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Promoting Independence

NICOLE CLEARY, MSS,
is the Executive Director of IDEAS

ONE OF THE MAIN JOBS OF PARENTING IS TO HELP CHILDREN DEVELOP THE SKILLS AND TOOLS THEY WILL NEED TO EVENTUALLY BECOME INDEPENDENT ADULTS.

This job is harder—often a lot harder—for parents of children with isodicentric or interstitial duplications of chromosome 15. When affected children are young, it is difficult to visualize what an “independent” adult life might look like. Often, it is easier to get through the daily tasks of dressing, eating, bathing, and transitioning to and from activities by doing things for our children, instead of finding ways to support them in doing it themselves. It takes an extraordinary amount of patience, commitment and dedication over many, many years to help our children become independent in their activities of daily living.

The whole idea of promoting independence for a son or daughter with a chromosome 15 duplication can be scary for parents. Often, our children need

to be protected from physical harm because of the nature of their disability. Parents naturally want to protect their children from pain or hurt they may experience in the wider community. It is understandably difficult for parents to think about “letting go” of a child for whom they have made a lot of personal sacrifices and whom they love unconditionally. However, parents have to balance these fears against the reality that in most cases we will either die first or get to an age that we will not be able to physically care for our children’s needs.

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Isodicentric 15, abbreviated idic(15), is a genetic disorder in which a child is born with extra genetic material from chromosome 15. In people with idic(15), the extra chromosome is made up of a piece of chromosome 15 which has been duplicated end-to-end like a mirror image. It is the presence of this extra genetic material that accounts for the symptoms seen in some people with idic(15). People born without an extra chromosome but who have a segment of duplicated materials within chromosome 15 (known as an interstitial duplication 15q) can have features similar to those with idic(15).

Promoting independence is not something that can be “put off” until a child nears adulthood. It is something that starts when you teach your newborn son or daughter to nurse from breast or bottle and continues throughout your child’s life. Unfortunately, there are no “how to” manuals when it comes to promoting independence in a child with a disability. That is why we are dedicating this issue of the **MIRROR** to the topic of promoting independence. We have collected the combined wisdom and experience of our **IDEAS** families on a range of issues involved in promoting independence from early childhood through adulthood. In these articles, you will see the amazing amount of work, creativity, and pleasure that parents have experienced as their children with chromosome 15 duplications become independent in their own lives.

Happy Reading!

With My Own Spoon: Learning to Eat Independently

PAUL & DAWN RIVARD

are parents to Megan (idic15) and her younger siblings Brooke and Kyle.



FROM BIRTH, MEGAN HAS HAD ISSUES WITH EATING. Now at age 9 she is fairly independent, but it's been a long road to get here. Her life started with the low sucking problem from low tone in her mouth. Using the softer bottle nipples was the only way Megan was able to drink from a bottle. But even with that modification, she took a long time to drink.

Megan progressed into baby food, which didn't pose any problems since the consistency was mostly all puree. As she got older and we started to introduce other foods and more solid portions we realized she could not control her own portions. She would cram food into her mouth until full and then sometimes gag. Or other times she would fail to chew her food and just try to swallow. This also gave way to gagging. The only silver lining during this phase was that we quickly found out she had a great gag reflex. She could always "fix" her choking issue herself. It was her special gift.

Concerned about her lack of chewing, we had a swallow study performed. The doctor discovered that Megan was taking her food into her mouth, mashing the food to the roof of her mouth, and then swallowing. She was not aspirating her food, but this was still not an optimal process. We next worked with our PT to help her on her chewing sensations. She was given different chew items and was allowed to "practice" her chewing. It all had to do with the sensory aspect of her mouth and food.



Right around when Megan turned 4 (I can't remember the exact age) she was self-feeding but it was only for finger style foods. If it had to be spoon fed, we still had to do it for her. We wrote into the IEP a goal about using utensils. The first focus was on using a spoon. Megan still had sensory issues with the "feel" of the spoon. While working with the therapist we found what worked well was a very fat, round spoon handle. This felt good to Megan's grip and she would tolerate holding it. To accomplish this task at home, I purchased some clear plastic tubing at a local hardware store and simply slipped the tubing over the handle, thus giving her a nice round surface to hold.

Once we had her sensory issues of chewing and holding a spoon addressed, we needed to work on the self-help skill of feeding herself. All her food is served in a bowl, and the bowl was placed on a Dycem mat (a non-slip surface) this helped to keep her bowl from moving as her mechanical motions were very crude. You can see samples at:

As she learned the motion of scooping out of the bowl, we needed to help by turning the bowl, as she would only spoon in one section repetitively. Once that area was clean of food, she didn't know to change area in the bowl. Over the years this continued to develop and she now seeks all food in the bowl wherever it is. This acquired skill, does come with a small price to pay. When feeding herself, the food will fall off her spoon onto herself or she might pick some portion up with her hands. So, large T-shirts have come in handy as a "bib like" protection for her clothing.

Megan's ability to try different foods has come along on her own. She has never been overly fussy, but she does have her favorites. Some of her favorites are chips, teddy grahams, and chocolate chip cookies. I sometimes think this must be boring for her to have the same thing over and over, but in her world of routine and stability, she probably very much enjoys the same thing since it is comforting to have routine. We still offer her different foods as we go along, but don't get too carried away with expanding her food repertoire.

One idea we have tried and has worked very well with Megan is "dipping." She loves to dip her foods into sauces. So we have taken some of the common things like French fries and hotdogs and have offered her ketchup and she absolutely loves to dip and eat. She now is almost at the point of demanding the ketchup.

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Toilet Training— A Big Step on the Road to Independence

TOM & SHARON MASER

are parents to Keith, Joshua, Aliya, Autumn, and Alexis (age 10, idic15). The family is moving to Safety Harbor, Florida, in June.



WHEN I WAS ASKED to write an article for the **MIRROR** on how my husband and I went about potty training our daughter Alexis, I thought, ok, I can do this. Little did I know that Alexis would have more “accidents” in the past month since agreeing to write the article, than she has over the entire last year! So my main thought I’d like to share with you all before getting started, is to never ever give up!

For a little background on us, Alexis was born to Tom and me a little later in life. We were not supposed to be able to have children so we adopted four beautiful children and after 16 years of marriage we received our surprise that I was pregnant. So, hence, our beautiful Alexis was born.

We received our diagnosis that Alexis has isodicentric 15 when she was just 11 months old. Through the almost 10 years since then, there have been so many ups and downs. Many more ups than downs I would say, but the most challenging has been potty training. Alexis does not have any speech yet, so I wanted her potty trained for us as well as for herself. I knew it would give her such independence. Alexis was fully “urine” trained, as in using cute little undies all the time, at the age of nine. Her BM training happened right after she turned 10 last year in

July. Summer time is “her time” so everything goes great in the summer. She has never had an accident with BM since she turned 10. Once she got that she got it!

As I sit here writing this article, our little bundle has just sprinted inside to use the bathroom. All I can do is sit here and smile. I wish that I could give you all a special formula that we used or a magical “potion” of some kind, but I have found that the best thing that has worked for us is consistency. In the beginning we took Alexis to the potty every 15 minutes and then I would expand it by 15 minutes when she would make it good for a week. I always, in the beginning, would reward her with M&Ms, which they say not to do, but I figure with our kids you do what works. Later just telling her I was absolutely proud of her was reward enough for her. This past August we had to make a trip to Florida from Oklahoma and she made it the whole way without any accidents. Needless to say, I was very proud.

For Alexis, bowel movements took a little longer than urine training. I believe it had to do with her low muscle tone and an actual fear of the toilet itself. We started giving her Metamucil in the mornings with her Tang and before we knew it she was going in the “potty” regularly. I think



the easier we can make a bowel movement for our kids the better. Alexis has always had a lot of sensory issues so finding what works for her has always been a challenge. Going to the potty out in public is still sometimes a challenge; it just depends how bad she really needs to go, she can hold it forever. She has such a fear of the automatic toilet flushers, but the bigger she gets, the better it is due to the toilet not going off sporadically.

I guess, my main thought to you all is, throw the potty training books away, throw every thought of how you did it with another child out the window, and do what works for your child. These kids are such a gift and if we can make their life a little more comfortable, such as giving M&Ms as rewards, I say do let’s do it. I have four grown children now and I can tell you that I have thrown every child-rearing book out. We are now writing our own book, so to say, with Alexis, and I must say...

IT WON'T BE BORING!

She Wants to be a Mommy When She Grows Up

MICHELLE HOKENSON

is the mother of Klara (idic15), and her sisters Hannah and Holly.



KLARA WAS BORN IN JUNE OF 1992. She was born with birth defects and Isodecentric15. Before Klara was born, I was hospitalized with a serious condition. "Hydrops" is diagnosed when the fetus (otherwise known as Klara!) does not process the amniotic fluid that a pregnant woman makes. The neonatologist suggested that she had fluid surrounding her lungs and would not be able to breathe when she was born. They needed our permission to take extreme measures to help her breathe at birth. We signed papers saying they could save her life.

When they broke my water to start labor, over five liters of amniotic fluid (the doctor's estimate) soaked the hospital bed. Labor and delivery followed quickly and Klara was born. The specialists (twenty two people in all!) poked large syringes into her chest cavity and sucked out a yellowish fluid. Other doctors pumped air into her lungs at the same time. Beginning on her chest, a pink glow began to appear

and soon she was a beautiful chubby baby with a full head of dark hair. She looked like my older brother and my oldest niece. Klara was rushed to the neonatal unit and they gave her a warming bed. Chest tubes helped the fluid drain from her body.

There are many other breath-taking stories about Klara's life and near death experiences. She pulled her own breathing tube out when she was three weeks old! She was diagnosed and then "un" diagnosed with many things like Cerebral Palsy, because doctors had never met anyone like her. Idic15 was very rare in 1992 and Klara was teaching the doctors about it!

If we fast-forward to today, we see a high-energy sister, daughter, and friend with an excellent sense of humor. Klara wants to be a mommy when she grows up. The first words out of her mouth when she met her baby sister Holly in 1995 was, "Baby Wiggles." Holly is nine now and hates that nickname!

Klara recently joined the demanding ranks of "womanhood." Just when I thought we had some things figured out, hormones kick in! While Klara will always be a one of a kind miracle child, she does exhibit some "typical" teenager characteristics. However, because of her disabilities, Klara and her family are experiencing some atypical issues as well. For instance, Klara was very upset when she began to menstruate because I would not take her to the emergency room!



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With my own Spoon: Learning to Eat Independently

PAUL & DAWN RIVARD

So we are now at the point where she can feed herself independently, either finger food, or with a spoon. She currently does not use a fork or a knife; those items are not critical at this time and may emerge at a later time. With all that said, sometimes Megan's table manners are not perfect. She will occasionally get "lazy" and not feed herself, but accept the food if we feed her. She will at times have the spoon between her fingers and wiggle the spoon. This can cause food splatter or sometimes she loses the spoon and it hits the floor. Portion control is getting better. She no longer stuffs food, but we still do cut her food into bite size portions. Megan has made much progress in feeding herself. It has been a collective effort with her therapists, her teachers in her school program, and the work we do at home.

At the end of the day, all the rest of the credit really goes to Megan. She continues to learn and refine her skills. We are definitely able to go to a restaurant and enjoy a meal, and that's nice for our family.

She was bleeding and I was calmly telling her everything was all right. With her unsteady gait, terrible balance, and ADHD symptoms, we have had our share of blood in the emergency room. When she began to believe me when I said this was

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normal, Klara began to target Hannah. Our fourteen-year old was bombarded with questions about her pads, tampons, underwear, and blood. Fourteen-year olds just love this topic! Hannah handled it very well and continues to be a caring, understanding sibling.

Holly was less understanding when Klara took her physical aggression out on her, the youngest in the family. This aggression increases a great deal at "that time of the month." Klara is angry, grouchy, and frustrated. Holly is a wonderful role model for Klara and teaches her all kinds of wonderful things. Sibshops helps Holly deal with Klara and her antics. Klara's academic abilities, attention span, and basic needs all regress during her period. She needs more naps, more food, and less stimulation.

Recently Klara has started taking birth control pills to help time her period better and regulate some of these behaviors we are seeing. We have a very smart doctor who also has a sense of humor. The best thing Dr. Lyke ever said to me was, "I don't know but I will find out." Having a doctor who needs to research answers for Klara makes me feel like I'm not supposed to have all the answers. Klara will always be Klara. She adds laughter and love to our lives everyday. Someday, I may have to explain why she can't be a mommy but right now I dream about the grandchildren we might share. One thing I have learned is don't create unnecessary problems. With children and special needs around, a new problem is always on its way!



GOT NEWS?

The MIRROR welcomes the stories, insights, and ideas of all parents and professionals interested in idic(15). We'd also like to hear your suggestions for future articles.

Send correspondence to Jane True, MIRROR Editor at:

JTRUE@kc.rr.com

or to IDEAS
PO Box 4616
Manchester, NH 03108.

Jane True, Editor

Lin Neighbors, Design & Layout

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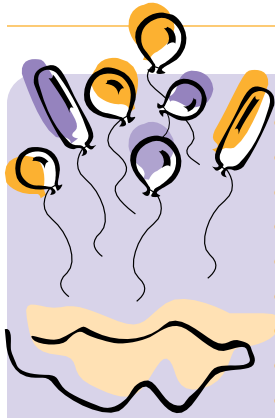
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Happy Birthday to these special people:

• Joelle G	05/02/94	• Douglas M	06/26/03	• Lauren C	07/11/00
• Jacob M	05/04/99	• Angel S	06/09/93	• Andrew H	07/11/89
• Shelby L	05/05/93	• Sarah H	06.26/93	• Erica A	07/12/86
• Jillian B	05/06/92	• Chris L	06/11/90	• Jessica M	07/18/98
• David W	05/08/91	• Mikaela O	06/28/00	• Kate S	07/20/96
• Albanelia R	05/08/84	• Tori M	06/12/92	• Clare T	07/25/80
• Erin R	05/09/00	• Alex S	06/29/96	• Colin O	07/30/98
• Anna M	05/09/88	• Heather W	06/16/92	• Gavin S	07/31/98
• Simon P	05/10/83	• Andrew B	06/18/99	• Emily M	07/31/80
• Austin E	05/13/92	• Richard H	06/18/96	• Rachel K	08/04/86
• Jaylin L	05/15/92	• James M	06/18/96	• Devon J	08/07/93
• John L	05/20/94	• Yuri P	06/20/75	• Jesse M	08/12/94
• Lindsey Y	05/22/98	• Cheyenne J	06/21/96	• Eli C	08/14/92
• Brenden O	05/24/91	• Krystyn B	06/22/98	• Austin V	08/15/96
• Joanne W	05/27/88	• Trevor B	06/23/94	• Spencer G	08/15/94
• Jarrett S	05/28/91	• Grace L	06/24/03	• Patrick S	08/16/98
• Madison M	05/31/01	• Kyle B	07/01/84	• Carly P	08/16/93
• Alyssa L	06/02/93	• Travis R	07/02/98	• Sarah D	08/23/98
• Jonah C	06/24/99	• Alexis M	07/05/94	• Colt C	08/24/93
• Kathleen M	06/04/93	• Samuel V	07/09/95	• Charlotte J	08/28/03
• Klara H	06/24/92	• Michael B	07/09/84	• Shannon N	08/30/94
• Jack R	06/07/02	• Clare G	07/09/82	• Kacey T	08/30/93

Johanna's Gifts

DIANE CREELEY

is mom to Meghan, Johanna (23 - idic15), Brian, and Sean. The family lives in New Hampshire.

IT'S HARD FOR ME TO BELIEVE, but my daughter just turned 23 in February. When Johanna was diagnosed in 1983, the neurologist had never seen a child with idic15. During one of our early visits, he handed me some pages copied out of a medical journal which documented young adults with idic15, but they were so profoundly disabled, I chose to ignore what I read. Though I had nothing to go on at the time, I refused to believe that my daughter would end up that way. Despite regular visits to many specialists, it was clear they were learning about the disability from Jo and me, not from any prior hands-on experience. So they offered little advice for me or hope for Johanna!

But I was very lucky and met some wonderful folks along the way, including amazing case managers and teachers and aides, who not only worked wonders with Jo, but who also taught me how to advocate on her behalf. It really hit me about the time Jo was a sophomore in high school that she only had a few more years left before she'd "age out" of the public school system and all its supports. So I started doing my homework on the funding and availability of adult services in our area, which was a real eye-opener! Jo would be placed on the state's



wait list and depending upon the funding available and where she fell on their priority list, the wait could be many years! (Jo was lucky and only on the wait list for about a year. Since then she's had a 40-hour-per-week day program with a one-on-one staff person.)

I felt it was imperative that Jo's remaining years in high school should focus on her life after high school. We needed to prepare her as best we could to be productive and self-sufficient in the adult world. It was also apparent that we needed to become more involved in our Area Agency on matters of funding and state budgets, which, as it turned out, was instrumental in getting Jo off the wait list!

Johanna's school offered internship programs where local businesses would take a student for one semester and train them in their business. Johanna interned at several nursing homes, a

publishing firm, a rehabilitation center, a retail store, and several other area businesses. These were great opportunities to see where Jo might find her niche without the very intimidating task of seeking out these potential jobs by ourselves.

One internship (at an assisted living facility) developed into a paid position in the summer of 2000. Jo currently works about 10 hours each week: three mornings she folds linens in the laundry area, and the other two mornings she vacuums the main dining hall. She needs no supervision or assistance while folding the linens, but that didn't happen overnight. It took a very devoted paraprofessional many, many months of modeling and reinforcing appropriate methods for Jo, until she "got it." But it still blows me away that she is able to fold so many different sizes of linens perfectly, each and every time! Jo has to have someone with her when she vacuums because her employer is very particular about the placement of tables and chairs. I thought maybe Jo would prefer to do something else because the vacuuming is a very physical job and Jo's not known for her stamina. But she really enjoys the vacuuming—I think mostly because it's a "backpack" sort of vacuum which gives her great stimulation!

Ever since she began working there, keeping Jo's supervisors

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(and co-workers) happy with her job performance has been a top priority for us. We regularly check in with her supervisors to see how she's doing and Jo occasionally takes home-baked goodies in to share with her co-workers! (You gotta eat!) If support staff is unable, then I take her to work. When her siblings still lived at home, they would take turns accompanying her. It was heartwarming to see them gladly take her to work and fold or vacuum right along side her!

I still remember the first time I went with Jo to her job. After years of Johanna following me around and taking her cues from me, the roles were reversed and I was following her...through the maze of hallways; to locate and punch her time card; then into the locker room to hang up her things; then into the laundry to learn the correct way to fold the linens... by watching Johanna do it! It brought me to tears!

Jo is not very verbal, but will sometimes acknowledge others with a smile, a touch or a silly laugh. It was through just such a gesture that Johanna developed a wonderful friendship with a couple who lived there. Their first encounter was memorable. One day as Jo was walking along a hallway, a woman (in the latter stages of Alzheimer's) was being wheeled past by her husband. Jo reached out and placed her hand

on the woman's shoulder and smiled. The woman responded in kind and her husband told us that his wife rarely reacted to anything and was amazed by this "gift" from my daughter! This became a frequent routine for them over the next year, until the woman passed away.

We are currently working with Easter Seals to find Jo another part-time job where, hopefully, she can be independent. In the meantime, Jo keeps busy with a number of activities. She volunteers one afternoon a week at the local humane society. She goes to the gym each morning and does the circuit three or four times around. She has been riding since she was about 10 years old at a nearby therapeutic horseback program and absolutely loves being with those horses each Thursday! She swims once a week and loves her instructor (Big Mike!). (She's always been an admirer of handsome young men!!) Jo likes to bicycle and go on long walks. She remains active in Special Olympics, participating in basketball, volleyball, and softball competitions throughout the year; and each February, she goes on a three-day trip with her team and coaches and competes in cross country ski events.

Part of her day program includes preparing a meal for herself and her support person (who is far more successful than I ever was in

getting Jo to stick through the entire process of making a meal!). Johanna has a laptop which she uses to practice her keyboarding skills by "writing" letters to her siblings or other family members; for educational programs; as well as for just playing games.

Jo is usually reluctant to do any vacuuming at home; but if I catch her at the right moment, she'll eagerly lend a hand. She helps with her laundry, though, and with dishwashing. She has also been responsible for feeding our pets.

We are now exploring alternate living arrangements for Johanna. Though we know this will take some time, we want her to be settled into a good living situation so that her siblings will not have that burden later on.

Most days it's still challenging to have a 23 year-old daughter with the ability and temperament of a small child, but she is truly a joy. Had it not been for Johanna, we would not have met some of the most amazing people or experienced the goodness and generosity of spirit of the many who meet and fall in love with her. She has given us so many "gifts" over the years. Sometimes it's difficult to keep moving forward when you're not really sure where you're headed, but when we least expect it, Johanna rewards us in some way...nearly every day...even now, 23 years after she came into our lives.

Creating Our Own Adult Services: Chad's Story

BRUCE & DEB LINDGREN are the parents of Rob and Chad, an adult with an interstitial duplication chromosome 15.



SOMEHOW THE YEARS HAVE flown by and Chad is over the age of 21, and can no longer attend public school programs. We first looked at the available programs in our state with the hope of finding the “perfect” model for Chad’s adult life, but we were not successful in finding something already in place. We decided we needed to create a program unique to Chad that included things like one-to-one supervision, space to move around, flexibility, how many people are around, and a variety of tasks. This is with hopes that once established, we would be able to turn it over to a company that provides day programs.

We realized almost immediately that Chad was a person that has abilities, but they are very inconsistent and even vary from day to day. This did not bode well for a typical job that demands promptness and has specific goals that need to be achieved in a specific period of time. Yet, we felt he needed a “real” job, because he was not stupid and would be able to see through a “made up” job. At this point, we decided to pursue volunteer positions, hoping this would take away the pressure of having to complete a specific amount of work in a specific time frame, but still have a real purpose for Chad’s life.

We thought about doing something

with a group that gave back to the community. We talked to a friend that was working for a local nonprofit group. This council included a food shelf, and she gave us the name of the director and suggested we call to check it out. Much to our delight, they needed volunteers and so the task of checking out the parameters began. It was an almost perfect situation for Chad. It was in the downstairs of a building that had a cement floor. This meant that on the days he was really needing to pace and bounce around, he was not going to disturb others on a lower floor. It had the flexibility of a volunteer job—if he was having a bad day or was sick, we could stay home or leave early. It had a variety of tasks—he can stock shelves, sort food, unload donations from trucks, help clients carry food to cars, and help package grocery orders by getting the needed items from the shelves. It even had a number of things that come encased in plastic, so Chad can satisfy some sensory needs by ripping them apart! We started working one morning a week and increased to two mornings. After a while, the council opened another food shelf in a nearby location that had a similar situation (i.e. cement floor with nothing below it) and we now work there one morning a week.

We heard of a ranch that was set up to give horseback riding lessons to sick or disabled kids. We started Chad with lessons and got to know the owners. They now let Chad come for lessons once a week and also let him volunteer. He can sweep, clean stalls, and brush, pet, feed, water, and groom horses—all flexible and dependent on what Chad is able to do that day. They also have a lot of wide-open space, with trails to walk, run,

and jump on without bothering a soul.

Even with these things in place, we still had both time and needs that had to be filled. We were able to find a music therapist, a massage therapist, and an occupational therapist to work with Chad. We also throw in things that Chad loves to do, such as go to museums, movies, historical sites, swimming, and amusement parks.

Chad's current schedule:

MONDAY AFTERNOON	Horse Ranch
TUESDAY MORNING	Food Shelf
TUESDAY AFTERNOON	Music Therapy
WEDNESDAY MORNING	Food Shelf
WEDNESDAY AFTERNOON	Activities
THURSDAY MORNING	Food shelf
THURSDAY AFTERNOON	Massage Therapy
	Project Explore Bowling
FRIDAY AFTERNOON	Activities

We have bought year passes to the YMCA, the zoo, the science museum, and an amusement park. Several of these have discounts for the disabled and allow them to include a caregiver with the passes. Chad was also able to qualify for an adult program that pays for the therapies and for some respite care that make this schedule financially possible. We are talking with some local companies about taking over this program.

We asked Chad a few questions about the adult services we’ve created together:

What do you do at the food shelf?

“I help pack groceries with my Mom, I vacuum, and I put away food.”

Do you like your job?

“Yes, I do, and I like to go to state capitols.”

Do you think this job helps people?

“Yes, I do. It gives poor people lots of food to eat.”

What about the horse ranch, what do you do there?

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The theme of independence has been selected by your editors for this issue of the MIRROR. For families and children with idic15, independence has many facets. Most of us are probably thinking “What skills do I need to teach my child to help him become more independent?” or “Where can I find the right living arrangement for her to live with a bit of independence as an adult?”

The flip side of such questions is “What am I doing to help make myself more independent from my child?” Whether we are planning a much-needed weekend of respite for ourselves, facing an unforeseen hospitalization, or are suddenly permanently removed from our child’s life, what can we do now to make the situation easier on our child?

Most of us would get some comfort from knowing that someone else could step in and know our child as we do, making for a relatively smooth transition. Even if we are just leaving for a weekend, telling the caregiver “Susie doesn’t

like spinach” on our way out the door won’t suffice for the complex care situation of a child with idic15.

We all have many things filed away in our heads that are specific to our child with idic15. We know, and hopefully have written down, all current medications, doses, and procedures for giving them (do we hide them in yogurt or applesauce, etc.). But do we have a written record of all the medicines that have ever been tried along with the length of the trial, results, allergies, etc.? Our doctors may or may not have accurate records, but what if we have to change doctors or the doctor who knows our child best is unavailable when a crisis hits? Many of us have already been through medical trial-and-error situations that we would never wish for our child to revisit.

Would a caregiver know your child’s everyday routines that may seem inconsequential but are of major importance to your child’s functioning? What are your child’s favorite places to go shopping, restaurants, foods, activities? What

will she refuse to eat? What upsets him? What form of discipline works best? What soothes your child? What time is your child accustomed to going to bed at night and awakening in the morning? What is the bedtime routine?

How do we best pass this information along to someone? We take a big step toward independence for ourselves when we write it down. This may seem to be an overwhelming task, but find the method that works best for you and get started. Keep a journal or a notebook of all of your child’s information. Keep adding to it as you encounter things in your daily life that are unique to your child, such as “counting dow” to prepare for transitions. Put your child’s picture on the cover both as a reminder to you of the importance of your task and to make it easier for someone to locate it in an emergency. Tell appropriate people where this document is stored and make sure it is easily accessible.

If this all seems too daunting, ask a family member or a friend to help you. Or come to our 2005 conference where Protected Tomorrows will explain their process called “My Special Life.” Whichever approach you choose, do something. The peace of mind that you will have knowing your child’s future caregivers will have the information they need during your planned and unplanned absences is a giant step toward your independence.

(CHAD’S STORY continued)

“I help sweep the floor in the barn, brush the horses, ride horses.”

Do like going to the ranch?

“I do, yes.”

What is your favorite thing to do at the ranch?

“Riding the horses.”

Maintaining Chad’s program is a lot of work, and some days are very frustrating. We have lost the OT, and

his program has “holes” in it that make it far from perfect, so we feel we are in a state of evolution. We are happy with the jobs, as they are real and give Chad a sense of worth. We feel it is a good base program and hope to continue to find a good mix of meeting his needs and providing him with a satisfying and successful life.

There's No Place Like Home— Or is There?

BRENDA FINUCANE, MS, CGC

is the Executive Director of Genetic Services at Elwyn, Inc. in Elwyn, PA. She is also the co-founder of IDEAS and serves on the IDEAS professional advisory board.



TO BECOME INDEPENDENT:

It is what parents strive for in all their children; it is the goal teachers aim for in schools; and it is what drives a determined preschooler to want to do everything “by myself.” The reality that a child may never grow up to be fully independent is at the heart of the devastation many parents feel when they first find out that their son or daughter has an isodicentric or interstitial duplication of chromosome 15. So they roll up their sleeves, learn as much as they can, and work as hard as possible to help that child become as independent as he or she is able to be. Hopefully, along the way, they also learn to appreciate the uniquely positive aspects of loving and raising a child with idic(15).

All children, disabled or not, are dependent on their families for food, shelter, love, and other life essentials. But as they approach adulthood, a clear difference emerges between children with developmental disabilities and their non-disabled siblings: while typical children begin to establish their own lives apart from their parents, most people with developmental disabilities are not able to live fully independent lives. This poses a dilemma: where is the most appropriate place for an adult with idic(15) or int dup(15) to live? There is no simple answer to this question, but it basically boils down to two main choices: (1) living with parents or other family members, or (2) living in a supervised setting apart

from one's biological family. Many different residential options exist, as described in the accompanying article by Hazel Yelverton; but these options are not available in all communities, and many have long waiting lists. For adults with idic(15) and their families, finding, funding, and getting into a “home away from home” represent only one side of the issue, though; the second, more difficult side, is an emotional one that forces parents to grapple with the dilemma of letting go of an adult who is not fully able to make it on his or her own.

Many people with developmental disabilities continue to live with their parents well into adulthood. One obvious benefit of this arrangement is that the person continues to be surrounded by the people who love him most: his family. Some parents find it very satisfying to play an active parenting role and to continue sharing their lives, as well as household responsibilities, with a disabled adult son or daughter. And many such parents point out that it is not so unusual, even among non-disabled people, for parents to share their home with grown children. On the negative side, as they age, many parents worry about who will take over for them after they're gone. In some families, siblings or other relatives are willing and able to provide a home for the person with idic(15) when his or her parents are no longer able to do so. But given the stresses of their own families and careers, few siblings are able to take

on the full responsibility of caring for a dependent adult brother or sister. If no arrangements have been made, a crisis situation often develops when parents die and rapid decisions must be made about the fate of their son or daughter. For a disabled person who has lived all of his or her adult life with family, suddenly being uprooted and brought to live among strangers can be a bewildering and frightening experience. It is far less disruptive if plans for residential placement can be worked out before a crisis situation occurs, when a person can be gradually introduced to semi-independent living, and while the parent is still able to have some input into her son or daughter's future.

Another possibly more significant drawback to living at home is the fact that many disabled adults have far fewer opportunities to develop independence while living with parents, and are not as functional as they could potentially be. The more active the parenting role, the more likely the adult will continue taking on a child's role, with little incentive to do things for him or herself. Some families have worked out an excellent compromise to this problem by having their disabled relative maintain a semi-independent lifestyle within or near their own homes. For example, one family I know has turned their garage into an apartment, with a separate entrance, bathroom, and kitchenette, for their adult son with mild mental retardation. They are there for him when needed, but he is also expected to take care of his own basic needs,

including doing his laundry, getting up on time for work, and fixing his own meals. He is also able to make his own decisions about socializing and bringing friends to his apartment.

While decisions about living situations are never easy ones, they are even more difficult when they involve the need for out-of-home placement for a child. Most children and adolescents with idic(15) do best at home, where they are part of a family and a community. However, among all children with developmental disabilities, there are those who have extraordinary medical and/or behavioral needs which cannot be easily met in the home, even with outside supports. One

example would be an adolescent with idic(15) who has extremely aggressive behavior and poses a physical threat to younger siblings in the home. After exhausting all other options, his parents may recognize that an outside residential placement is the only choice, yet the decision remains an agonizing one. Parents may fear the abuse, neglect, and other horrors associated with some large “institutions” of the past, despite the fact that many different kinds of home-like settings and options are available today. Another difficulty is the sense of failure that parents may experience when they must turn to other people to care for their child, even though in most cases, it is the

child’s exceptional behavioral needs, and not the parenting style, that require extra help. Many such parents, reading about the “success stories” of other children with idic(15), feel cheated and even more isolated to realize that their child is once again different, even from his same-diagnosis peers. The truth is that for every extraordinary success story, there is an equally remarkable situation where a child poses extraordinary challenges.

Whether it happens in adulthood or before, today’s residential options allow many families and children to actually gain control over their behavior, their lives, and their independence.

Understanding the Choices for Independent Living

HAZEL J. YELVERTON

is the Director of Admissions for Adult Residential Services at Elwyn, Inc.

FOR MANY YEARS, INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES HAD LIMITED OPTIONS for where they could live. Most often, people with developmental disabilities were restricted to living at home with their parents or relatives, or living in large, congregate care settings (“institutions”) offered at private or state-run facilities. For families who chose the former, the question of “What will happen when I’m gone?” weighed heavily on decisions for the future. In the late 1960s, community living arrangements (group homes) emerged as a viable alternative. But for some, this option lacked the flexibility of services to accommodate

those who required more support, as well as those who, if given the chance, could live even more independently.

Today, to the relief of many families, residential options and support services have been greatly expanded and now offer more choices for people with varying levels of ability and independence. Individuals with disabilities are encouraged to participate fully in their communities by enjoying local activities that include picnics in the community parks, attending services at churches or synagogues, shopping at the grocery stores and malls, and going to local sporting and

entertainment events. Services in the home include assistance in the activities of daily living that support a person’s personal and intellectual development, physical and personal care, recreation, and socialization in the community.

Community living options are not simply based on a one-size-fits-all philosophy. Depending upon the individual and family needs, support can range from 24-hour supervision, to support on an as-needed basis, in a variety of settings. As a long-standing provider of services for individuals with developmental disabilities, Elwyn Inc. provides a variety of community residential

supports that is representative of what families today may be able to choose in their communities. The options described below may go under a variety of different names, depending upon the provider, so families should check with local state and county agencies to find out what is available.

■ **Life Sharing Program**—Adults with developmental disabilities live as part of a family, (other than their family of origin) who have received special training to teach and assist with building the necessary skills for growth and independence in a nurturing home environment. Goals are developed for the new family member and are based on the person’s current needs and plans for future endeavors. Life sharing providers are homeowners who receive a monthly stipend to provide services within their home.

■ **Optional Living Program**—A resource for families who want to help their relative with developmental disabilities realize the dream of establishing a home of their own. Options can be for the individual to live alone or with a roommate; to rent an apartment; or to purchase a home. The Optional Living team directs the family to government services that can support some of the specific needs.

■ **In-Home Supports**—In-Home Supports strives to provide services to people with challenges in their own homes. Individuals may be living with their families or independently. This program allows individuals access to services that improve the quality of their lives on their own terms through the concept of self-determination. The

type of service, the frequency of service, and the times of service are tailored to the individual’s needs. An In-Home Supports Manager matches appropriate support staff with each consumer and works closely with the individual, their county Supports Coordinator, and the person’s circle of support to develop and monitor delivered services.

■ **Evaluation and Training**—Through this service, families receive evaluation and training in their own home to help their family member establish a more independent living environment. Sometimes the result is adjusting their current home-life to allow for more independence; sometimes it is taking steps now to prepare for the future possibility of moving out; and sometimes it is assisting individuals with their move to a new home. Together, staff and families determine the degree of support that will be needed and what types of housing would be suitable. Before an individual and their family locate housing, plans are made for adaptive measures and instructional designs, which can improve the living environment. Often, individuals who have been living at home for an extended period of time will need some additional training to learn to do more for them. This training is also provided for families in the convenience of their own home.

■ **Supported Living Services**—This type of program is for individuals, 18 years or older, who are either living independently in a community setting, such as a group home, or preparing to establish a home of their own in an apartment, condominium, or a house.

Supported living provides part-time assistance to individuals residing in apartments. Staff support varies according to the individual’s needs. For example, some may need help with budgeting and banking, while others may need assistance/training in food shopping, meal preparation, using public transportation/travel training, cleaning and maintaining their home.

■ **Community Living, Minimal Support**—For adults who can do much for themselves, but still require assistance and minimal supervision (less than 20 hours per week), this program supplements their abilities with instruction and assistance as they live in a community home, apartment or condominium. Some typical areas of assistance are: vocational planning, social/leisure activities, recreation, adult skill development, relationship building, and financial management.

■ **Community Living, Moderate Support**—For adults with developmental disabilities who demonstrate independence in adult development skills and survival skills, community living in a house, apartment, or condominium will be supplemented with moderate support (20 hours of staff support per week).

■ **Community Living, Maximum Support**—For adults with developmental disabilities who require intensive support and supervision, 24-hour supervision is provided in their community living environment (house/apartment). Services under this program may include more intense medical support.

Lis Lis Reiter

CHRISTIAN REITER & ANETTE RÖHR
are parents of Lis, age 7 (idic15). The family
lives in Bersenbrück, Germany.

AFTER WHAT SEEMED LIKE A NORMAL PREGNANCY, Anette had to go to the hospital in the 7th month, because doctors were worried that the baby was too small. There they carried out a HAES-therapy (a combination of sugars, proteins, minerals and vitamins), because they were afraid that the placenta was insufficient. Different measurements were made with Lis using ultrasound. The diameter of her head was measured. It was assumed that she would be retarded concerning size-development. In short intervals until the birth in March, 1998, several investigations were made to control the efficient supply nutrients to Lis. Besides the size nothing else was noticed.

Birth was induced at the 6th of March, 1998. Immediately the labor started. Lis was pulled out after seven long hours. Her heart-frequency during the birth was low. The Apgar-value was 0.8, so she was immediately brought to a special treatment (oxygen-tent). During the birth her clavicle was broken and she had a big birthmark underneath her right ear. Her weight and her size were 3030g and 53cm—in a normal range opposite to the expectation!

The first days of life Lis slept very much and did not scream. She did not nurse, so Anette pumped her milk and we fed her with a syringe and fingers. In that time we kept a diary and wrote down every milliliter she drank. She lost up to 10% of her birth weight. The first 2 years she was considered too small in the height/weight charts (lowest statistical level).

Some of the vertebra in Lis's pelvis and neck-region are incorrectly positioned (KISS-Syndrome), and her motor development is retarded. We tried Cranio-sacral-therapy provided by a special educated Orthopedist. This helped to remove the blocking of her vertebra. Her motor development improved



very soon concerning crawling, sitting, standing, walking. In monthly intervals we controlled the reformation of the blocked vertebra and Lis is having physiotherapy.

Her overall development was significantly delayed compared to other children of the same age. She was diagnosed as “mentally retarded” so we started at her 12th month with “Frühförderung” (early promotion). In the Hospital she was not seen as a typical syndrome-child, so the doctors told us that no genetic test was necessary. The EEG did not show a clear result. But more and more we noticed that something was wrong with Lis, and at the age of 2 we went to a neurology institute to Göttingen. There—without a further study—they said that Lis looks as if she has the Angelman-syndrome. We had never heard about it and were very shocked!

After that experience we let our paediatrician do a test for Angelman, with a negative result. But no chromosome-test was made at that time.

At the age of 3 Lis visited the “Integrative Kindergarten” (children with and without handicaps are educated together). There she made big developmental steps. She always had her own fantasy-language, but now she started improving her correct speech. Her motor skills improved too. She started running but still fell often. She had screaming and panic attacks especially when her mother was not there or she heard unknown sounds.

We decided to make an analysis of her chromosomes. We got the result in autumn 2002, defined as idic15 (q12). We informed ourselves through the internet and immediately found the site www.idic15.org

and the story of Sven at www.leona-ev.de. We contacted the people behind these addresses, and that was and is a very positive experience.

Since summer 2003, Lis visits the “Heilpädagogischen Kindergarten Priggenhagen” for disabled kids in Bersenbrück, where we bought a house. Lis is there in a group with 6 other kids and there are 3 caregivers. In the beginning she was shy but after some time she felt more safe. Since summer 2004, Lis visits weekly the Autism-therapy. At the Kindergarten she gets weekly Logopädie (since she is 3 years) and Ergotherapy. She is also doing therapy with animals and some weeks ago she started to ride an island-horse named “Vengör.”

Today she speaks whole sentences. Her motor skills are still getting better. She loves to jump on a trampoline. She can name colours, starts counting, and can recognize her name. She loves music and dances until exhaustion. She is open to people and animals. She loves especially frogs, storks and ducks. Taking a bath is only possible with at least 50 plastic-animals! Most of the time she is a happy little girl and loves to go to the Kindergarten, but sometimes she starts screaming (when she gets tired; but other kids do that too, I have heard...). She enjoys tearing newspaper into small pieces, probably because of the sound it makes. She has a restless sleep. That is why we thought about giving her Melatonin, but did not try it yet. We did not get very far with the toilet-training, but are still trying. She always says “tomorrow” which seems to be unreachably far away to her.

Lis still has panic reaction when she hears some loud sounds, especially when she does not see or know the source of the noise. But more and more we can explain it to her and she then stops screaming. She has a very good ability to memorize music (melodies) and names. Sometimes she can be a very inflexible little dictator. She likes to eat, but we have to take care of her wheat allergy.

For us it is good to see that the development of our little Lis is still progressing—slowly but steadily.

IDEAS

is a non profit organization dedicated to providing information, education and support to families with individuals affected by isodicentric and interstitial duplications of chromosome 15. **IDEAS** unites families, researchers, and professionals; and promotes research, awareness and understanding of Isodicentric 15 and related disorders.

Third International Conference on Isodicentric 15 & Related Disorders

DATE: June 23 - 25, 2005

PLACE: Hyatt Regency Woodfield
1800 East Golf Road • Schaumburg, IL

CONTACT: Jane True • 816.453.4862

jtrue@kc.rr.com

Germany: Idic15 Evening Seminar for Parents & Specialists

DATE: 5 July 2005, 19.00 - 22.00 o'clock

PLACE: Puchheim near to Munic • Cost: 25,00 Euro

CONTACT: Montessori-Praxis, Misses Lore Anderlik,
Buergermeister-Koch-Str.25, 82178 Puchheim
Fax: 089/ 89 02 71 19

LAnderlik@aol.com

The organizers will show videos taken during the therapies with idic15 kids. They will demonstrate how Montessori can be used for education, without creating limits by a deficit-thinking ("the child is disabled, so it can not..."), but finding out the real possibility of development of the child. The organizers have been working for years with idic15 children as also with children with other chromosome disorders and their parents.