Financial planning for special needs kids

Many families have difficulty finding right services

NEW YORK — Millions of American parents struggle with the day-to-day responsibilities of caring for physically or mentally disabled children, but often their biggest challenge is putting financial strategies in place to ensure that the kids are taken care of as they all grow older.

Major Market Indices

For Christine and Donald Kriescher of New Franken, Wis., that has meant getting guardianship papers in order as their son Nick, 19, who is severely retarded and suffers from obsessive-compulsive disorder, approaches adulthood. And they'll need a power of attorney to help guide 20-year-old daughter Kandy, who has mild cognitive disabilities, into new programs next year when she leaves school.

In addition, the Krieschers plan to redo their will and set up a special needs trust to transfer their insurance and savings to care for the children after their deaths.

"I will die a happy person if I can find a way so they can live and be happy and be productive, too," Christine Kriescher said. Kriescher, who is 42, added: "Putting things in place gives you peace of mind."

The U.S. Census Bureau estimates that more than one in 10 Americans between the ages of 16 and 64 suffers from some physical, mental or emotional impairment. Finding the right services — and arranging future financial support — for them can be tricky because parents can't risk jeopardizing a disabled person's public benefits.

Many of the disabled qualify for government-sponsored care or training programs. They also can get financial help through the Supplemental Security Income program, which provides a monthly allowance and generally ensures that the disabled person is eligible for important Medicaid health benefits.

But that assistance could be cut off if parents or well-meaning grandparents give a few thousand dollars to a disabled grandchild, unwittingly making them ineligible for SSI and health care because their assets surpass the $2,000 limit, according to the ARC of the United States, a national organization based in Silver Spring, Md., for the mentally and developmentally disabled.

Complex planning

A growing number of insurance and brokerage houses have set up units focused on financial planning for special needs children, including help in setting up wills and trusts that don't threaten a child's benefits.

Nadine Vogel, who helped set up MetLife Inc.'s Division of Estate Planning for Special Kids, or MetDESK, in 1998, knows first hand what challenges the parents of disabled children face. Her first daughter, Gretchen, who is now 13, was born with serious disabilities that have required physical, occupational and speech therapy. A second daughter, Rachel, 5, has a heart condition.

"Dealing with the legal and financial complexities in estate planning — including life insurance, trusts and taxes — can be daunting," Vogel said.

Worried parents

Ken Wirtz, a MetDESK agent who has worked with the Krieschers in Wisconsin, said that in addition to financial guidance, he keeps up with community resources that can be of help to parents.

"Most of the parents are more worried about the children than themselves ... so we need to assess the overall situation and determine how we can support the parents so they can physically and financially take care of their children, even after they're gone," he said.
Michael Byrne, a financial planner with Lincoln Financial Advisors in Cherry Hill, N.J., said he got involved in assisting families with special needs "after watching my mother, who is 74 now, working to keep my brothers qualified for benefits as the rules kept changing." Two of his brothers, he said, suffered brain damage when a genetic disorder known as PKU, or phenylketonuria, was not diagnosed at birth.

Byrne also has a 14-year-old daughter, Kelsey, who was born with Williams syndrome, a form of mental retardation.

He said that the prayer of parents with a special needs child is simple: "We wish for the child a long and happy life — and wish that we can live one day longer."

But that generally doesn't happen, so parents often need to put wills and special trusts in place to ensure that their kids are cared for.

Special needs trust
One of the best things a family can do is to set up a special needs trust. Also known as supplemental needs trusts, they allow parents to leave assets for the disabled child — for transportation, recreation, vacations, a personal-care attendant — without disrupting the government benefits the child may need to survive, Byrne said.

Families also need to consider the financial demands of their non-disabled children, putting college savings plans and insurance coverage in place for them.

Richard and Christine Harrison of Mansfield, Mass., have worked hard to plan for the needs of their two daughters, Julia, who is 5, and Katie, who was born with Down syndrome three years ago.

Katie requires medication for a thyroid disorder, and the family has invested in speech and physical therapy for her, including sign language classes that allow her to communicate more easily.

The Harrisons recently purchased an insurance policy; if something happens to them, the money will go to a special needs trust for Katie.

"That life insurance policy is a way of saving for Katie," Christine Harrison said. "At the same time, we've saving for Julia's future by saving for college.

"In a way it's the same goals, but different plans of attack."
Does a Disabled Child Equal a Disabled Family?

6 tips for preventing family stress
By Melinda Copp

Parents of developmentally disabled children know that the disability affects everyone and everything in the family. The stress of uncertainty and lack of control can cause marriages to suffer and even end. Parents immerse themselves in caregiving and often neglect their own personal needs and the needs of their other children. And the situation often forces other children in the family to take on the role of babysitter, which can sometimes cause a loss of personal identity for that child.

These are common occurrences in families with disabled children. What most parents don’t realize is that raising a disabled child doesn’t mean that the whole family has to be "disabled" as well. This tendency for families to focus everything they have on their disabled child is why author Wayne Hower wrote his book, Does a Disabled Child = a Disabled Family?.

"Many books address how to handle and care for your disabled child, but there aren't as many about how parents can take care of themselves and their other children when there is a developmentally delayed child in the family," Hower says. "It's so easy to get caught up, and other siblings get lost in the shuffle just because the disabled child needs so much care."

Hower, who has helped raise his now adult developmentally delayed stepdaughter since she was 6 years old, runs a group home with his wife for disabled children who are contracted by the state of Nevada. He understands, on both a personal and professional level, the challenges that families with disabled children face.

"We've seen the wrong things that happen in a family under the stress of raising a developmentally delayed child," Hower says. "My wife got divorced."

So what can you do in your life to prevent the needs of your disabled child from disabling your entire family? Hower offers the following 6 tips:

1. Laugh a little.
"Maintain a sense of humor because there are so many serious things that happen when you're raising a developmentally delayed child," Hower says. "And if you don't have a sense of humor, then maybe you need to find one because it isn't easy."

Raising and caring for a developmentally disabled person is serious business. But the ability to laugh and have fun with your family despite the tough times will help keep everyone close.

2. Find support.
Next, you need to build up a solid support system. Look for state agencies, community support groups, family and friends who can help you, listen to you and offer advice. "If you try to go it alone, you'll lose yourself," Hower says. Surround yourself with people you can call when you need someone.
3. Stand your ground.
Once you have a support system in place, you have to remember that you need to stand your ground. Don't be afraid to do what you feel is best for your child, regardless of what anyone else says.

"No one knows your child better than you," Hower says. "Professionals know technical things, and they know what works for their other patients, but when it comes to your family, what works for everyone else might not work for you."

Don't be afraid to go with your gut feelings when it comes to your child's education and care.

4. Learn the lingo.
Another important part of raising a disabled child is to understand the medical terminology that doctors and other professionals use to describe your child's condition. Hower and his wife learned the importance of this the hard way. When doctors described their daughter as "developmentally delayed," Hower's wife was under the impression that if she was delayed, she would eventually catch up.

"She thought because 'delayed' means something temporary, like, 'I am delayed in traffic, but I'll catch up to you later,' that our daughter would eventually catch up to other kids as she grew," Hower says. "It wasn't until she was 6 years old that my wife realized she would never catch up to other kids."

The effects of a misunderstanding like this can obviously be devastating. So be realistic and keep in mind that just because a word means one thing in everyday conversation, it can mean something completely different in medical terms.

5. Get Dad involved.
When you have a disabled child in your family, Dad needs to be more involved.

"Many times fathers are considered peripheral parents," Hower says. "It's not that they care any less about their children, but a lot of times Dad goes off to work and Mom takes care of everything."

In a family with a disabled child, fathers need to be included in doctor's appointments and meetings with teachers and caregivers. This not only supports Mom, but it also helps make sure that everyone is clear about what's going on with your child.

6. Pursue outside interests.
Finally, and perhaps most important, everyone needs to take time to maintain a life outside the demands of the family. Siblings should be encouraged to participate in extracurricular activities, and both parents should take time for themselves as well.

"It's easy to get wrapped up in thinking, 'I have a handicapped child; that's who I am,'" Hower says. "Really that's only part of who you are, and pursuing other interests will help maintain yourself as an individual."

Although it's easy to think that if you give everything you have to your disabled child you're being a good parent, you can't be the best parent possible when you don't take care of yourself and your other family members. Having a disabled child is a life-altering event, but for your family's sake, you can't allow it to disable everything else in your life, too.
Aiming For Liftoff: Supporting Your Developmentally Disabled Child and the Whole Family During the Transition to Adulthood

Child And Family Mental Health

Jonah Green and Associates, Kensington, MD

If you are a parent of a child with a developmental disability such as autism, mental retardation, and Down Syndrome, you probably face particular challenges as your disabled child approaches adulthood. Whereas parents of typical children face the challenge of the “empty nest syndrome”, you may be struggling to help your child grow in independence, even as you face an increased burden of care. As your child ages out of a full-time school program, available resources generally become both less available and less coordinated. The task of maximizing your child’s independence and relieving the burden of caretaking may begin to feel urgent.

The challenges of transition come as a shock to many parents, who by this time often have overcome many challenges and may have achieved a level of calm. Families with young children with developmental disabilities face a number of stressors, which may include conflicting diagnoses and treatment recommendations, painful emotions, conflicts over how to address their children’s needs, and heavy time and resource demands. By late adolescence, many families have clarified diagnostic issues, found programs to maximize children’s development, and made progress towards addressing many of the emotional challenges related to their children’s disabilities.

Probably the biggest factor that helps families cope as their children grow up is the array of educational, therapeutic and other services that are available. Parents of infants and toddlers can make use of federally-mandated programs that offer diagnostic evaluations, speech/language therapy, and respite care. Parents of school age children are able to obtain accommodations and supports via Individualized Education Plans (IEPs), and can often access recreational activities and specialized treatments outside the school setting. Through these programs you can often find parents in similar situations who can offer information and support.

Parents of transition-age children, in contrast, usually lack comprehensive and coordinated services. While all jurisdictions offer some programs for adults with disabilities, waiting lists are usually long, and people are typically only able to access a fraction of the supports they need. In addition, parents have to coordinate navigate a myriad of agencies.

You can take a number of steps to obtain to move your children towards greater independence, relieve the burdens of caretaking, and help your whole family cope:

- Search out a local ARC or other organizations (such as the local chapter of the American Autism Society or the National Association for Down Syndrome) that offers comprehensive lists of programs that support independent living, vocational assessments, educational programs, or housing assistance, as well information about how to access them.

- Continue efforts to develop your child’s functional living skills. Because the behavior of children with disabilities often calms during late adolescence, you may have a “second chance” to improve their teen’s hygiene, organizational ability, and pragmatic social skills.

- Make use of available transition resources. All schools are required by law to begin transition services when children are 14. Some government entities provide funding for transition programs that include eligibility screening and assistance accessing vocational and/or educational supports.
• Seek out professionals who can help you obtain services. Disability lawyers can help young people apply for Social Security Disability Insurance, financial professionals can set up special needs trusts, and case managers can help you navigate and access the maze of service agencies. Some nonprofits also provide case management services for families.

• Search out multiple resources to transport your children to their activities. Train your young adult as much as possible to use public transportation, and take advantage of the transportation programs that are available in your area. Consider carpooling, which can help both you and your child to build social connections.

• Connect with parents in similar situations. ARCs, private organizations, and online groups can be a great source of both information and support.

• Connect your child with peers, mentors, and professional counselors. A number of private and governmental organizations offer discussion groups, recreational activities, and supervised social events where your child can socialize. Mentors through programs such as “Best Buddies” can help your child develop their independence and navigate the adult world. Counselors and therapists who are trained in working with those with developmental disabilities can be particularly useful in helping your child cope with the transition to adulthood.

• Consider making use of therapy for yourselves and other family members. No matter how many efforts you make to maximize your child’s independence and utilize all of the available resources, you will continue to be confronted with an ongoing burden of care. Moreover, whatever you may have done to help your child develop, his or her life is likely to begin to contrast more sharply with those of his or her peers. Family therapy can help you and other family members to manage these challenges and support each other.

The steps you take to facilitate your child’s independence, relieve the burdens of caretaking, manage your emotions, and strengthen your relationships will help your child as well as all family members to transitions more successfully, and will position all of you to achieve satisfaction as you enter the next stage of your lives.
The developmentally disabled are aging too

By Rebekah Gordon
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Living in a group home for developmentally disabled older adults on 30th Street in Manhattan, Charlie Wattenstein does pretty well for himself. The 64-year-old, who has Down syndrome, contributes to house chores, works odd jobs such as stuffing purses with tissue paper, and gets around the neighborhood on his own.

But one Saturday after work nearby, Wattenstein became confused and couldn’t find his way back, an early-stage sign of dementia. “He wasn’t getting older, it seemed like he was just stable,” said Patricia Williams, the assistant manager of the home, which is run by the Association for the Help of Retarded Children (AHRC). “And all of sudden, one day you look at him, and then it’s as if he has aged ten years. And you think, but wait a minute, what’s going on here?”

It is not uncommon that Wattenstein developed this new complication, or that he has lived as long as he has. Thanks to medical advances and better treatment, for the first time in history people with developmental disabilities like Down syndrome are living normal life spans. But with this phenomenon has come uncharted territory for doctors, social workers and caregivers to understand and address the unique medical and social issues the developmentally disabled face as they age.

The 2015 Project at New York State’s Department of Aging estimates that as many as 500,000 elderly in the U.S. are developmentally disabled, and that the number is expected to double by 2030. While any chronic disability that begins before age 22 and severely impacts major life activities like language and independent living is considered a developmental disability, the aging effect in Down syndrome is particularly noticeable.

“It’s like Alzheimer’s and Down syndrome are both genetic mutations of the 21st chromosome, Minde said, so the diseases are closely related. As a result, there is a high probability that a person with Down syndrome will develop Alzheimer’s or Alzheimer’s-like dementia after the age of 50. It makes caring for them more difficult and severely limits their already inhibited independent functioning.

But cognitive decline is not the only challenge. “What I’ve found with Down syndrome in general, and with most developmental disabilities,” said Marcia Richman, a registered nurse and the health care coordinator for group homes at AHRC, “is that they age at least 10 to 20 years sooner than your typical adult would age.”

Symptoms of aging like diminished hearing, the development of cataracts, respiratory difficulties, the onset of menopause, and obesity-related diseases like high cholesterol and diabetes can all occur earlier in those with Down syndrome, she said.

In addition, for those with developmental disabilities who are cared for at home, living a normal lifespan leaves them now outliving their parents. “There are times when you have a 50-year-old and an 80-year-old parent, and that 50-year-old is having cognitive declines, as is that 80-year-old,” Richman said. With the 50-year-old Down syndrome patient
really functioning at a level of someone at least ten years their senior, Richman said, the needs of the parent and child can be nearly identical. “So you wonder, who is taking care of who?”

Most end up being moved to group or nursing homes after their parents pass away or become too frail to care for them, a massive life transition that can trigger depression. Though group homes can help ease the individual in, nursing homes are not geared to handle someone with Down syndrome, Minde said, where their needs are largely ignored or misunderstood. “You need to be able to gear the human side of things to the individuals,” he said. “Nursing homes are not doing the job.”

And as Wattenstein struggles with his added complications, caregivers at his group home like Williams, the assistant manager, struggle along with him. “You watch them every day get a little bit older, a little bit more forgetful, a little bit more difficult, a little bit more demanding,” she said with a tinge of laughter.

“The needs of the disabled are only the senior needs increased by a factor of ten,” Minde said. “It’s an area that’s got to get addressed. It’s only starting to be recognized now.”
“Adam, I am not helping you put your underwear on! You are nearly 20 years old. You should be able to do this yourself.”

Adam, an adult with developmental disabilities, just sat there naked on the bench in the men’s locker room, staring at the floor, sucking on the fingers of his right hand. He was born a twin, but he had a stroke in-utero. His brother didn’t suffer the same fate.

Adam’s limitations are substantial, and yet, in spite of them, he is a pleasant young man to be around. He never has anything bad to say about anyone, has a pleasant smile, a contagious laugh and loves to receive positive feedback. Adam’s one obstacle is that other people do everything for him. And I mean everything! At least they did until I showed up.

**Teacher for Adults with Developmental Disabilities**

I work as a para-educator for a transitional program designed to assist young disabled adults to become more independent. Adam is one of my students, and, with him, we have had a great deal of success. Some days are better than others, but Adam is growing up, slowly but surely. Why? Because he gets it, most of the time, and tries very hard to accomplish the goals set for him.

On the other hand, our students’ parents can be a bigger problem. Simply put, they won’t allow their young adults to grow up. Rather than teaching and mentoring their young adults with developmental disabilities and allowing them to grow up, they simply wait on their grown children, hand-and-foot. Heck, if someone else were doing this for me, while I sat on my butt all day, I’d take advantage of them, too!

This, however, isn’t the life that these young adults are supposed to be living. When their family members are gone, what will these young adults do? I’m sad to say that they will be left alone without the necessary training to be independent. We are giving them an excuse to be mediocre. I would say that mediocrity isn’t what Adam, or any adult with developmental disabilities, needs to be.

How am I qualified to talk to you about this issue? I am a person with disabilities. Now, most of the parents who are reading this article are probably thinking, “So what’s your point?” My point is this: your young, developmentally disabled adult will not have you around forever! If you think you will never die, you’ve been deceived. You, dear parent, are going to die some day, and what have you done for your young adult to prepare him/her for their life without you? Here are
some of the truths that your young adult will be facing in their future:

- They will have to understand how to get from one place to another in their community. If they won’t be able to drive, they will have to know how to use public transportation.

- They may need to get a job that is best suited to their limitations and their financial needs. Some companies hire the disabled. This might be a great place for your young adult to start. Are you encouraging them to look for work, or are they sitting at home being transformed into some form of couch potato?

- Depending on their limitations, your young adults should know how to feed themselves, get dressed, perform personal hygiene, do their own laundry, go shopping, travel, socialize, eat out, go to the library, and have sex, to name a few.

Parents of Adults with Developmental Disabilities Key to Their Success

If your young adult isn’t being taught to be independent, you might be their problem. If you don’t teach them, who will? Do you think a public servant is somehow going to suddenly appear out of thin air to take over where you left off? How naïve is that thought process? Here are a few pieces of advice:

- Cut the apron strings and don’t look back!

- Get off your butt and show your young adult how to really live independently! Show them how you do it! If this includes toilet hygiene, toss your false sense of modesty and embarrassment out the window! Moralizations have no place in a home where a person with disabilities lives. I should know. I live with one 24/7. Me.

- Stop doing everything for them! Be a living example in their daily life, but allow them to accomplish what they can. Don’t reprimand them for their failure or struggles. Encourage them every step of the way. You are the only person from whom they will get positive, loving feedback.

- Give them more credit than you have thus far. Every young adult has the desire to be someone important. There have been men and women who were disabled and who became some of the most influential individuals in history. The same is true for your sons and daughters. If you don’t think big for them, they will NEVER think big for themselves.

- Stop making excuses for your young adult’s behavior! Wean them off their dependency on you. Allow them to suffer the consequences for their actions, whether positive or negative. They will learn.

- Grow up with your young adult! When they are allowed to grow into their adulthood, you grow into being their mentor. This is your chance to make a difference in your young adult’s life. It could be the catalyst that turns them into another Albert Einstein, who himself was autistic.

Now, what are you going to do with your young, developmentally disabled adult? Will they stay tied to your apron strings, or are you going to help them become independent? Will you continue to wallow in self-pity, or will you grow up with your young adult?

Only you can give your developmentally disabled young adult the tools they need to succeed. They can be the manifestation of the choices you make on their behalf. Don’t let this opportunity pass you by. Your young adult’s independence will be the crown you wear with pride.

*Michael A. McGrath is a retired, disabled U.S. Navy veteran and the author of several books, as well as providing the illustration for this article.*
Transition to independence:  
Parents can make it happen for developmentally disabled

February 07, 2008

All parents worry how their child will make that transformation from student to job-holding member of society. For parents of the mentally disabled, however, it can seem like the impossible dream.

More than 700 students with developmental disabilities transition from Georgia high schools to the community each year. The road to increased independence, productivity, and a meaningful life, including possible employment, can be filled with obstacles.

The parents of these young adults often don't have enough information about services and supports available for their children to help navigate the system and plan for their future.

Roswell was the last stop Jan. 8 in a series of statewide forums for parents and Georgia leaders hosted by the Atlanta Alliance on Developmental Disabilities and presented by the Governor's Council on Developmental Disabilities.

"Conversations that Matter: Town Hall Meetings on School-to-Work Transition Planning for Young Adults with a Disability" was an opportunity to deliver vital information on three critically important areas: education, work, and the types of supports youth with disabilities need to be successful in the community.

For information visit www.unlockthewaitinglists.com/ConversationsthatMatter.html or contact event coordinators Debbie Currere at 770-641-8927 debbieanne6@charter.net or Jennifer Carroll at 770-998-1703 jenniferofroswell@msn.com.

Top Five Tips for Parents

1. Start planning years in advance. The first year of high school is a good time to begin to thinking about what your child's future will look like in terms of employment, housing and recreation.

2. Talk to other parents. Attend meetings where you can speak with others who are working on transitioning students with disabilities into the workforce and living in the community.

3. Develop plans with your child's school for the transition from school to the community.

4. Contact other agencies like Vocational Rehabilitation Services, the Department of Human Resources, and the Social Security Administration for information on services and how your child can qualify.

5. Join Unlock the Waiting Lists! campaign (www.unlockthewaitinglists.com) to get vital information on advocacy related activities across the state and how to stay informed and get involved.

More information online at www.AADD.org.
Rick’s Corner: Advancing Individual, Not Professional, Choice

About the author: Rick Eastin has been on staff with Evangelicals for Social Action in Fresno, California since 1992. He is a ministry associate of Joni and Friends Central California, and the primary keynote speaker for many of their training events. Rick also founded and directed The Cornerstone (1987-2002), a Christian education and respite program for adults with mental retardation and their caregivers.

My name is Rick Eastin. I was born with cerebral palsy and as a result of my disability I attended special classes for persons with mental and physical disabilities from the age of 3 to 14. My time at the school was, in many ways, a painful experience because my own disability impacts me in three different ways: physical, emotional, and in my ability to learn. Physically, I have a hard time walking and talking. As a kid, I behaved in some very awkward social ways that caused my peers who were just physically disabled to ostracize me. I had trouble with stress at times, overreacting in ways that aggravated rather than resolved the situation. I still have a very difficult time with things like spelling and punctuation.

Although my early education was in segregated settings, I had limited contact with persons with mental retardation. They considered placing me in a class with persons who are mentally retarded at one time. I told them, “I’m not going in a class with those ‘retards’”. My views began to change as a result of a chance encounter with a young woman on the playground. I was surprised to learn that she was 18 and came to understand that some of my fellow students would not leave that school until they were 21. I began to appreciate that many of us have real limitations and that ignoring them was unrealistic. I have continued my quest to better understand people who are retarded and their families.

My academic and social skills improved about the time that I was ready for high school. I was mainstreamed into the regular ed. classrooms for most of the day. I became more independent when I learned to use public transportation and I began to expand my social circle. Eventually, I earned a BA in social work. I have also drawn upon what I've learned from a number of friends including a Sunday school teacher and a ministry team.

Since 1979 I have been, in various capacities, involved in working with adults with mental retardation. Most of my involvement has been in the Christian community. However, I have sought to study and understand both what has been done historically and what is being done currently in the human services sector to serve persons with this disability. One of my major concerns about where I see services going for people with mental retardation is that while there is much talk about giving them choices, in reality we are ignoring what these individuals really want.

We have abandoned the normal stage developmental model of understanding mental retardation and replaced it with what is known as the functional skills and/or the “top-down” model. It is based on research that was being done at university levels that demonstrated that people with mental retardation could learn to do things previously thought too difficult. Through the use of behavior modification, persons with moderate or severe retardation were being taught to do complex assemblies. This same approach is used to teach daily living skills like toileting, eating and personal hygiene. Those who hold to the "Functional Skills" view, support teaching individuals to perform tasks even though they may not have any comprehension of what they are doing or why they are doing it. They also work to eliminate behavior that the mainstream society does not applaud. All of this is done so that these people can become integrated into the mainstream community life. We reject the developmental stage model because we do not like the results that it yields.

The behavioral approach to developmental services is directly related to Wolfensberger’s principle of normalization. The focus of normalization is on providing services in the most culturally valued way possible. The hope is that it will result in persons behaving in ways that are esteemed by the general culture. According to Dr. Wolfensberger, it is not enough to ask people without disabilities to accept persons with mental retardation; for true acceptance to occur the person without the disability must experience the encounter in a positive way. Normalization asserts that all persons who are mentally
retarded/developmentally disabled should be socially integrated into the mainstream community. They should be placed in regular schools, jobs in the real world, and be part of non-disabled groups in regards to every aspect of their lives. The advocates of this movement understand that many of these people will need ongoing support to participate in integrated settings.

An important facet of normalization is called the “dignity of risk”. Wolfensberger advocates for exposing people to challenges in which they may succeed or fail. The purpose of this is to give them the opportunity to learn from these experiences. However, we need to let people experience a “dignity of risk” within the context of their intellectual development. This is how we treat persons without disabilities. For example, we would never say it’s all right for a child of three to go to a downtown city unsupervised. However, if we fast forward to that person being fifteen, it would be perfectly legitimate to expect that the person would be able to be downtown independently. Persons with disabilities are often exposed to risks that exceed their ability to understand. Because they cannot understand, they are not able to appreciate the value of the opportunities being presented. In some cases, they are, in fact, exposed to risks that are even beyond their ability to keep themselves safe as well. The reason this happens is that in our social interaction with others many of the judgments that we have to make occur in situations that are unplanned. I am not saying that a person with a mental disability should not have these opportunities; I believe that they should enjoy the same opportunities that we all have. They should also have the supports necessary to empower them to be as successful as possible and to keep themselves safe.

Another part of this ideology is to treat persons with mental retardation according to their chronological age rather than their mental age. This approach often creates problems for persons who are mentally retarded/developmentally disabled. Consider, for example, supported employment. According to the supporters of social integration, sheltered work environments are indefensible. (McLoughlin Garner and Callahan, 1987). However, research done with persons who are mentally retarded in the form of interviews, shows that many of these individuals prefer sheltered workshops over employment in mainstream society. In the growing enthusiasm for programs for supported work, many clients have been more or less forced to leave sheltered workshops to accept work placements in the competitive economy. Because many of these people left all of their friends at their sheltered workplaces, it is common place for them to express great unhappiness about their new and improved lives. Some clients who resist their counselor’s pressure to enter supported work are openly threatened or strongly persuaded to comply. This is all in the name of serving them and improving the quality of their lives, with little regard to the individual's perception concerning their own well-being. (Edgerton, 1990 p.152)

This philosophy also impacts the families of the developmentally disabled. Often times these parents are seen as overprotective. As a person with a physical disability myself, I personally know what it’s like to have family members who are overprotective. However, the concept of over-protection has been greatly misused and abused when it comes to persons with developmental disabilities. Most parents of the severely handicapped are primarily concerned with their child’s welfare from a developmental viewpoint as opposed to a behavioral one. The developmental model says we learn in stages, one stage builds on another stage. As a person moves from one stage to another his understanding is expanded so he is able to understand subject matter of a more complex nature and perform tasks accordingly.

The social integration movement is based on two different ideologies: social deviancy and equalitarianism. These ideologies, however, are incompatible with each other. Social deviancy says one must change to be acceptable, whereas equalitarianism says that all people are to be accepted as equal. Although the goal of the social integration movement is to empower people to live lives of dignity and respect, advocates of this approach do not respect the needs and desires of the people they aim to serve. If the human service community is to maintain its commitment to the values of self-determination and informed consent we must acknowledge the needs and desires of those who are being served. When their needs and desires are not what we consider to be in accord with the current social integration ideology, we need to be advocates for this group in that we uphold and respect their choices. We also need to realize that although the normal stage developmental model has been rejected. This does not change the fact that people understand the world according to their mental ability. There is a need to help the general public understand these individuals in the context of their mental abilities, and when they do, this helps eliminate what I view as an injustice. Rather than seeing these persons as deviants, they will see them in a different light. If the human service
community does not respect the felt needs and desires of this group, we are not treating them with dignity. In which case, we are not treating them in an ethical manner.

We should learn from the history of the human rights movement. People from disenfranchised races and cultures often began by trying to “fit in” with society at large. Over time, these groups recognized that they had a right to be respected by society without giving up their heritage and unique attributes (that society was what needed to change.) If we are to remain true to our commitment about choices, then we need to honor the choices of the people with the disabilities. This should be so even when their choices are not in line with what we happen to consider “age appropriate.” In contrast, the reason we want persons with mental retardation to behave in age appropriate ways is so that they will "fit in" with and be treated better by non-disabled people. In relation to other marginalized groups, we now demand that these people groups are treated respectfully and that society embrace their differences as such. Society's treatment of anyone should be based simply on their value as a human being. When people groups are not treated fairly, we see it as a great injustice on the part of our society (and rightfully so.) I am proposing that we view people with mental retardation in the same light as these other groups of people. When they are not treated according to their ability to understand, they are not being treated in a just or fair manner. There is a lot of talk about advocating for people with mental retardation, but this advocacy is not often based on what individuals in this condition truly want.

I believe the material above clearly shows that the reason "integration" has not taken place is because the demands that are being placed on these individuals are beyond their understanding. Whenever people in general are placed in conditions they do not understand this creates stress in their lives and this often creates problems in their social adjustment to their environment. The provision of services to persons with mental retardation should be based on what science tells us about what mental retardation is. It is also important to have a strong value base when approaching individual scenarios.

There are two broad sectors to consider. University professors and researchers often promote their own ideas about how persons with mental retardation should be treated. Families often have a very different view of the services that their family member needs. We need to find ways for both of these sectors to dialogue together in the hope of arriving at a more mutual understanding of what it is that mentally retarded persons actually need. Both groups of people have something very valuable to offer the other. Professionals have shown that we are able to teach people with severe disabilities things that were once considered impossible. We need to capitalize on that and use that technology to help these persons have as much control over their lives as is possible. On the other hand, professionals need to understand that just because we can get a person to perform certain tasks, doesn’t necessarily guarantee that we are expanding their understanding of what is taking place. We need to find ways to integrate the skills that we teach people into their lives in such a way that we are also mindful and respectful of their limitations in the area of their understanding.

Parents need to understand that college professors and researchers are just people. Therefore, they can be questioned and should be challenged just as we would do in any other field. For example, in our society there are parents who feel that they can best educate their children through the means of home schooling rather than the typical public education system. This is a clear instance of parents challenging professional opinion. In the same way, parents of a person with mental retardation need to feel confident enough to speak up for their disabled family member. This is so even when these parents feel like they are contradicting professionals.

Resources:

Edgerton Robert, Quality of Life a Longitudinal Perspective ; In Quality of Life Perspectives and Issues Robert L. Schalock (Ed). American Association on Mental Retardation Washington D.C.

Parents of severely disabled child often face 'ambiguous loss'

Submitted by administrator on Mon, 07/23/2007

By JENNIFER BARNETT
Salt Lake Tribune
Monday, July 23, 2007

Parents of a severely disabled child often feel the same sense of unresolved grief as parents of missing children or people who lose a loved one to the cloudy depths of Alzheimer’s, according to a new study done at Brigham Young University.

In the journal Family Relations, professor Susanne Olsen Roper and doctoral candidate Jeffrey B. Jackson show that these families face "ambiguous loss."

Other studies have looked at ambiguous loss: in the cases of soldiers missing in action, victims of the 9/11 attacks whose bodies were never recovered or seniors who are living but whose minds have been snatched away by Alzheimer’s. In such cases, families often feel that they can’t get closure on the painful event.

“No one has really gone out and talked to (parents of severely disabled children) to see if they were experiencing the same kinds of feelings,” said Roper.

The BYU study looked at 20 families in which a profoundly disabled child was placed in specialized care outside the home. Of the 36 parents who participated, 75 percent said they felt a sense of loss while raising a disabled child at home as the reality sunk in that the child was not the person they envisioned during pregnancy. Once a child was placed in out-of-home care, 65 percent of parents said the child was always on their mind. One mother whose son is in professional care said their weekly meetings were like a funeral every week because each visit meant saying goodbye again.

“It’s like the child is out of their life, but not out of their life,” said Roper. “They wonder, ‘Am I really their mother, even though I’m not feeding them three meals a day and I’m not living in the same house?’ ”

Families “may feel guilty for placing their child, then relieved of a huge burden, and then another dose of guilt for feeling relieved,” said Jackson.

The researchers hope their work will help families learn how to process the complicated emotions that follow placing a family member in professional care. They recommend parents look for meaning in their family experiences before and after placement, temper the need to feel in control, redefine their relationship with the child after placement and accept their conflicting emotions as normal.

Pauline Boss, an emeritus professor at the University of Minnesota who originated the concept of ambiguous loss, said the BYU study is a “major contribution” to understanding the trauma and distress parents of profoundly disabled children face.

(jbarrett(at)slttrib.com.)
When aging parents can no longer care for their disabled children

By Regine Labossiere
Seattle Times staff reporter

Delia Cano's body no longer moves as easily as it used to, so now she's had to do something more painful than the perpetual aches in her bones: Give up primary care of her daughter.

At 78 years old, she can no longer take care of her developmentally disabled daughter on a full-time basis. So she has arranged for her daughter, Guadalupe, to move into an apartment in Shoreline with two other women. She wants her to learn to live independently.

"I don't want for her to leave home, but I'm getting old. When I die or when I'm much older and won't be able to take care of her, she needs to have her own place," Cano says.

During the last week of July and the first week of August, Guadalupe "Lupita" Cano and Martha Hinojosa, both 34, and Florence Ulrich, 43, moved into their new apartment. The three women are different in many ways, but in some they are alike: They all have Down syndrome, and their parents have become too old to take care of them.

Planning for the transition

Experts agree that caregivers must realize their own mortality and plan for what will happen to their dependent adult children or family members once they've passed away.

The best approach is to have a variety of choices, because no single approach will work for everyone.

Options include moving into shared housing or into a home with supervised care, moving into the home of a younger relative, or seeking respite care. Cano, Ulrich and Hinojosa decided to move into shared housing.

Lani Scheman, a case manager for the Department of Social and Health Services' Division of Developmental Disabilities, put the three women together because they have similar needs: Ulrich and Hinojosa have diabetes, and Cano is borderline diabetic.

In addition, "The families liked each other. It was just a really good combination."

Arranging for the move took more than a year of planning and coordinating among a variety of agencies and support services.

One crucial issue was selecting an agency to serve their daily needs. In early 2003 they settled on Banchero Friends Services, an organization that helps adults with developmental disabilities run their lives.

Finally, on July 26, the three women moved.

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Developmental disabilities

According to The Arc, a national nonprofit advocacy organization for people with developmental disabilities, about 1.9 million developmentally disabled individuals live at home or with a family caregiver. About 25 percent of these caregivers are age 60 or older.

In Washington, there are at least 1,230 individuals with developmental disabilities living with caregivers who are older than 60.

Down syndrome, a developmental disability associated with mild to moderate mental retardation and a cluster of other symptoms, occurs in 1 in every 800 to 1,000 live births.

Individuals with Down syndrome generally have a life expectancy 15-20 years shorter than the general population, according to The Arc. However, their life expectancy is increasing as medical technology improves.
The feeling of having their own apartment and being on their own transcends the complications they've faced in the process.

Heather Paul, Banchero's program manager, remembers Ulrich's reaction to getting the key to the front door.

"Yes! I have my own key to my own apartment!" Ulrich shouted.

"I've never seen somebody be so happy to have their own key to their own apartment," Paul says.

**Keeping busy**

On a recent sunny Monday afternoon, Cano stared intently at the television screen. Her favorite show, "Sabrina, the Animated Series," was on. She was relaxing after her day volunteering at the arts studio in the Center House in Seattle Center.

Ulrich had just returned home from the Elder and Adult Day Services in Bellevue, where she spends three days a week doing arts and crafts, singing and playing bingo. Hinojosa arrived soon after, from her volunteer job at the Children's Museum.

"I'm so happy now I moved with the two girls," Hinojosa says. "Lupita is my oldest friend. We planned to live together since we were little girls."

Lupita and Martha were 2 years old when they attended the first University of Washington class for children with Down syndrome in 1971. That program paved the way for Cano to break stereotypes later in life.

Cano's extraordinary accomplishments have been documented over the years in a variety of local publications. In 1997, The Seattle Times wrote a story about Lupita's plan to move out on her own. The idea proved too daunting then. Instead, she and her mother, Delia, created a home inside a home: They renovated the basement to make it seem as if Cano was really on her own.

In addition to her volunteer work, she is a businesswoman and an artist with a lifelong love of painting.

With the help of family and supporters from the Division of Vocational Rehabilitation, last year she launched a greeting-card company featuring her original artwork. She named the company A.E. Designs, after her favorite character, Ariel, of Disney's "The Little Mermaid," and her long-term boyfriend, Eric.

The first order for 500 cards sold out quickly.

The cards are available in several Seattle stores, including Best Regards in Ballard, Frame Up in Fremont, Flourish Greetings in Wallingford and Queen Anne Office Supply and Stationery.

**Settling in**

After a few weeks at the apartment in Shoreline, the three are settling into a routine.

"This is brand-new for them. From experience, it takes a good six months to a year for people to get into the groove," Scheman says. "They've got a big learning curve, which of course is hard if you have a developmental disability."

Buzzing about the apartment on a sunny Monday afternoon were Cano's mother, Delia, and the program manager Heather Paul.

Rama Mboob, their caregiver, was cooking their dinner, to be served promptly at 5 p.m.

Ulrich, when asked why she likes the new living arrangement, replies, "We eat together, the three of us."
Mboob, who visits the women five afternoons a week, notes that they also do chores, such as washing the dishes and vacuuming the living room.

"They crack me up. Everybody has something to say," says Mboob.

The three women rely on public transportation to get them where they need to go. Hinojosa takes the city bus by herself, Cano takes the ACCESS bus (public transportation for the disabled and the elderly) and Ulrich either takes ACCESS or Medical Transport Services.

They’re also learning from each other. Hinojosa took a class on diabetes when she was younger and is able to administer insulin shots to herself. Ulrich never learned how, but Hinojosa is changing that.

"I like to help Florence learn about blood sugar," she explains.

Hinojosa's older sister, Sandra, calls her a social butterfly who is often too busy to call home. Covering a bulletin board in her bedroom are 18 Special Olympics medals. She can spit out facts about Gary Payton, her favorite basketball player, and a replica of his old Seattle Sonics jersey hangs on her bedroom wall.

"He's born the same year as me," she says.

Aside from volunteering, the women spend their day "doing girlie-girl stuff," according to Cano.

Ulrich is known for her love of country music. The Judds are her favorite musical group, and her hot pink cassette-tape case is full of country music albums, including seven by the Judds. The news of Johnny Cash's death greatly saddened her.

"I was singing his music," she says. "That's my guy."

The move has also been a test for the three women.

"Since moving in together, they're learning to respect each other's space," acknowledges Paul. "They've bickered."

One of the latest altercations, between Cano and Ulrich, resulted in the creation of house rules.

The rules, taped to the wall over the dining table, include apologize and forgive, touch in friendship only (meaning handshakes and hugs, rather than pushing), and be happy and healthy.

The hardest thing

While the women are excited to begin a new adventure, the transition has been bittersweet for other family members.

"We were best friends," Delia Cano says. "We lived together. We traveled together."

And Lupita was also her mother's teacher, says Cano, who came to the United States from Peru in 1957.

"My English is not very good, and I learned from her a lot of English," explains Cano. "The whole thing is so hard. This is the hardest decision I ever made in my life."

Ulrich's mother also has had a difficult time with letting Florence move into her own home.

"I had to let her go because I'm sick," says Wadia Ulrich, 80.

Ulrich, who lives in Seattle's Ballard neighborhood by herself now, explains that her age and her condition haven't left her much choice. Her osteoporosis has worsened in the past four years, and she can hardly walk. She can't take care of her daughter.
"I miss her," says Ulrich. "I always took care of her."

Hinojosa's sister Sandra, 38, has been Martha's primary caregiver since their mother was hospitalized with tuberculosis three years ago.

"I've always known, even as a child, that one day she would be mine to take care of," Sandra says.

The entire Hinojosa family misses Martha, but Sandra believes it's for the best.

"We went and visited Banchero, and I just saw how great everything is there, and it amazed me that she would have that kind of support in learning to be an independent person," Sandra says. "The support she's getting to learn new skills is much more than I could ever do for her."

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Parents Devoted To a Disabled Child Confront Old Age
Failing Strength May Force The Communal Care They Dreaded for So Long

By CLARE ANSBERRY
Staff Reporter of THE WALL STREET JOURNAL

PITTSBURGH -- Donald Tullis, 84 years old, wakes each morning in the room he shares with his youngest son, their beds only feet apart.

He ties his son's tennis shoes, helps him with his pants and suspenders, and shaves him. He makes cereal the way Tim, 49 and autistic, likes, with water rather than milk, and packs a hamburger, apple and cherry pie in a brown paper bag. At 8:30 a.m., a van arrives at the curb and honks, ready to take Tim to a training center for developmentally disabled adults, where he learns how to fold his clothes and write words on a chalkboard.

For a few hours it is quiet in their small apartment, save for news updates from the radio or TV, or traffic noises outside. While his son is away, Mr. Tullis rinses the dishes and makes their beds. When Tim returns shortly before 3 p.m., Mr. Tullis pops some popcorn for his son and gives him the day's junk mail to sort through, maintaining the routines so critical to those with autism. They share a quiet dinner in a tiny kitchen, Mr. Tullis reminding his son to use his spoon for mashed potatoes and fork for meat. Both father and son are big men, though Tim is far larger than his father, having outgrown the 44-inch-waist pants that Mr. Tullis now wears.

If Lawrence Welk is on, the two watch it together, Tim smiling and rocking in his favorite rocking chair, so worn that it's held together with a wire hanger and nails. On other nights, they listen to records of Scottish and Irish singers, or read. Mr. Tullis prefers mysteries, his son magazines, flipping through them for both the pictures and the occasional familiar word.

Mr. Tullis's wife, "the Missus" he calls her, a tiny lady named Gert, died a few years ago. Since then, Mr. Tullis has assumed total care of his son. Tim adores his father, his few sentences often about Daddy. Likewise his father, a soft-spoken man, beams when he talks of the progress his son, once declared a "mental defective," has made. A few years ago, Tim received an award and plaque for his spirit and determination from the Ross Center, where he goes each day. His father, then 81, attended his son's first award ceremony.

His biggest concern is what will happen to Tim when he dies. Although Mr. Tullis doesn't suffer from any major medical problems, he must deal with the normal course of aging. He shuffles when he walks, wears a hearing aid and has arthritis, which swells his hands and causes pain in his back. "Eighty-four is getting up there," says Mr. Tullis. "The hard part is that it's going to be harder on him than me."

After a lifetime of caring for their developmentally disabled children, a generation of parents are reaching the same painful crossroads, realizing that they can't do this much longer. During the 1950s and 1960s, these pioneering mothers and fathers were among the first to shun institutional care, insisting on a place for their children in society rather than on its fringes. They were a major force behind laws requiring schools to allow disabled children into mainstream classrooms or to set up special programs for them.

In raising their children at home, these parents had little support from outside organizations, leaving them largely on their own to be parent, nurse and teacher for children with then-baffling conditions. They saved the government hundreds of millions of dollars in expensive care. They also set the standard that subsequent generations of parents have embraced. Today, about 76% of the 4.3 million people with developmental disabilities live at home, a quarter of them cared for by a family member who is at least 60 years old. Most of the rest live in supervised settings or on their own.

That dedication enriched lives and created a symbiosis between parent and child that strengthened over time, but that time likewise makes untenable. Now in their 60s, 70s and 80s, some with weak hearts or limbs and others coming off bypass surgeries or chemotherapy, these aging parents are realizing that carrying a disabled adult child down steps is dangerous. Tending to breathing tubes throughout the night is exhausting. These parents' lifelong concern with their child's mortality is coupled with a growing awareness of their own.
Limited Options

Yet for the most part, these 670,000 older parents -- those 60 years plus -- continue because they are afraid not to. Relinquishing care of a fragile child prone to violent seizures or terror of the unfamiliar is difficult even as it becomes physically harder to provide. And in spite of the progress of the past 40 years, there are still limited options for the disabled once they pass through mandated education programs, which generally stop when they reach the age of 21.

Nationwide, 80,000 families are on waiting lists for government-funded residential services such as in-home help; some have been waiting for a decade. The figure doesn't include untold others -- by some estimates 40% of caregivers -- who haven't asked for service because they don't know it's available. In some cases, bad past experiences keep families from reaching out for help. Years ago, Tim spent three months in a state mental-health institution because he was eating uncontrollably; he came home with unexplained sores and bruises. He apparently had been bullied by others there who ordered the then-26-year-old man to tie their shoes.

The tandem needs of an aging parent caring for an aging disabled child are beginning to draw attention. The Administration on Aging of the U.S. Department of Health and Human Services and The Arc, a nonprofit organization for the developmentally disabled based in Silver Spring, Md., are in the early stages of developing a program to give help and counseling for older caregivers. In the meantime, these parents continue dressing, bathing and feeding their children, concerned more about their offspring's welfare than their own needs.

"There are a lot of quiet heroes and heroines out there," says Diane Len, of Family Links, a nonprofit agency based in Pittsburgh that coordinates government-funded services for the Tullises and others like them.

Their paths cross over coffee in the cafeteria of the Ross Center, which works with their adult children, about 40 in all, who are severely developmentally disabled. Martha Misson, a widow and 79-year-old stepmother, had triple bypass surgery in 2000 and cares for her 44-year-old stepdaughter, who has seizures so severe she must wear a motorcycle helmet at all times. Frank and Susie Simons, both in their 60s, must spoon-feed soft foods to their 36-year-old son. The O'Sheas, Robert and Catherine, who are in their late 60s, installed a lift above their quadriplegic son's bed because Mr. O'Shea has a weak heart and can no longer lift him. Frank Hricak's wife, Alice, 78, dresses and bathes their 49-year-old daughter, who suffers from an undiagnosed mental disability. Mia Ramaeckers waits until her 72-year-old husband, Martin, comes home at 9 p.m. from a part-time job cleaning offices to take their 37-year-old daughter, her body curved like an S, up to bed. "It is easier with both of us lifting her up," says Mr. Ramaeckers. "She's not getting bigger. We're just getting older."

In many ways, these lives reflect the great successes of technology and medicine. Both parent and child are living longer than previous generations. A child with mental retardation today has a life expectancy of 66 years, compared with 19 years in the 1930s. In the past, a child who could not swallow or was prone to seizures would have been raised in an institution. With portable breathing machines and drugs to help reduce seizures, they can live at home.

Such is the case of Mary Lou Ramaeckers. Tiny Mary Lou, whose toothy grin fills half of her delicate face, spends much her time at home lying on a mat in the family room of their two-story brick home, where she watches "Wheel of Fortune," a blanket tucked around her, a pillow under her head. Windmills from the Ramaeckerses' native Holland line the walls.

Doctors have never been able to identify her disability. When she was about three years old, she began walking ducklike on her toes. Doctors operated, pulling her muscles down to help her walk flat-footed, and thought she might have cerebral palsy. They later ruled that out. When she began shaking uncontrollably, they said she had a rare neurological syndrome. They later concluded she had an undetermined metabolic disorder. When her spine began to curve from scoliosis, they said it made no sense to operate. "They thought it wasn't necessary because she wouldn't live long," says Mrs. Ramaeckers. "She was going to be a teenager and that was it."

Mary Lou's body grew twisted from the untreated scoliosis, and her muscles deteriorated. She weighs about 75 pounds, though it's hard to tell how tall she is because her body won't straighten out. She can't walk, talk, sit up on her own, swallow or eat solid food. A dozen years ago, doctors suggested a nursing home. Her parents said no.
"Look at her," says Mrs. Ramaeckers, nodding to Mary Lou. "A girl who can't talk, who can't push a button for help. What are they going to do with her? She would just lie there. You put her in the best nursing home you want, even if you have the money, and she is not going to be taken care of like she is at home."

It's not just physical care they provide. Mrs. Ramaeckers dresses Mary Lou in color-coordinated outfits, often in her daughter's favorite purple, and styles her hair when they go out to dinner and to the movies. Wanting her daughter to be well-mannered, Mrs. Ramaeckers tells her to smile to convey thanks, sensing her wide grin warms and disarms those who might be uncomfortable seeing her. "Give them a smile," she coaxes. "It's what you can do."

Her parents alone can sense almost imperceptible messages from their daughter. Mary Lou glances in a certain direction to tell her parents when she is hungry, has to use the bathroom, or wants the TV station changed. When Mary Lou has a painful muscle spasm, her mother says her eyes go blank. "I tell the doctors, 'Her eyes go, she leaves me,' " she says. "They don't know what I mean."

They detect the slight gurgling sound amid conversation and laughter, and take turns suctioning saliva from the tube that acts as Mary Lou's trachea so she won't choke. The sound wakes them up several times each night.

"It's just like having a new baby. You hear them," explains Mrs. Ramaeckers -- only she is 70 years old, not a new mother. "You do slow down, but you manage," she says.

Mr. Ramaeckers dotes on Mary Lou, slipping her a dollar bill when she goes on a field trip with others at the Ross Center to the Dollar Store, and teasing her gently to make her laugh. "You gain another ounce and I'm through with you," says the slight Mr. Ramaeckers in a mock threat, as he carries his daughter up 16 steps to her bedroom. It is her favorite room in the house, with paintings of hot-air balloons and peacocks on the wall and blue Smurfs resting on her bed. She seems to like it better when her father carries her, giving him a smile and making a noise when her mother does. Mrs. Ramaeckers says she hugs Mary Lou tightly because she is afraid of dropping her.

"We are lucky," says Mr. Ramaeckers. But he worries about the future. "We've got another 10 years. Then what? Who will take care of her?"

They haven't asked their other four children to do so. "They probably would, but it's not fair," says Mrs. Ramaeckers. "They have their own family, their own life. You don't want to put the burden on them."

Few would criticize this generation of parents for choosing a selfless yet ultimately unsustainable path. Many might say that the intangible benefit of being at home and surrounded by comforting smells and sounds, family and friends, is itself good medicine. Still, those who work in the field of developmental disability gently encourage parents to make plans for their child for when they are gone, if only to ease the transition for both. Too often, they note, an older parent dies and a middle-aged child with the functioning level of a 3-year-old is left overwhelmed dealing with the loss of both parent and home.

"With this population, you have to do some planning. There's too much trauma in a new setting," says Prof. Tamar Heller, who heads the Disability and Human Development Department of the University of Illinois at Chicago.

Especially for a person like Tim Tullis.

**On Their Own**

It's difficult, all these years later, to pinpoint just when the Tullises first realized something was wrong with Tim, the youngest of their four children, who was born in 1954. Mr. Tullis says he was a beautiful baby with deep dimples. Tim walked and seemed fine until he was about 3, when his parents noticed he wouldn't talk. They sent him to school but he was dismissed after two months. At age 7, Tim was declared uneducable and mentally retarded.

Mr. Tullis, who grew up on a cattle ranch in Nevada, and Mrs. Tullis, from a small town in West Virginia, were left largely on their own to deal with the bewildering condition of autism. Even today the disorder, marked by hypersensitivity, obsessive behavior and an inability to relate to others, isn't fully understood.
Schools weren’t required then to accommodate children with developmental disabilities. Still, Mrs. Tullis remained hopeful, having Tim tested every year to see if he could attend school. Each year, he was refused, and his mother brought him back home to their yellow clapboard home on Blossom Way, and gave him books and pencils and paper. When Tim was in his early 20s, his mother got so frustrated and angry that she went to court and persuaded the judge that Tim needed a treatment program. The judge ruled that the county had to admit him into one.

By then, it seemed as if it was too late. Tim had never been in group settings before. He was kicked out of the program for being disruptive. "At present there is no place for Tim except to remain in the care of his parents," one psychiatrist concluded. "Community resources available to Tim are virtually non-existent."

Tim's parents did what they could on their own to fill his life. They gave him books and magazines. Mr. Tullis says he never made a lot of money, maybe $6 an hour at his peak, driving equipment for a construction company. But every summer, they took a long car trip with Tim, eventually seeing nearly all 50 states, staying in roadside motels until their money ran out and taking pictures until the camera got lost. They visited Yellowstone’s hot springs, Hell's Half Acre in Wyoming and Mount St. Helens months after it erupted.

Several years ago, Mrs. Tullis was diagnosed with Alzheimer's and began acting strangely, wearing socks in the bathtub and forgetting how to sign her name. She didn't recognize Tim and wondered who this big person was. Taking care of both his wife and son was difficult, but Mr. Tullis managed until one afternoon, when his wife fell off the back porch and broke her leg.

From the hospital, doctors transferred her directly into a nearby nursing home. Mr. Tullis would get Tim ready for school, spend the day with Mrs. Tullis, then return in time to greet Tim from school and make his popcorn. His father never took Tim to visit his mother at either the hospital or nursing home, for fear he wouldn’t leave. She died about five years ago. For a long time after, at unexpected moments, Tim would blurt out, "Mommy in the hospital." When he and his father got ready for weekend drives, Tim would say, "Wait for Mommy."

Their apartment misses touches she might have lent. Plastic supermarket bags dangle from lamps. Two umbrellas lean against each other in a bookless bookshelf where 80 years’ worth of photographs are stuffed in envelopes. Mr. Tullis washes his laundry in the bathtub because there is no washing-machine hookup in his apartment. This past Christmas, the artificial tree stayed in the cellar.

Mr. Tullis takes Tim on outings in the family's Dodge Caravan. On weekends, they pick a direction and head out to the rolling Pennsylvania countryside for the day. Tim sits in the back seat, his hands folded across his expansive stomach. Little is said. If Tim sees a barn, he says, "Mail pouch, big barn," remembering the chewing-tobacco advertisements that are often painted on barns. They stop at Arby's or Wendy's and eat lunch in the van on TV trays to avoid the crowds. On Christmas day, the other Tullis children visit their apartment, but one family at a time so as not to overwhelm Tim.

His youngest daughter, Linda Biegenwald, says her father has never asked his children to take care of Tim when he's gone, and it's not a comfortable subject for any of them to broach. "You don't like to speak about parents dying," says Mrs. Biegenwald, who is 50 and has two daughters living at home, both of whom suffer from mental disorders. "I don't know if I could do it." She hopes, along with her siblings, that Tim will be able to live in a supervised residential program. "No matter where he is, we'll be as active as possible in making sure Timmy is taken care of."

For now, it's up to his father. "His dad takes very special care of Tim," says Sister Jeanne, Tim's counselor at the Ross Center.

The Ross Center tries to help where it can, but it's under budget pressures because of federal and state cutbacks in funding. Staff members do more than is required. Sister Jeanne patches holes in Tim's pants, knowing an aberration in the form of a small rip can unnerve someone with autism. She found a new apartment for the Tullises when the old one had mold growing on the walls.

Sister Jeanne, who is also a member of the School Sisters of Notre Dame order, works patiently with Tim, trying to get him comfortable to new people and experiences. She made six trips with him to an office building to have his photo identification picture taken before he would get out of the car, go inside and have the picture snapped. Weeks in advance of each new outing, she compiles construction-paper booklets to review with him. There's "Let's Go to the Bookmobile" and "Tim's Physician" and "Tim Buys a Plant."
The efforts have paid off. When Tim first started coming to the Ross Center, he hid in the closet and could tolerate only 15 minutes of being at the center before he had to be taken home. Now he stays for the full five hours. He demonstrates a fascination with words and likes to type groups of nouns thematically with no space: FRITOLAYBRACHS. SPIROAGNEW. Once described as aggressive, he gets up in the classroom to offer his seat to someone who doesn't have one. In stores, he keeps his hands behind his back so as not to disturb anything. This past Christmas at a staff member's house, he watched a train set, hummed softly to himself and ate stir-fried chicken for the first time.

In a recent breakthrough, Tim allowed Sister Jeanne to comb his hair, something only his father had done before.

The big challenge now is to prepare Tim to spend a night away from home -- the first step to readying him for life without his father. Mr. Tullis is supportive of these preparations. "I never thought about it before. He was just here and that was that," he says. "Now we have to make provisions for him to go on his own ... Pretty soon, you know, I won't be around for him to come home to."

On a recent afternoon, Marianne Badaczewski, who provides care for disabled adults to give their caregivers a rest, welcomed Tim into her home. Well-coached by Sister Jeanne, she had popcorn waiting on the table for him. One of her six children sat with Tim and drew pictures with him. He ate his dinner quietly with the family, but was ready to get home when the sun set. Sometimes in his visits he is anxious and says, "Go see Daddy," she says, but seems to be getting more comfortable every time.

In a few weeks, Sister Jeanne will put together a small suitcase with washcloths and a toothbrush. That way, Tim can wash his face and brush his teeth after dinner at Mrs. Badaczewski's house, all things that he has done only at home with his father's help. And for when Tim is ready, an unused day bed in her son's room is made up and waiting for him.

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