoliosis surgery at the age of fourteen. Aside from tapping people to get their attention, Erika does not use her hands in any way and needs to be fed. She is not an efficient chewer so her food is either soft or we cut it into small pieces for her. In spite of this Erika enjoys all types of ethnic foods and will often demand food from our plates (usually by tapping us) when we neglect to prepare something for her. About four years ago she learned to drink from a straw and this has increased her liquid intake and lessened messiness at meal times.

Erika's main method of communication is by facial expression. She does make different sounds when she is happy or upset. Generally, she displays good eye contact and appears very aware of what is going on in her environment. She loves to watch television and her favorite program is still Sesame Street. She is pretty willing to watch most things, however, particularly if she is cuddled. She also loves to look at pictures, especially family photographs. Erika wears diapers, but is put on the potty at scheduled times with pretty good success. She is very proud of this accomplishment.

We take Erika just about everywhere we go. She enjoys eating out in restaurants, shopping, visiting friends and relatives (especially when food is served), and going to the movies. Erika also takes swimming lessons. She has enjoyed her private swimming class for about eight years and gets very excited about her time in the water. Each summer Erika attends a special needs overnight camp for a week. She has been doing this since she was ten years old and really loves it. She never looks ready to come home, but would be happy to stay at Camp Jabberwacky all summer! This has been a wonderful enriching experience for Erika and a wonderful time for Mom and Dad to take a summer vacation.

Erika continues to be a very cheerful, happy young woman and we attempt to make her life interesting and full. We look forward to "the look of love" we sometimes get from Erika when she lets us know she is having a good time. Planning for the future, we will soon start to visit residential options in our area. We do not see her leaving home immediately, but we do want to be able to choose a future home for Erika and see her settled into it before we find it too difficult to physically care for her. There is always more to be done in caring for Erika and in planning for her future, but we feel fortunate that we have met many people along the way who have shown great kindness and concern for Erika and have made our task a little easier.

Becky Harness

Linda Harness,

El Lago, TX

Becky Harness celebrated her 29th birthday in November. It's hard to believe so much time has passed. Looking back, there were many times of frustration and tears, yet such moments of joy over the smallest accomplishments. We did not learn about RS until Becky was 13 years old. While at Shriners Hospital, another mother approached us with her young daughter, asking, "Have you heard of Rett syndrome?" She told us about her daughter and passed on the IRSA newsletters. If it hadn't been for Becky's scoliosis surgery, we may still be wondering.

Over time, we learned to cope. The later years have been much easier for Becky. She's so good. We can wake her up in the middle of the night and she still flashes that big smile. She understands much more than she's given credit for at times.

Becky lives at home and attends a day program during the week. She loves anything to do with music and has attended numerous musicals. Her siblings are an important part of her life and her big sister has cared for Becky as if she were her own. They still go shopping and cruising for boys together. Tammie became a special education teacher and we're sure her choice of career was greatly influenced by Becky.

In September, 1999, Becky starred on Houston's Channel 11 television health segment. They profiled our family and discussed Rett syndrome. Little did we know that we were being used to help announce the wonderful discovery of the Rett gene!

Yvonne Penner

Irma and Peter Penner,

Fredericton, New Brunswick, Canada

Yvonne Penner, 30, still lives at home with us. Since leaving the school system at age 21, she has had a day-time companion. Her companion, who is funded through Adult Services, comes to the house Monday through Friday at 9:00 am. If Yvonne isn't ready to leave (maybe still sleeping because she had a rough night), they get going later. However, for almost three years now, Yvonne usually has her jacket on when her companion arrives! They go for drives, shopping, visiting friends, hiking, or as her companion says, "We do whatever Yvonne wants to do." They arrive back home at 4:00 pm.

Yvonne walks very well. Her kyphosis began at 12 years, progressed to 90+degrees in her mid-teens and has stayed that way. We had agonized over doing surgery but decided against it when the doctor couldn't guarantee that she would walk again. We were also assured that the curvature did not restrict her respiratory system.

It's difficult to measure Yvonne's height accurately, but she is near 5-feet. Her weight is fairly steady around 90 pounds. She goes through what I term "her dieting phases" when she eats less and dips down to 85 or even 80 pounds. After a few weeks or months, she has a ferocious appetite and slowly gains her weight back again. It's hard to know why this happens but we no longer worry about it because we've experienced it so often.

Yvonne is extremely limited in what she can eat, but generally she eats a lot! Every time Yvonne leaves the house, her food bag goes along! She can't eat anything except what we make for her. If she "snitches" other food, she'll be awake

and crying at night from allergies.

When the irritants aren't there, Yvonne laughs joyfully, has a radiant smile, and often hums softly. She truly brightens up everyone's day! She always looks forward to seeing her married sister, brother-in-law, and 3 nieces and 1 nephew who range in age from 18 months to 12 years. Still, she prefers to participate "from the sideline." Sometimes she'll leave the busy scene and stretch out on her bed--but always listening! We know because she'll laugh out loudly at very appropriate times.

We're in the process of making long-term plans for Yvonne. Our vision is for Yvonne to remain living in our home with a trusted caregiver, and to spend the day with her companion. (We would live elsewhere.) As we are able, we would be involved to help with the food and clothing, and provide "respite" for the caregiver.

We hope that this summary of Yvonne's adult life will be an encouragement to younger parents. In Yvonne's early years we advocated for inclusion. When this was finally achieved, at age 15, Yvonne blossomed. Yvonne pointed "YES" that I could write "The Right to Belong: The Story of Yvonne," in the hopes that it could help other children experience inclusion.

Though younger parents may learn from us older parents through our trials, errors, and successes, we, in turn, feel uplifted and encouraged by the attitudes, determination and enthusiasm of the younger parents! You have helped to re-energize us; thank you, and keep up the good work!

Lisa Norris

Joyce Norris,

Neodesha,KS

My daughter, Lisa Norris, 34, was 18 years old when I first heard of Rett Syndrome. My sister saw a story on the news about Jayne Jarsulic. She called me and told me about it, saying, "That was Lisa!" My sister contacted the T.V. station and they gave her the Jarsulic's address. Susan put me in contact with IRSA and I couldn't believe what I read when I got the information on Rett. It was like reading Lisa's life history. I didn't know where to go from there so I sent Dr. Percy Lisa's developmental history. He said he would see her, but he was sure from reading about her that she did have RS. Financially, we were not able to make that trip but two years later, we found Dr. Murphy in Kansas City, who was able to officially diagnosis Rett syndrome. The next few years were pretty much the same except it became more difficult to get out with Lisa. Noises and crowds disturbed her. Just as soon as we would get someplace, the screaming would start and we'd have to leave. Unfortunately at that time, there wasn't the help that is available now. It was pretty much me doing it all 24/7/365. I wouldn't advise that for anyone, It can really wear on you. There were several things that went into the decision to place Lisa in a care facility when she was 25. There were no services with her at home for physical therapy or social interaction, and I worried what would happen if I should get sick and we would have to place her just any place we could find. Also, it was our son's last year in high school and we felt we needed to give him more attention. Our girls dealt pretty well with Lisa, but Jason always had a hard time.

In the last few years, Lisa's health has deteriorated. She has had a broken toe, stress fracture, blood clots due to immobility, and then a G-tube became necessary. Lisa hasn't screamed for several years now and is happy when she's feeling well. But the days she isn't feeling well seem to be getting more and more. Lisa requires complete care. She is immobile, and takes nothing by mouth. Bowel, urinary tract infections and ear infections seem to be her biggest problems now. We see her at least twice a week and I go to doctors appointments with her. If she has to be hospitalized, I stay with her. We have her home on holidays. She now weighs 140 lbs., so I am unable to handle her by myself. She has been in a group home with 4-5 other clients for the last four years and it's only a 30 minute drive from our house. She's the center of our life now. I think in some ways, it has been easier on her to be in a group home. She had gotten to the place she really didn't like going very much and usually ended up fussing about it. Since she has been in the group home, she never screams like she used to. It's probably harder for us than her. I'm always sad to leave her even though she never seems to mind. Having her in a group home does free me to be able to attend to other family needs that were a real problem before. It's hard to give everyone in the family the attention they need. Sometimes we get so wrapped up in special needs that we forget that the everyday needs of the rest of the family are just as important.

Heather Klingensmith

Nancy Klingensmith

My daughter, Heather Klingensmith, 26, was going in for spinal fusion at the age of 12 when I received a complimentary copy of the "The Invisible Enemy," by Claudia Weisz. That day, my whole life with Heather was on paper. I knew I wasn't alone and other children had gone through what she had gone through. I cried in happiness that I wasn't alone. To us, that day was our freedom from the unknown. I know a lot of the younger parents think that the diagnosis is a terrible thing to be given, but when you go for 12 years of not knowing -- it was tears of joy. I learned different and new ways of teaching. At home, it is hard to spell words and not get a head shake and laugh -- you know those important words Burger King, drive through, camping, going for a ride. Of course, then came graduation, loss of friends and boredom. Heather was fortunate to be close to a private adult day program which she loves, and she attends during the week for 6 hours a day. It's not perfect, but what for our children do we think is?

My family has always been the believers that if Heather couldn't be included, then it wasn't worth doing. Heather enjoys anything we do -- camping, swimming, trips, anything a normal family can do together. Heather is woman in her own right and enjoys her life as her life, no one else's. She has been and still is my greatest teacher. Heather graduated from school at 21 and her transition plan stated she would be home with parents after graduation. In our county, there are several sheltered workshops, but she couldn't go because she couldn't feed or toilet herself. I had been working on changing these rules for years with no luck. There was one day program about 25 miles from us and county transportation would take her 3 days a week. It was babysitting and not a real program, but she went for 3 months until the three-hour bus rides each way became too much. Then, a private group home started a day program five miles from us and the county agreed to pay for it if we would drive her. They do range of motion exercises and she works on speech, gross and fine motor skills, feeding and toileting. There are things I would like to improve, but this has been the best we could find, and Heather likes it. The program is five days a week from 8:30-2:30. They have outings like eating out and bowling. It seems like opportunities for adults are hard to find and we do more settling as they get older. I guess that falls under giving in or accepting Rett as a lifestyle. Believe me, we can never stop fighting, but we can accept and become as comfortable as possible with acceptance. As a family, we make her a part of the community, even if the community makes it hard. But, the way funding is changing in many states, it is getting better. Maybe things we "older Rett angels" are trying to change today will help years from now for all the little angels out there.

Tammy Dodd

Sandra Dodd

The first year my daughter, Tammy Dodd, lived away from home, will always remain a nightmare in my mind. She was 9 years old. I know now how an amputee feels when losing a limb, for it truly felt as if I'd lost a part of myself. If it hadn't been for my youngest child, Julie, who was only a baby and needed a Mother's love and attention, I have no doubt that I, too, would have had to have been institutionalized myself. In the years to come, we did adjust. We'd bring her home for day visits and vacations. Life went on. Our other kids did well and they, too, adjusted, although there always seemed an empty hole in our lives. And though I carried around with me a tremendous amount of guilt, I began to learn that perhaps we had done the right thing. At least mentally I knew this. Just try telling a Mother's heart that, though. In the mid 1980's, a doctor was visiting the institution and saw Tammy rocking away in her own little world. She asked to see her medical records and then after evaluating them, asked for Tammy to be taken to the University of Washington to be tested. It was then that we learned our daughter did not have cerebral palsy. She had been misdiagnosed all of these years and suddenly so much made sense, we understood. That knowledge in itself helped tremendously. In the mid 1980's a doctor was visiting the institution and saw Tammy rocking away in her own little world. She asked to see her medical records and then after evaluating them, asked for Tammy to be taken to the University of Washington to be tested. It was then that we learned our daughter did not have cerebral palsy. She had Rett syndrome. She had been misdiagnosed all of these years and suddenly, so much made sense. Shortly after this diagnosis, all of our lives changed, and a long-awaited prayer was answered. Though Tammy received excellent care, we always had hopes that one day she would not have to be in an institution. A program had begun where people who were in institutions were being removed and placed in group homes or apartments in their communities. Twenty-four hour care would be provided. Tammy was fortunately accepted and placed in the program. On the day she left the institution, I swear the sun shone the brightest I have ever seen it shine. And even Tammy realized what a milestone it was. You could see her outlook changing daily. Today, Tammy is 29 years old. She has finished her schooling. She has us, her family, and countless other people who support and care for her and love her just as much as we do. She goes shopping, to dances. Her life is full. I look back at these twenty odd years and though some of those times were bad and I am in awe of how I coped, I truly would not change a thing. True, it would be wonderful if Tammy did not have RS, but I believe God put her here for a specific reason. Perhaps to teach us about unconditional love. To give our other children the

knowledge that all people are not the same, but should still be loved and respected. To learn that no matter how rough life can be, if we give it a little time and put it in God's hands, it can get better. Sometimes our journey gets a little long, but as long as you've got someone to walk it with you, it's a journey worth taking. Though Tammy does not speak, as she smiles and looks into our eyes, I know she is happy we walked that journey with her.

Shelley Knight

Joan Hood,
Beaverton,OR

My daughter, Shelley Knight, will be 40 years old in July. She used to walk up and down the stairs, but that stopped around the age of 8 or 9. She walks, but has many problems with her spine and balance. She started screaming and sobbing again, a few years ago. After all those years of not screaming, it started up. We treated her for bladder infections, teeth, you name it -- we checked it. When Shelley is on antibiotics, she feels good and is more alert. I wish she could be on it for a good couple months, along with pills for yeast problems.

She was never happy in groups at school; she is much more content to be at home with me and her dad. She likes the fact the other kids have left home and she is the Queen all day long. She loves music and her routine. She is mostly a happy gal and is content to be with Mom and Dad and family. She watches TV and plays in her room, and she loves her books.

Shelley does not talk, but she makes noises that I understand. She walks and feeds herself, although messy. She does not like sitting on the toilet, because it hurts her back. Shelley has scoliosis, and walks with an odd gait. She suffers terrible periods and constipation has always been a big problem. When the screaming started up the neurologist her on Haldol for a time. The Haldol helps when she is "way out of it," but I do not give it more than a two or three days as it may cause muscle spasm. Shelley does not have a day program. She is home with me and follows me around the house. She will put all the pennies in the piggy bank. She likes to put objects into boxes and buckets for fun. She likes TV and radio and she likes to go for short rides. She enjoys going out to eat with us and visiting her siblings' homes. She does a lot of walking. She did go to school until she was 19 years old. Day programs close to us that I have checked on are really not for Shelley. They are too noisy, and the boys are too rough around her. She is lost in a large group. Shelley and I go for walks, but she is always glad to get home.

Jocelyn Curtin

Marlyn Curtin,
Concord

NH

My daughter, Jocelyn Curtin is 23. She graduated high school at 18 and has been program-free since then. What she does have is a person who will support her up to 40 hours per week, through Medicaid/ Home Assistance). Her first support person was Meloney, who was a few years older than Joce. They would just hang or do whatever they felt like doing. Mel provided personal care, baths, meals, and they would go to the pool and work on stretches, go out to eat with friends, shopping, movies, massages, haircuts, walks, beach, concerts, etc. They became best friends and even went on vacation together for 3 years (a week at the beach in a condo). Mel also supported Jocelyn in some of her classes. She has taken one class each semester at the University of NH for 3 years now and loves it. Jocelyn bought an accessible van four years ago and Mel could drive them anywhere.

Mel moved last December, and Dayvie has filled this void with the exception of being able to drive Jocelyn places -- her

employer does not allow driving. So, does all the personal care stuff, does stretching at home, takes Joce in the hot tub and pool at home, and goes for walks from home. They play games, cook, watch movies at home, read, and just hang out. They also have visitors. Jocelyn's friends stop by and all of them really like Dayvie. They have found that they actually have some mutual friends who stop to visit them both. Although I am still trying to find a loophole to allow them to drive places, Dayvie makes the days fun and they rarely get bored. Still, it would be great if she could take Jocelyn for her haircuts, massages, shopping etc. Jocelyn still takes classes at UNH, although this year she is co-teaching the class and I drive her there each Monday night. After class, we usually go out to grab a bite on campus. I also support her working at the theater, where we are volunteer ushers and collect tickets at the door. We go skiing once a week during the week to avoid the crowds and lines. Jocelyn also has friends from high school and college who drop by or take her out from time to time. I have also called some of these people to do weekends or even a week last year when we were between support people and had planned a couples-only vacation. It worked out great.

Jocelyn has received a section 8 housing voucher (not a handicap program, open to anyone, income-eligible). I applied for her about three years ago, knowing there was a long wait, but I wasn't even close to being ready then, anyway. Well, now she has it and I asked her if she was ready to look for her own place. She smiled, looked at my right hand (yes) and also reached up and grabbed it pulling it down to the table. Jocelyn also doesn't have much hand use and usually has a delayed response time - not that time though! We have found a two-bedroom accessible apartment just five miles from our house and she has applied and been accepted, but with a 6-9 month wait for availability. This is actually a good thing, as we need to work out the supports before we can let her move, and technically, she doesn't have any funding available through the DD adult service system. She will be able to cover the whole rent and can offer a roommate free rent in exchange for some support, (mostly nights and some weekends). With her voucher, she will be able to pay one-third of her income (currently only her SSI) and the rest will be subsidized. If her roommate is considered a caregiver, her income will not be considered. Jocelyn will still have the 40 hours of support and I am in the process of trying to increase this to 60 hours / week to cover some weekend time, too. I plan on being available as needed as well and hope to make this work so that her roommate will still have a life and a regular day (or night) job. I am not looking for someone 24/7 but mostly nights and some weekends. Jocelyn has a number of friends or acquaintances that I can ask. She will give her approval of who is selected. I have never regretted having her leave the school support at 18 rather than staying till 21. We have found tons of things to do and found ways to make them work for us. I am still amazed that going on five years later we are still moving ahead and not in a rut. We do have our days, but overall it has worked out very well.

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