

SUMMER ■ 2004

Educating Children with Chromosome 15 Duplications

NICOLE CLEARY, MSS, Executive Director

When families receive a diagnosis of *idic(15)* or related disorders, they are usually told some version of the following: "There is no treatment that can undo your child's genetic condition. However, therapy and special education will help your child reach his/her full potential." Education immediately becomes the focus of a parent's energy, and remains so for the first 21 years of a child's life.

What kind of therapy should my child receive? What kind of classroom should they be in? What should I ask for during the IEP? Is my child getting enough therapy? Are the educational practices a good match for my child's learning style? These and many more questions are often heard from parents of children with *idic(15)* and related disorders. This issue of the **MIRROR** aims to address some of these questions.

Children with duplications of Chromosome 15 are educated in classrooms of all types, ranging from self-contained special education classes for children with autism, to inclusion in regular education classes. We are still

learning how to teach children with chromosome 15 duplications in the most effective ways. It is an ongoing process. What we do know is that all children with *idic(15)* and related disorders can and do learn, often much more than the "experts" expect! Teaching should be based on each child's ability and learning style. The goal in education should be to provide our kids with the most stimulating educational opportunities in the least restrictive environment appropriate for each child's individual needs.

At the current time, a specific behavioral and learning profile of individuals with *idic(15)* has not been established. While we do not yet have a set of formal "best practice recommendations" for educating children with *idic(15)*, there are good resources for parents. The **IDEAS** listserv provides families with a forum to share their concerns and get information from other families. **IDEAS** conferences combine the opportunity for families to talk to each other with opportunities to hear from professionals and educators. Finally, this issue of the **MIRROR** highlights education issues

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 material withing chromosome 15 (known as an interstitial duplication 15q) can have features similar to those with idic(15).

starting from a child's first year through transition from school to adult life. Looking toward the future, **IDEAS** can act as a catalyst to bring together parents and professionals to compile a behavioral and learning profile of students with *idic(15)*. We will then be able to make more definitive recommendations about how to teach children with chromosome 15 duplications in the most effective ways.

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Education, Treatment & Intervention Models: Implications for children with idic(15) & related disorders

BARBARA HAAS GIVLER, M ED
 Educational consultant based in Pennsylvania
 IDEAS professional advisory board member

Designing an individualized education plan for your child with idic(15) or related disorders is as comprehensive as building your dream home. At times, the process can be staggering with overwhelming decisions. There are unfamiliar terms, personal preferences, family needs, codes and laws, ideal versus real plans, budgetary restraints, as well as trust factors. Just like building your dream home, there are proposed designs, plans, tools, and many professionals who need to come together with you to create your child's educational plan.

Many individuals with idic(15) and related disorders exhibit behaviors that meet the diagnostic criteria for PDD-NOS or Autistic Disorder, both of which fall under the Pervasive Developmental Disorders of the DSM-IV-R, a Psychiatric Manual. Some of these behaviors and needs include sensory issues, communication needs, difficulty with transitions, stereotypical and or ritualistic behaviors, and unusual fears. As a result, many of the educational practices and interventions recommended for children with autistic spectrum

disorders can be successfully used for children with idic(15) and related disorders. Consider the following as you build your child's Education Plan.

Assessment

The first step in designing a child's education program is an assessment of the present level of performance. Often each therapist or specialist involved with your child will complete their own assessment and then come together with goals at an IEP.

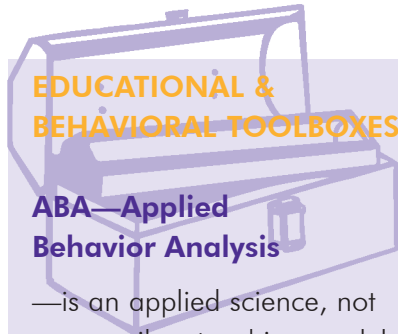
Each school district will have a battery of standardized tests and scales they will use in the assessment process. One relatively new assessment tool that some parents of children with idic(15) have found to be helpful for children is the **ABLLS**. The Assessment of Basic Language and Learning Styles recently developed by Drs. Partington and Sundberg is a comprehensive assessment, curriculum guide and skills tracking tool. The assessment lends itself to writing specific goals/objectives across all domains for implementation across settings.

www.behavioranalysts.com

Establishing a good foundation

As with any other kind of construction, a child's educational plans need to rest on a good foundation. Are there consistent daily routines? Firm, well defined limits? Is there an environment rich in positive reinforcement? Does the philosophical approach encourage choices and foster independence? Are there opportunities for inclusion with typical peers? Is the staff calm, patient and nurturing? This can be especially important for children with idic(15) since many experience some degree of anxiety. The specially designed instruction and materials on the IEP and implemented in the classroom should address sensory issues, communication, and for many, seizure activity and related medical issues. According to the recent Elwyn survey, over half of children with idic(15) and other related disorders have seizure activity with accompanying medication issues. Many children will benefit from related services including Speech and Language, Occupational and Physical therapy and Adapted Physical Education. Some children will need a Behavior Intervention Plan.

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Choosing the right tools

Parents and educators alike often have a difficult time sorting through the various educational models and approaches out there. It may be useful to think of each intervention model as a toolbox, many of which have accompanying tools. You need to know what each toolbox is used for (i.e. the philosophical or theoretical basis of each intervention), and understand the tools (specific strategies or techniques) that can be used for the different challenges experienced by your child. Following is a description of the most common toolboxes and tools used in the education of children with autistic spectrum disorders, including idic (15).

ABA—Applied Behavior Analysis

—is an applied science, not necessarily a teaching model, that develops methods of changing behavior. A behavior analysis program is based on empirical research, includes direct observation and measurement of behavior, and utilizes antecedent stimuli, positive reinforcement, and other consequences to produce behavior change. ABA is often mistakenly called the Lovaas method because Lovaas initiated intensive intervention at UCLA in the early 1970s for young children with autistic spectrum disorders. **DTT—Discrete Trial Training**—is a tool used with ABA approaches. This teaching technique, usually provided in a 1:1 setting, is intensive specific instruction to consistently get a response to a stimulus with reinforcement provided. There is systematic presentation of materials, fading of prompts, and various schedules of reinforcement.

There are emerging behavioral approaches that more naturalistic and child centered. The authors of the ABLLS and other Behavior Analysts including Dr. Vincent Carbone are advancing ABA with a verbal

behavior emphasis. This approach is more child friendly (parent and therapist as well), focuses more on positive "pairing" of the child with people and activities, encourages intentional communication by the child.

www.verbalbehaviornetwork.com

and www.carbone.net are sites to help differentiate and distinguish the characteristics of this approach.

PRT—Pivotal Response Training

—another naturalistic and child centered behavioral treatment intervention based on ABA and derived from the work of Koegel, Schreibman, Dunlap, Horner, and other researchers. Key pivotal behaviors have been identified for children with autism, including motivation and responsivity to multiple cues (Koegel & Koegel). PRT has demonstrated positive changes in these "pivotal behaviors" with widespread effects on many other behaviors associated with language and social interaction. Pivotal Response Training (PRT) provides a guideline for teaching skills and has been most successful for language, play and social interaction skills in children with autism. See

www.users.qwest.net/~tbharris/prt.htm

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TEACCH—Treatment and Education of Autistic and Related Communication Handicapped Children

—Developed in the early 1970s by Eric Schopler, the TEACCH program is a statewide initiative in North Carolina. A broadly-based intervention strategy includes building on existing skills and interests. Structured teaching, organizing the environment, clear expectations to foster independent skills is components of this approach. Visual schedules and visual materials are tools associated with the www.teacch.com TEACCH program.

EMOTIONAL RELATIONSHIP & SENSORY TOOLBOXES

DIR—Developmental Individual—Difference, Relationship

—is a comprehensive model to identify and analyze a child and family’s strengths/needs and developmental levels. Developed by Stanley Greenspan and Serena Wieder this child oriented/centered program focuses on meeting the child at his current level building relationships, “circles” of communication, and particular attention to developmental and

sensory issues. Floor time is a tool of this model and generally speaking is getting down on the floor with the child for many activities building from the child’s framework. You can find more information at

www.stanleygreenspan.com

and www.floortime.org

SI—Sensory Integration

—therapy is a strategy utilized by some Occupational Therapists. Generally speaking it is therapy that has goals of improving sensory processing, regulation, and integration. While there is not a great deal of empirical data to support this method many parents and educators have noted the positive effects of such a program. The activities are rich in proprioceptive and tactile input and depending on the individual address areas including visual motor and auditory processing. Fidget toys, transition helpers, deep compression, weighted vests, spinning, brushing are all tools that are associated with this toolbox.

www.sinetwork.com

or www.sensoryint.com

COMMUNICATION TOOLBOXES & TOOLS

Toolboxes that are specifically designed to address the core communication areas are those such as the PECS and Total Communication Approach. Usually a school program will have other curriculum to address areas such as behavior, social, academic, self sufficiency goals.

PECS—Picture Exchange Communication System

—developed in the early 1990s www.pecs.com by Bondy and Frost—this approach teaches children to exchange (not just point to) pictures to communicate with others. Frequently the Mayer-Johnson pictures and photos are utilized with the PECS program. The use of www.mayer-johnson.com the photo or picture icons is a tool that is utilized in many educational settings to develop visual schedules, communication boards, choice schedules and behavior charts.

Total Communication Approach

—as it generally applies to those individuals with autistic spectrum disorders is the use of sign language in addition to spoken word or vocalization to foster communication and reduce frustration.

Social Stories

A Social Story is a tool that may be utilized with any toolbox. A short story—defined by specific characteristics—that describes a situation, concept, or social skill using a format that is meaningful for people with Autistic Spectrum Disorders. Social Stories were developed by Carol Gray in 1991. For more information, see

www.thegraycenter.org

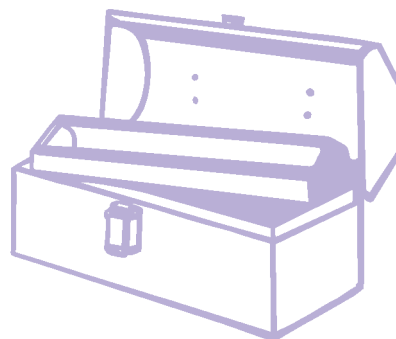
Choosing the program

The final step in your child’s education plan is selecting the placement where your child will receive their education. Every child has specific needs including communication, behavior, social, and medical. Some programs are behavioral intervention models, while others are communication system models. Some questions to consider when choosing a program for your child:

- Is it a child centered or adult directed program?

- Does this program address your child's specific needs?
- Is there a parent-program match? Some programs are financially costly or demand many hours of implementation in the home.
- Is this model readily implemented in self- contained special school programs or for school programs with more inclusion opportunities?
- Is this program readily implemented for specific age or grade levels?

Given the complex needs of children with idic (15) and related disorders, it is important that the educational setting can provide staff that are experienced using a range of strategies across various theoretical models. The members of the educational team with the parent as an equal member need to work together and continuously review the effectiveness of the program model and associated strategies and techniques.



Trust yourself—promises & practices

Is there an exact right program for the child with idic (15) and other related disorders? The answer is no. There are a lot of great educational strategies out there, and knowledge is power. Parents should sort through what is available using their own experience and the experience of other families with idic (15) and other related disorders. Too often parents feel guilty that they aren't doing enough for their child or look back with regret, wishing that new approaches or treatments had been available when their child was younger. This is counter productive and oftentimes is looking at the glass as half empty.

Educational practices and intervention techniques come and go much like a pendulum swings. Keep in mind that some programs are simply new packages for old techniques. Some toolboxes and tools are refinements or new and improved treatment models or strategies. Parents and professionals are cautioned to seek whenever possible empirical or scientific evidence of the efficacy of programs, approaches. What is most important is finding out what works and is right for your child.

The First Year: A top 10 list



WHAT ARE THE TOP 10 THINGS/TIPS THAT HELPED YOUR CHILD THRIVE IN HIS OR HER FIRST YEAR?

This was a question that Kathleen Marino from Marblehead, Massachusetts, asked to the experts on IsoDicentric 15 and related disorders—other PARENTS who participate in the IDEAS listserve. This is the list of recommendations from our parent experts!

1. Sensory Integration

Children with idic(15) and related disorders often have difficulty with sensory processing, and this can be evident as soon as the first year of life. One of the most helpful books describing sensory integration is **The Out-Of-Sync Child**, by Carol Stock Kranowitz and Larry B. Silver. Addressing your child's sensory needs is the number one recommendation of parents raising a child with idic(15).

2. Water Play/Swimming

Swimming and water play provide a lot of sensory input to your child and are wonderful, fun activities that you can do together! Parents note that these activities help their child's arousal level, muscle development, appetite, and are just good plain fun!

3. Involve a Physical Therapist*

A physical therapist (PT) can help assess and make recommendations regarding your child's gross motor development. There are a lot of gross motor milestones in the first year (holding up the head, rolling, sitting, standing, cruising, and walking). A PT can help identify any delays that may be present, and provide suggestions of activities you can do with your child throughout the day to help build their gross motor skills.

4. Involve an Occupational Therapist*

An occupational therapist (OT) can help assess and make recommendations regarding your child's fine motor development and sensory integration needs. One Mom wrote "a real weakness for my 7 year old is her fine motor skills. I wish I had concentrated more on this when she was younger."

5. Involve a Speech & Language Therapist*

A speech and language therapist (SLP) can help assess and make recommendations regarding your child's early communication skills as well as any feeding/chewing/swallowing issues you may have in the first year.

6. Music & Song

Many children with idic(15) and related disorders really love music and parents report that music and song is helpful for gaining and maintaining their child's attention. It is calming for children as well. Children learn language through song and some children with idic(15) seem to pick up on their favorite melodies and can hum tunes before they can speak.

7. Physical

Demonstrations of Love

Our children, like all children, need to feel loved. However, they sometimes don't pick up on subtle cues the way typical kids do. Make your demonstrations of love BIG and FUN and REGULAR. It's good for them, and good for you too!

8. Exposure to Typical Children

Exposure to typical siblings or other typically-developing age mates is another top 10 tip—seeing them do things is a great motivator.

9. Talk, Talk, Talk

The stimulation parents and other caregivers provide in the first three years sets the stage for communication skills that will last a lifetime. One mom described it as "getting right up in her face every day with talking & labeling what I was doing (when diapering her, bathing her, dressing her etc)."

10. Develop Predictable Daily Routines

Keep things as predictable as possible for the most part—meals, naps, bath time, bedtime routines, etc. A daily routine provides a consistent, predictable sequence of events that gives young children a sense of familiarity and control over what happens in their day. Parents of older children report that a predictable daily routine is something that is still important for their children.

* Physical, Occupational, and Speech/Language therapy services can be accessed through your community's early intervention program or sometimes through private health insurance.

Making the Most of Early Intervention

KADI LUCHSINGER

is a Physical Therapist and mother to Ethan, 3, interstitial duplication of chromosome 15

As both a professional and parent, Kadi shares her experience and recommendations for families to make the most of the early intervention experience



EARLY INTERVENTION (EI) HAS BEEN AN INTERESTING EXPERIENCE FOR US. Prior to having Ethan, I worked as a physical therapist in EI. So my journey began before I ever realized it. Ethan, now 3, was our first child. I had him evaluated at 6 months of age, as he wasn't meeting his motor milestones. Being on both sides of EI, I feel like I can offer some words of advice.

There are some real keys to making the most of EI. First, it is so important to find quality therapists. I can't tell you how many therapists we have been through who didn't "make the cut". Your therapists should be knowledgeable and dynamic, while providing you with handouts and learning materials. EI is really a learning time for the family. The parents are still the ones who provide the bulk of the therapy, as the therapists are in for such a short time. I found it helpful to have a binder with handouts and things to work on, which was my homework! You can see such a difference in children whose parents carry over therapy with their children. Please keep in mind that we had lots of time to just play and let Ethan be a kid!

I insisted that Ethan have PT, OT, Speech, and a teacher, as he qualified for all of these. Some

people argue that this is confusing for the child, as they have so many people coming in and out, but I disagree. This is the time where you need all of the experts in their discipline educating you on where to put your focus. This also helped me to see what style of therapist worked well for Ethan, meaning aggressive vs. passive, or silly vs serious, etc. That helped me in weeding out a lot of therapists who were either under qualified, in my opinion, or had a different style that didn't work well for Ethan. Then, when issues came up, Ethan had already bonded with that therapist and we weren't calling in a new person. On a side note, therapists should ALWAYS wash their hands when entering your home and all equipment brought in should be clean!

Another issue is co-visits. I am not a real fan of co-visits except under rare circumstances. I feel like it is confusing for the children to have multiple people working with the kids at the same time. I also found that some therapists who are not as dynamic will insist on co-visits, as they rely on the other therapist to direct all of the session. I also felt that visits were best provided in the house at a young age. Now that Ethan is older we do some visits outside of

the home, where he has access to large equipment for therapy.

I was most surprised about the lack of information that service coordinators provide to families. In our case, they never offered anything but the bare minimum. Thank goodness I worked in EI, so I knew what was available to me. I knew that I was entitled to respite, aquatics, and playgroups, which were never offered to me and thus they were added. EI should cover equipment needs as well. I had EI pay for Ethan's huggy vest, feeding supplies, and PECS system. I also requested a social worker, who really advocated for our family. She told us about various community resources that we never knew existed. For example, she found funding for a swing set, slide, tricycle, sandbox, sensory table, and many other items to help Ethan. She also connected me with families in our school district who had already been through the process. I would strongly suggest getting a social worker.

Finally, but most importantly, EI is a time to learn and plan for school. I started touring preschools for Ethan when he was 9 months old, thanks to our social worker. I found "the one" for him and had him on the waiting list on his first birthday. I made frequent visits to the school and made sure that they all knew Ethan. I am happy to report that Ethan will be going to the school next year. They had 7

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Making the Most of Early Intervention

KADI LUCHSINGER

openings and over 100 kids on the waiting list! I would send them to school as early as possible (age 2), as Ethan has made so much progress by being with his peers.

Early intervention is a whirlwind, but so beneficial for the children. I equate it to being in college for 3 years. You are constantly learning and taking classes from the therapists. I did find it exhausting and overwhelming at times, but the end result is so worth it. I have made life long friends with Ethan's therapists and I have a core group of people that are always in his corner. EI can be great, but it takes work. The key is the team manager, who is you! I wish you all the best of luck and if you need any further information please let me know.

KADI CAN BE REACHED AT:

tkeluch@aol.com

Working with an Educational Advocate

HEATHER & RON BRUCE

have three daughters, including Anna, age 4 (idic15)

Heather and Ron encountered problems with Anna's early childhood special education placement and sought the assistance of an educational advocate to resolve these problems.

The transition from early intervention to preschool was not a process that Ron and I were too excited about. We were very happy with our early intervention experience where we received basically any service that we requested in our home. In addition, we had heard plenty of horror stories about dealing with school systems.

Luckily, we happened upon a wonderful out-of-district private preschool that our district actually agreed to pay for. So, the transition

proved to be quite painless.

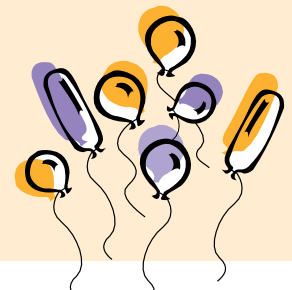
However, the honeymoon was over when, at the end of the school year, we were informed that the school would be closing due to funding loss. What followed would line up more with the nightmare experiences we had heard about and dreaded!

Ron and I visited quite a few preschools in our district, but cited safety concerns with most—or even neglect of the more profoundly affected children in others. We were placed on the

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Happy Birthday to these special kids:

• Alyssa L	06/02/93	• Jonah C	06/24/99	• Jessica M	07/18/98	• Charlotte J	08/28/03	• Jeremy L	09/17/88
• Kathleen M	06/04/93	• Klara H	06/24/92	• Clare T	07/25/80	• Shannon N	08/30/94	• Conor M	09/19/96
• Jack R	06/07/02	• Douglas M	06/26/03	• Colin O	07/30/98	• Kacey T	08/30/93	• Brandon J	09/24/97
• Angel S	06/09/93	• Sarah H	06/26/93	• Gavin S	07/31/98	• Brenda M	09/02/89	• Sarah L	09/23/95
• Chris L	06/11/90	• Mikaela O	06/28/00	• Emily M	07/31/80	• Cheyenne D	09/08/92	• Evan	09/28/94
• Tori M	06/12/92	• Alex S	06/29/96	• Rachel K	08/04/86	• Bente S	09/09/97	• Stephen "Chase" G	09/30/99
• Heather W	06/16/92	• Kyle B	07/01/84	• Devon J	08/07/93	• Elana K	09/09/88	• Cara V	09/30/92
• Andrew B	06/18/99	• Travis R	07/02/98	• Jesse M	08/12/94	• Dante R	09/10/98		
• Richard H	06/18/96	• Alexis M	07/05/94	• Eli C	08/14/92	• Thomas N	09/10/93		
• James M	06/18/96	• Samuel V	07/09/95	• Austin V	08/15/96	• James S	09/11/93		
• Yuri P	06/20/75	• Michael B	07/09/84	• Spencer G	08/15/94	• Waawiiya W	09/11/93		
• Cheyenne J	06/21/96	• Clare G	07/09/82	• Patrick S	08/16/98	• Julia W	09/12/96		
• Krystyn B	06/22/98	• Lauren C	07/11/00	• Carly P	08/16/93	• Raquel L	09/14/00		
• Trevor B	06/23/94	• Andrew H	07/11/89	• Sarah D	08/23/98	• Rachel M	09/14/94		
• Grace L	06/24/03	• Erica A	07/12/86	• Colt C	08/24/93	• Breanna E	09/15/95		



waiting list of a private preschool and assured she would probably be placed pretty quickly.

In the mean time, we attempted to use home-based services through the school district. We had problems with the therapists not showing up and decided we should try again to find a school for Anna. We decided on one of the preschools that we had already observed and were assured the safety concerns were corrected.

When I arrived to take Anna for her first day, nothing had changed. I took her back home and immediately began attempts to reach the supervisor of special education. When none of our calls were returned, we knew that we needed some help. We called our state ARC office and were given the number for an advocate. Her

services were free to us - paid for by the state. She attended a meeting with the director of special education, supervisor of special education, principal of the school, the classroom teacher, the school district's maintenance safety employee, and Ron and I. We felt that her presence alone worked to our advantage. The director and supervisor were definitely familiar with her. We felt they took us more seriously with the advocate by our side. We ended up finding a school that we had never been informed of by the school district.

While we don't feel that the advocate did quite as much intervening as she should, or could have during the meeting, we are thankful that we had someone there with us who knew the laws forward and backward to be sure

we were treated fairly. Our experience with the advocate has prompted me to look into taking the necessary classes to become an advocate.

We have tried to find the positive from this experience and have decided that while it was unfortunate that Anna lost so many months of services, we have learned early that we don't have to be alone when dealing with school districts. An advocate can be a helpful tool in coming to a compromise with opinion differences we will definitely not hesitate to use in the future!

VISIT

www.thearc.org

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Perspectives on Inclusion

Julia: A highly inclusive 1st grade

I have to say that John and I were apprehensive about sending Julia off to a big elementary school, but our district is 100% in favor of inclusion. There are no PDD classrooms. Children with special needs are included as much as possible. Out of the 30 possible hours each week that Julia could be included with her peers, she is with them for 19 hours. The 11 hours that she is not included is when she receives her therapies, 1-on-1 instruction for math and reading, and lunchtime.

In order for Julia to be successfully included with her typical 1st grade peers, many modifications have been made to her program. Typical first graders at Julia's elementary school have music only once a week, but Julia's team decided that the Enrichment class (a class that involves critical thinking) was not going to be beneficial to Julia, so she attends an extra music class in its place. Lucky Julia! She, like many of our children, loves music and also adores her music teacher. Julia's team decided that the lunchroom would be much too

Inclusion of children with disabilities in the general education environment is an educational policy that has gained some momentum with the federal No Child Left Behind law. The following article provides perspectives from two parents regarding the inclusion experiences of their children. Julia and Corrina are both first grade students with idic(15).

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Perspectives on Inclusion

loud and over-stimulating for her, so she has her lunch in a small room with a lunch buddy (a child from her classroom). During lunch, her assistant works with Julia on conversation skills. Scripts have been written to promote conversation between Julia and her lunch buddy. To assist with transitions, Julia has a daily strip schedule that shows her what she will be doing during that day. If she becomes inattentive/disruptive in the classroom, her assistant will take Julia for a sensory break. Sometimes all that she needs is a walk. At other times, they go into the OT room and swing. Occasionally she will wear a weighted vest. For the short time that Julia is in the classroom during reading and math, if modifications cannot be made for Julia to participate, she sits in the back of the room with her assistant and works on the skills that she is learning in her 1-on-1 reading and math instructions.

Julia participates in the science/social studies lesson but with modifications. She recently learned about how maple syrup is made. Her classmates wrote stories and drew pictures about how to make maple syrup. Since Julia cannot write or draw, her assistant put together a little book about the making of syrup, complete with pictures of Julia. After looking at the pictures, Julia supplied the words for the story. Her assistant used the "Writing with Symbols" program to type Julia's words and then pasted them

into the book. Since coloring is difficult for Julia, other arts and crafts supplies are used. When her class studied birds, Julia glued feathers and bird seed onto her picture rather than coloring the birds.

Julia participates in her class morning meeting and most often, when called upon to answer a question, she is correct! When Julia is in the classroom during part of the reading lesson, she listens along as the children or teacher read. When asked questions about what has been read, she again, is most often correct. Her classmates are so proud of her when she does answer correctly that they have been known to cheer for her!

Julia is learning to read. She currently has a sight word vocabulary of over 50 words. I can't tell you how thrilling it is to see Julia read!

Julia struggles with 1-to-1 correspondence. She has, however, recently, independently counted items by dropping them into a bowl one at a time. Baby steps, but progress.

About a month ago, Julia buttoned a button! Her OT was absolutely thrilled as was I. We don't take anything for granted. Every gain is huge in our lives.

Her peers accept Julia. I was recently at the school for a conference, and saw Julia walking hand in hand with her lunch buddy. At recess recently, Julia played Duck Duck Goose with at least 20 other

children! The gains she has made in the area of socialization are the most heartwarming to me because just a year ago, Julia was very apprehensive about being around her peers. She's much more comfortable with them now.

Julia has been on two field trips with her class and participated in a Christmas concert. All 3 events went exceptionally well.

Julia's experience in an inclusionary setting has been very positive thus far. I stay involved with what is going on at the school by having monthly meetings with her entire team, and weekly conferences with her case manager, teacher, and assistant. I occasionally also observe Julia during her therapies and 1-on-1 instruction. I think it is very important to stay involved. We, as parents, are crucial members of our child's educational

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team! If anyone would like to find out more about Julia's school experience, feel free to email me at:

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Perspectives on Inclusion

Corrina: A self-contained classroom for 1st grade

Corrina's classroom placement is in a self-contained classroom of 8 students with autism spectrum disorders. Of the 30 hours each week that Corrina is in school, she is included with a typical first grade class for roughly 3 hours. Her inclusion opportunities include library time (30 minutes/week), PE (30 minutes per week), afternoon choosing centers (30 minutes twice a week), and art class (60 minutes per week). Because Corrina's inclusion time has been so limited, it is challenging to build peer relationships with the typical first graders in the classroom.

At the beginning of the year, I went to the first grade classroom and did a presentation to the kids about Corrina. I told them that Corrina's brain was different than theirs, and that she can only think of one thing at a time. The students were interested in the idea of only being able to think of one thing at a time and we discussed how they might do things differently in their daily lives if their brains could only think of one thing at a time. Using



this image, I explained to them that Corrina cannot speak and it is hard for

her to pay attention during class. This was very easy for the children to relate to, having been given a chance to talk about what it would be like to only be able to think about one thing at a time. I showed them examples of Corrina's PECS system, and then we talked about the things Corrina likes to do that are just like what they like to do (swimming, watching TV, going to the park, eating pizza, etc). Overall, I think that this 45 minute introduction to Corrina really made it much easier for the typical kids to understand and relate to Corrina's challenges.

One of the typical first graders volunteers each week to be Corrina's buddy. When she joins them for library or afternoon choosing centers, the volunteer interacts with Corrina using her picture system. Corrina's para-educator often provides something that Corrina likes to her peer buddy. Corrina has become very consistent at approaching the peer with her communication book, gaining the peer's attention and requesting the item using her book. We are now expanding this goal so that Corrina's peer buddy will read

books and share materials with Corrina during her inclusion time. You can see that some of the children really like being Corrina's buddy!

I volunteer each week for the one hour art class and I think that this has been helpful in building the children's acceptance and interest in Corrina. I'm just another volunteer mom (there are many in the school), which makes Corrina just like everyone else. Unfortunately it is harder for Corrina to pay attention to her art project when I'm in the room, but the benefits in terms of getting to know her peers, answer their questions, and show them that Corrina's mom is involved in their class just like their moms is worth the cost in terms of Corrina's distractibility.

As far as Corrina's academics go, we believe that at this time her needs are better served in the self contained classroom where there are more opportunities for 1-to-1 learning, and the sensory environment is better controlled. However, we highly value Corrina's inclusion opportunities. Our school district is shifting the way that special education services are delivered to a much more inclusive model, so Corrina will likely have more inclusion time than she does now. Having learned a lot about how to make inclusion successful for her during her kindergarten and first grade years, we feel confident that Corrina will continue to thrive in her school setting.

Introducing our new look...



Transition Trials

CHARLIE & LAURIE BRADY

Parents of two children:

Mackenzie, age 8, & Michael, age 19, who is diagnosed with idic(15)

We have been transitioning since Michael was 18 hours old and stopped breathing 9 times. We spent the first week of his life in the ICU ward at St. John’s Hospital in St. Louis County where we all live. From that day forward we transition on an hourly basis.

When asked to share some of our experiences with transition at first we were hesitant. We were worried that our experiences might scare all the parents with children younger than Michael, which is most of the group. But the things in our lives are not always happy and positive, so I decided to share with you some of our transitions.

The dictionary defines transition as a passage from one state to another, or change. Michael was born in 1984. He was born with the use of forceps and broke Laurie’s tailbone. He had a big bruise on his head but APG scores were good. Later that night he stopped breathing several times. So Laurie, at 19, and I, at 22, lived in the hospital ICU for a week while they tried to figure out what had happened. Trauma from birth was the diagnosis. So we took our new baby home to our one bedroom apartment and he slept in a borrowed bassinet at the foot of our bed.

The next 19 years of our family life were characterized by constant change. From 9 months of age Michael received all kinds of therapies and diagnoses, ranging from CP to Autism to, at age 5, Inverted Duplication of Chromosome 15. At the time there were only 3 articles on Chromosome 15 duplications or inversions in the world. At this time we had an intake with the Special School District and he experienced some small achievements in the language area. Then at age 7 he had his first seizure. With medicine, he was seizure-free for several months. We took him off the medicine and he was seizure-free till age 10, when the seizures returned with a vengeance.

Since then we have been on every medicine approved and not approved for seizures. I think the number of medicines is in the low 30s. We tried the Ketogenic diet. I was Master Keno Cook and even devised a way for him to have Thanksgiving Dinner that year. At 14 Michael underwent 2 brain surgeries to separate the two sides of his brain. We knew we would have to re-teach his speech, walking, and every skill he had learned since he was born. The surgery has helped a little with the

hard seizures. At 15 Michael had a VNS (Vagal Nerve Stimulator) implant. In addition he has had his tonsils and adenoids out to make more room for him to breathe and had procedures to check his bone density, as he has broken his leg twice and his arm once.

A very bright spot in Michael's life is his sister Mackenzie. They have a typical brother/sister relationship. She gets mad when he goes into her room and he gets mad when she plays with one of his toys. Yet on a different level, Mackenzie knows when Michael is having a subtle seizure, the ones only Mom and Dad can tell. She always remembers to ask for a second “special prize” like if she is at the dentist and gets a coloring book, she asks for a second for “my brother Michael.” Michael asks where she is when she is at Brownies or dance. I remember Michael lying on the living room floor covered up with his weighted blanket, and Mackenzie laying on him on a pillow both watching Saturday morning cartoons.

So now after 5 surgeries, 30 or so doctors, several dozen medicines, several vitamin supplements, special diets, 5 official diagnoses at school, 16 IEPs, 12 different teachers, and 60 or so therapists, we come to our last year of school. What do we do with him for the next 45 to 60 years? As you can see, we have been transitioning on an hourly basis for 19 years. What we have now at school is

When we walk to the edge
of all the light
we have known and
we take a step into
the darkness of the unknown,
we must believe one of two
things will happen...
there will be something solid
to stand on,
or we will be taught to fly.

—S. MARTIN EDGES

what Michael will need forever, but it is not out there. He needs constant supervision and we have developed a transition plan in his last 3 IEPs with our thoughts about what would be best for Michael after school ends. But there is not a single program out there that comes close.

We sit here in 2004 and our baby is soon to be 20. We are lost. This is the very sad side I did not want to talk about, but here goes. For us, our transition goes nowhere. We live each and every day simply taking care of the here and now needs. We have done and tried it all. Michael will never marry, drive, or have a family of his own. It appears that Laurie and I will transition Michael back to where he started, in his room with us in our house. The realistic truth for our transition is that there is and will not be one.

So our transition story does not

yet have a happy ending, but we would like to share a vision of our ideal happy ending anyway. Michael's perfect transition setting would be a caring and loving day program that mirrored his current school setting. He

would have transportation to and from the location. He would get one-on-one care from a professional trained in autism, epilepsy, and behavior modification. He would take part in group and individual home skill classes as well as individual and group therapies. Trips into the community for experience learning and enrichment would be organized like field trips at other schools. He would continue to have goals for learning and also life enriching opportunities. He would find joy in his life as each day he grew toward becoming 100% of what Michael can be.

In my search for transition options I have collected a lot of information that I hope can help other families in their quest to bring out the best their child can achieve and make their life special. In the shared files section of the Yahoo Groups site, you can find 15 pages of references and resources.

IDEAS

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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:

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Jane True, Editor

Lin Neighbors, Design & Layout

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The Changing Life of Clare

CLARE

is a 23-year-old woman who has idic(15).

She has been living away at her college for 4 months.

Many thanks are due her teacher Lisa for helping with this interview.

“I have excellent memories about my life.”

When I was little some things were easy for me, like riding my tricycle. Some things were hard for me to do, like learning to play with my toys and stuff. Some of my favorite toys were Cookie Monster, Bert and Ernie, and the Care Bears. Some of my other favorite toys when I was little were my Legos and Lincoln Logs. I really liked playing with my brother Tyler. I also remember my finger puppet Cookie Monster. It got flushed down the toilet. I said, “Boo hoo-how sad!”

I remember my therapists Fran, Melanie, and Marge. I talked a lot to them—they were really nice. I rode there in the red station wagon. With my therapist Fran when I was a little girl (pre-school) I sang:

*“ I like to walk with you
I like to talk with you
Share my blocks with you
'Cause you're my friend.”*

I cut my lip open on the bookshelf at school and had to get stitches.

Some of the really important people in my life have been my Mom, my Dad, my Papa Ray and Mama Clare, and my other Grandma. I would go to the farm to visit my Grandma Mahala. I played around with the tractor-the cows and horses stunk.

I feel better that I have brothers and my friend Marie. It makes me very happy when my brother Toby teases me and runs around. He hides under my bed to scare me but it makes me laugh instead. Tyler plays special songs for me on the piano and the viola. I like the viola the best. It makes me have tears in my eyes.

One of my favorite teachers was Mrs. Gaskill who noticed that my favorite color was black. Mrs. Crosby taught me to read—my grandparents felt very happy about that. Today I feel very excited about myself and very proud that I can read.

I liked being in the choir in middle school. I enjoyed high school a lot. In high school I sang the National Anthem at the girls' soccer game. I was trying to earn my “N” letter. My life was very special that day. I got a letter jacket for choir—that was the best part about high school. I liked typing on the computer with Mrs. Pontz. She was awesome.

Skiing is fun. Kathy was one of my ski instructors. Allan was my teacher for skiing too. I had a “wedgie” ski toy on my skis so I wouldn't fall down a lot. It isn't easy to get off the chair lift. I like to ski in Whistler with my friend Mary and at Snow Creek for Special Olympics with the Kansas City Ski Team and with all the other kids. I love



Snowbird with my brothers Toby and Tyler.

Before I came to college I had a job at Certified Safety Manufacturing. I liked punching out boxes. I miss my friends there and I miss my boss Pam Gerson. She wore neat clothes, mostly jeans, and was very funny.

Everything about my life is changing. Now I am at college. I have my own room with posters of Miss Piggy and Elmo. I like my room and the CD player and the television. It is fun living with a bunch of women for a change instead of brothers. I can live my life better. I feel pretty good about being in college. Everything is so neat. I feel proud of myself for doing the best I can do. I would like to learn new things at college about nature, plants, and other stuff.

In the future I might like to work in the hospital.

My favorite song on the radio doesn't change. It is “My Girl” 'cause “I've got sunshine on a cloudy day...When it's cold outside I've got the month of May...”

Brain GABA_A Receptor Abnormalities in Children with Chromosome 15q11-13 Mutations

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What is GABA?

GABA stands for Gamma-Amino Butyric Acid, and it is a neurotransmitter in the brain. Neurotransmitters are used by nerve cells to communicate with other nerve cells. When GABA is released from a nerve cell, it can communicate with another neighboring nerve cell by binding to a protein called the GABA_A receptor, which is present on the surface of the neighboring nerve cell. When GABA communicates other nerve cells, it causes them not to respond to other stimulatory signals in brain. Thus, GABA is considered an inhibitory neurotransmitter. The overall effect of GABA and GABA_A receptors is to stabilize the activity of nerve cells.

Why do we think it is important to study GABA_A receptors in children with idic(15) and related disorders?

Children with idic(15) and related disorders can experience cognitive disabilities, autism and seizures. On Chromosome 15, in the region most commonly duplicated in idic(15) and related disorders, there are 3 GABA receptor genes. Impaired GABA function, especially GABA_A receptor function, has been proposed to play an important role in the pathophysiology of numerous

neurodevelopmental and genetic disorders including autism and Angelman syndrome (Wagstaff 1991, Cook 1997). GABA also plays an important role in seizures. Because GABA inhibits neurons from firing, and seizures are caused by inappropriate or unregulated firing of nerve cells, increasing GABA activity through its receptors can cause the system to stabilize and decrease seizures. A lot of seizure medications work by increasing GABA activity or responsiveness (some have GABA in their names—ViGABAtrin, GABAptentin etc). One might guess that having more GABA receptors should stabilize the system more (since in theory, they would be able to respond better to GABA), but it is likely that the balance needs to be maintained and the extra receptors from this extra chromosome 15 may confuse the cells. It is also possible that there are specific regions of brain which contain these abnormal number of GABA_A receptor, which could be responsible for the mental retardation, seizures and autistic features in these children. A similar study in Angelman syndrome (a syndrome with similar chromosome 15 abnormalities) individuals, showed abnormalities of brain GABA_A receptors (Holopainen, 2001). No one has studied the

GABA_A receptors in the brains of idic(15) individuals. We think that it is important to study and learn more about the abnormalities of GABA_A receptors in these children, in order to develop new treatment strategies.

What are we studying?

The purpose of this study is to understand how changes in the genes of people with abnormalities of chromosome 15q11-13 may cause changes in GABA_A receptors. Another purpose of the study is to understand how changes in the GABA_A receptors are related to cognitive disabilities, autism and epilepsy.

Who are we studying?

We are hoping to recruit twenty-five subjects (aged 2-18 years) with autism and chromosome 15q11-13 abnormalities for this study. Our study is open to any family with a family member who has a chromosome 15q11-13 abnormality, regardless of where they live. However, since we only have pilot funds at this time we cannot pay for travel. When we have more data, we can write a grant that could support travel.

How can families learn more and get involved?

Families who wish to learn more about this study may contact me by email at dchugani@pet.wayne.edu or by phone at 313-993-3847.

IDEAS

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

2004 Meeting of European Families Raising Children with idic(15)

DATE: September 4, 2004

PLACE: Bersenbrück, Northern Germany close to Hannover, Bremen, Hamburg, Osnabrück

CONTACT: Christian Reiter

lissypapa@yahoo.com

Third International Conference on Isodicentric 15

DATE: Save the Date of June 23 - 25, 2005

PLACE: Chicago, Illinois

CONTACT: If you have any topics that you would like to have addressed at the conference, or if you'd like to get involved with conference planning, contact Jane True, conference planning committee chair, at 816.453.4862

jtrue@kc.rr.com