

THE BADDOUR CENTER

EDUCATION & RESEARCH NEWSLETTER

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The Quarterly Update

Welcome to the Dog Days of Summer! We hope you are taking care of yourself in these extreme temperatures. This quarter, we have a lot of information to share. With regard to E&R initiatives, we give you an update on the 3G Network, our program that emphasizes good deeds through positive reinforcement and volunteerism. Lauren Flegle describes a project using video self-modeling to teach social skills. Brooke Walters takes the lead in giving some background on our research on parental advocacy. Patricia Ofili gives a good overview of the Dr. Phil George Spring Symposium on Seizure Disorders, which was led by Dr. Georgia Montouris of Boston Medical Center, while Samantha Wood describes our in-house training on Autism and Shannon Hill shares news from the annual meeting of the American Association on Intellectual and Development Disabilities.

Additionally, we have an update on how the PCP meetings are going from Case Manager Ashley Price. Carly Gardner interviewed the ever-popular AVS staff member John Burton for the Meet and Greet column, while Corinn Johnson writes about Senatobia House resident Andy, who was nice enough to share some travel stories with us. We introduce a new column called "Innovative Concepts," in which we keep an eye on cool things going on around the country to share with our readers.

We hope you enjoy this edition of the E&R newsletter. Please drop us a line anytime with suggestions or comments. 

Inside This Issue

- Video Self-Modeling....p. 2*
- Innovative Concepts....p. 2*
- AAIDD Conference....p.3*
- Autism Trainingp.4*
- John Burton....p.5*
- Fall Symposium Information....p. 5*
- Resident Report: Andy....p.6*
- PCP Update....p.7*
- Seizure Disorders Workshop....p.9*
- Journal Scan: Parental Advocacy....p.11*
- 3G Network Update....p.13*
- Accomplishments....p.13*
- Book Report: Dolphins!....p.13*

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Research Corner: Video Self-Modeling

Lauren Flegle, Intern
Education & Research Division


As always, exciting things are happening in the Education and Research division of The Baddour Center. This time, Denny House is in on the action. Since October 2009, the ladies of the Denny House have been meeting almost every week to spend time socializing, working together, and dealing with problems in the house. As the E&R intern assigned to this house, I have been in charge of “Social Club” since its conception and now I am pleased to be joined by another summer intern named Samantha Wood.

In early May, Sam and I sat down with all the Denny girls and talked about the social skills they thought they were good at and those they thought they could improve on. Using this conversation and our own observations, we have identified target social skills for each of the girls that we are excited to teach using an up-and-coming technique in the psychological world called Video Self Modeling (VSM).

Video modeling is a relatively new intervention that involves using models who demonstrate the desired behavior on a videotape that is shown to the person receiving the intervention (Raynor, Denholm, Sigafoos, 2008). Measurements of the target behaviors are taken both before and after the intervention, and it is hoped that the outcome measures demonstrate either an increase in positive behaviors or a decrease in negative, depending on the goal of a given intervention.


There are two different ways of doing video modeling: feedforward and positive self-review. Feedforward techniques involve modeling tasks that the person has not already used or modeling behavior in settings where a behavior has not been used before. Positive self-review has to do with increasing positive behaviors that the person already knows but may not use enough. We will be using the positive self-review approach with the girls in the Denny House, as the goal is to increase their use of positive social behaviors.

In addition to helping the ladies here develop and use positive social behaviors, the Education and Research division hopes that this project will add some much needed information to the body of literature pertaining to VSM. Currently, VSM has been studied almost exclusively with children who have an autism spectrum disorder (Bellini & Akullian, 2007). However, the research suggests that success is likely with other populations as well, because certain traits of autism spectrum disorders targeted by VSM are common to all developmental disabilities.

We are really excited about this project and the girls are already having a great time making their videotapes. Video self-modeling interventions are just another way that The Baddour Center is striving to improve the quality of life through the social interactions of our residents. 

Innovative Concepts: Shepherds College

Shannon Hill, Director
Education & Research Division

Shepherds College is a three-year private post-secondary educational program for people with intellectual disabilities, located in Union Grove, Wisconsin. Students receive training in independent living skills, functional academics, social/emotional skills, and spiritual life, as well as vocational training options in the culinary arts or horticulture. Students live in campus dormitories with learning and social activities planned during the week and on weekends. For more information, see www.shepherdscollege.org. 

Conference Notes


Shannon Hill, Division Director
Education and Research Division

American Association on Intellectual and Developmental Disabilities

The American Association on Intellectual and Developmental Disabilities (AAIDD) met in Providence in June for their annual meeting. One topic that received a lot of focus is the release of the 11th edition of the AAIDD definition manual. Historically, the organization has led the evolution of the nomenclature and definition of Intellectual Disabilities in America. Their work, which has been updated and expanded eleven times since the original 1921 definition, is widely incorporated into state and federal legislation and funding formulas. The definition plays a particularly important role in the lives of many people, especially those whose IQs and adaptive skills lie at the top end of the spectrum, between Borderline Intellectual Functioning and Mild Intellectual Disability. Service eligibility, school accommodations, and financial subsidies can all be affected, depending on the language of this definition and how government agencies choose to interpret it.

For almost 20 years, AAIDD has been trying to create a change in the way we think about intellectual disabilities through its authoritative definition manuals. The ninth edition (1992) manual incorporated major philosophical changes to the way people generally think about intellectual disability, and even what a definition is supposed to do. In addition to the traditional “tweaking” of cut-off scores and a more refined definition of the concept of “adaptive behavior,” the authors introduced the idea that people should not be classified in terms of their levels of disability (i.e., mild, moderate, severe, and profound), but instead should be described in terms of the levels of supports they require (i.e., intermittent, limited, extensive, and pervasive). This was an act designed to shift the focus from a person’s limitations to what he or she needs to be successful. Following criticism, the 10th edition (2002) manual offered suggestions for measuring those needs and focused more on how this new way of thinking would be incorporated into service delivery. The clarifications were based on their own initiative to develop a system of assessment that would guide professionals through the process of utilizing the new way of thinking. This system was published soon after, and has garnered a huge following. Some states now require it in order to obtain funding.

Still, the supports paradigm is not widely accepted by the field. Change in the way we think is always hard, but this change also required a lot of rewriting of rules, regulations, and legislation. Also, switching over to the new assessment system could be more difficult for smaller systems, as utilizing it successfully depends upon going through specialized training, and the systems is expensive (as assessment products usually are). Additionally, the scientific community had difficulty embracing the new supports classification system because the authors seemed to pull it out of the air; they were being asked to abandon a system that had years of scientific validation for a very complex one that had none.

The 11th edition is meant to retain the philosophy of the 9th and 10th, while addressing some of the concerns of its critics. The language is officially changed from “mental retardation” to “intellectual disability.” The classification of needed supports is more general and person-centered, though it is given a different name. There seems to be increased emphasis on the understanding that there are differences between a comprehensive definition and an operational one, and permission seems to be “granted” to professionals to use the simpler, operational definition for eligibility and classification purposes, while the comprehensive version is to be used for developing those individualized supports (e.g., person-centered plans). Additionally, special attention is paid to people who have higher IQs, making this one of the broader, more inclusive definitions, which will provide access to services and supports to more people. 

Training Report

Samantha Wood, Intern
Education & Research Division

This quarter's in-service training was titled *Living in the World of Autism*. It was taught by Education and Research staff Corinn Johnson and Carly Gardner. The purpose was to inform Baddour Center staff on the basic symptoms of Autism, what Autism feels like to the individual, and tips on how to identify and help residents. While the Baddour Center does not have but a few residents with a diagnosis of Autism, other residents may often display Autistic-like behaviors.

At the beginning of the workshop, a small piece of sandpaper was handed out to each attendant; they were instructed to put it closely on their skin and then later comment on how it felt. Some staff commented that it did not feel so great after a few minutes! Others had no complaints. Just like us, for an individual with Autism, sensory receptors can be different. They may feel a slight stimulation as being intolerable. This activity was a great example of the difference between how individuals with Autism view the world from you and me.


What It Is:

Autism has been a rather interesting and highly studied research subject in recent years. To be clinically diagnosed with Autism, an individual must show deficits within three core areas: socially, communicative, and repetitive/restricting behaviors. Although there has been much debate, unfortunately a cause for Autism has not been officially found. The cause has been attributed to a number of things over the years, such as vaccinations, genetics, and even chemicals. No matter the cause, helping people reach their greatest potential is the overall goal. Helping those with Autism include treatments that use psychopharmacology and behaviorally based interventions.

How it Affects Individuals and What We Can Do:

Autism is a peculiar disorder and causes individuals to depict the world in specific ways. Those with Autism seem to be very "picture oriented". This could be a result from verbal and nonverbal processing deficits, or even difficulties in using logical thinking skills. To compensate for this, we should use sign language or hand gestures to prompt behaviors. Using pictures to explain a task instead of wordy sentences can make a huge impact on how an autistic individual processes information. Also, using simple, concrete words can facilitate better results than speaking in large sentences.

Not only is communication altered, so are emotions. Individuals with Autism can possess flat affect- in which they appear to show very little emotion and social interests. This does not mean they cannot experience emotion, but rather have difficulties expressing it. Being sensitive to the emotions of people with Autism is important, as well as observing the environment to see all possible causes for behavior change. Another characteristic is very specific behaviors. Some affected with Autism show repetitive interests or behaviors and become fixated only on that subject.

As Baddour staff, we should focus on identifying and understanding Autistic characteristics, therefore, allowing the information to effect how we communicate with residents. Having appropriate expectations from residents and attempting to understand their view can make all the difference! 

Meet and Greet: John Burton

Carly Gardner, Research Assistant
Education and Research Division

This morning, like every morning for the last 6 years, John Burton woke looking forward to this day working at the Baddour Center. John began work at the Baddour Center in May 2004. After graduating from North Panola High School, his aunt, Caroline Caradine who also works at the Baddour Center encouraged him to become a part of the Baddour Family. He admits to being a little intimidated on his first day at the workshop but found that when he “was himself” the residents were very welcoming and friendly. From that time until May of 2007 he worked part-time, on an as-needed basis, in the Conwood workshop. In May of 2007 he was hired for a full-time general labor position in Fed EX. Finally, in August of 2007, John joined AVS as an assistant. Since then, he has become involved in Horticulture Therapy. John reported loving his work at the Baddour Center. He smiled and said, “I wouldn’t trade it for nothing’.”

In his free time John likes to sing. He winced shyly and referred to his singing as a “hidden talent.” While he sang in the choir at North Panola he does not currently sing publicly. He has not sung for a staff talent show but giggled as he recalled his performance as a Jamaican drummer. John also enjoys arranging flowers. Prior to his involvement with Horticulture Therapy he arranged primarily artificial flowers. He credits his learning about organic flowers and growing plants to the residents’ instruction. John describes himself as loud, although he says that few people at work see that side of him. As a member of a large family he says that he likes to be the center of attention, the entertainer. Recently, John has spent his time house training his tea-cup Chihuahua, Tinker Bell, the newest member of his family.

John offered some advice for those considering work at the Baddour Center. He says, “Don’t be afraid to be yourself.” When asked about what advice he has for the residents he thought for a moment and smiled as he said that he had none. He feels as though they were living as they should. John does feel that teaching the residents to be independent is important. Skills like personal care and cooking are among skills that should be taught to facilitate independence. The Baddour Center is blessed to have such a dedicated staff. His co-workers praised John’s work ethic and creativity, and residents were pleased to call him “friend”. ♡



John and Darren at work

Dr. Phil George 2010 Fall Symposium

Inclusive Faith Communities

with

Mark Crenshaw, Executive Director of the Interfaith Disability Network

A workshop for ministers, future ministers, and church leaders interested in nurturing the spiritual lives of people with intellectual disabilities. Please invite your pastors!

October 21, 2010 at The Baddour Center Chapel.

For information or registration: 662-366-6902 or skill@baddour.org

Resident Report

Andy's Travels

Corinn Johnson, Research Assistant
Education & Research Division


Our featured resident this quarter, Andy, can certainly be described as a travel extraordinaire. Andy has been a resident of the Baddour Center for a little over six years. During that time, Andy has been to exciting places in the continents of Africa and Australia. Andy took some time out of his traveling schedule to be interviewed for the newsletter.

In 2007 Andy's family went to Africa. While there, Andy spent time hunting wild-beasts with his dad. He also went bungee jumping into a gorge. Last, but certainly not least, Andy's family went on a safari and was able to see giraffes and lions in their natural habitat.

As exciting as Africa was, Andy described his Australian trip as, "even more fun." According to him, it took two different plane rides to get to their destination. First, his family traveled from Memphis to California, where they were able to spend some time at Disneyland before continuing on their journey. Next, they boarded a plane at 10:30 at night and many hours later, arrived in Australia. While they visited multiple areas in Australia, most of Andy's fun occurred in the cities of Sydney and Brisbane.

In Sydney, Andy ate a kangaroo burger for the first time. When asked what he thought of it, Andy said that it "tastes different than other burgers," and that he "liked kangaroo burgers better because they're thicker." Andy's family also took a boat to Fraser Island, where he and his family went snorkeling and took a rainforest tour. Fraser Island was described as "beautiful" by Andy, since he was able to see starfish, clownfish, and a variety of butterflies and birds. Andy's favorite part about Sydney was climbing the Sydney Harbour Bridge. According to Andy, it took about 3- and-a-half hours to climb the bridge and the view was wonderful.

In Brisbane, Andy got to see shows at the "Croc-aseum" and the Imax theatre, as well as ride a variety of roller coasters. His favorite rides were the Batwing and the Superman Escape. The Batwing was pretty scary because it shoots you straight up into the air. The Superman Escape is the longest roller coaster in Australia. Andy loved it so much that he rode it two times.

Also in Brisbane, Andy and his family visited the Australia Zoo. The Australia Zoo is known for being the home of Steve Irwin. At the front of the zoo there was even a bronze statue of Steve Irwin and the Irwin family. Andy loved seeing the bronze statue because he loved watching the Crocodile Hunter and he felt honored to be in a place the Crocodile Hunter loved. Andy described the zoo as having some different animals than what is seen in our zoos. They were able to see things such as Australian elephants and saltwater crocodiles. At the zoo Andy was able to hold both a big snake and a koala bear. Holding the koala was, "just like holding a teddy bear, he was so soft." Overall, Andy really enjoyed his trip. When asked what was his favorite part of the trip, he explained that he enjoyed being able to walk in Steve Irwin (AKA the Crocodile Hunter)'s footsteps. That was most definitely his favorite part. 



Andy with a friend from the
Australia Zoo.

PCP Update

Ashley Price, Case Manager
Programs & Residential Services Division

“I can express my viewpoints.”

“It feels more relaxed.”

“It feels wide open.”

“Very comfortable.”

These are all direct quotes from residents who have already experienced their Person Centered Planning (PCP) meeting. For those who are not familiar with PCP – it’s a new, more person centered approach to the annual staffings of yesteryear. The “old” process was definitely much quicker (we would typically move through 5-6 people daily), but they were also less personable. The “new” meetings are held on Tuesday, Wednesday, and Thursday mornings, beginning at 9:00 am and lasting 3 to 4 hours – per resident.

PCP meetings require a great deal of pre-planning and require more time to conduct; however, the end result is a plan that is very unique and exciting because the resident assisted in the design and assumes ownership and responsibility for its completion. And while this has been a learning process for everyone, there is one thing that’s been clear from the very beginning: Person-Centered Planning is one of the most exciting and important things to hit the Baddour Center in quite some time!

The driving force behind this movement is, of course, the residents. They are leading and guiding the meetings, which is the way it should be, considering this process is “all about them.”

Every meeting that I’ve attended has been a learning experience. I’ve learned new things about people that I thought I knew inside and out, whether it’s through things they share in their meeting or from input from their family and friends.

I recently attended one such meeting. We began the meeting by discussing the “ground rules”. These are

guidelines that are designed to help navigate the meeting in a positive and respectful direction. We then moved to the next section: What people like and admire about... This is one of the neatest parts of the PCP process. Between family and friends, we compiled a list of over 60 traits that we liked and admired about this person. The list was pretty diverse, including everything from honest, responsible, very spiritual, cooperative, and passionate about learning, all the way to good fisherman, proud uncle, good looking guy, and great golfer!



Next up we moved to one of the most important sections of the meeting, entitled appropriately enough: What’s important to... In this particular section, the resident discusses things that are important to them personally. In this meeting, a list of over 30 things was compiled with family heading the top of the list.

If you have the opportunity to attend one of these meetings, you’ll quickly learn that the most vital component to making it successful is simply, listening. This particular person stated that “keeping busy” was important to him. While discussing his desire to “keep busy” and “help others”, it was brought up that one of his main motivators is recognition which then led to the next thing on his “important to” list, “being rewarded for a job well done.”

Watching the meeting evolve through conversation and listening to what someone has to say is truly an awesome experience. Listening...such a simple task; however, a task which we might sometimes hurry through for so many different reasons.

continued on page 8

PCP Update

continued from page 7


In the next section, we discussed what is needed in order to maintain a healthy and safe existence. Examples on this list included: keep and maintain doctor appointments, exercise, knowledge of emergency situations (i.e. fire drills, tornado drills, etc...), and take meds as prescribed. After finalizing health and safety issues, we asked the resident to state in his own words, “hopes and dreams for the future?” The resident was prompted to talk about dreams for where he wanted to live, work, and have fun. He was also asked to tell his team who he wanted as part of his life in the future.

This individual expressed a dream of one day living in an apartment in Memphis. The family reported that he had actually lived in an apartment in a community setting in the past, and discussed with us the many successes as well as challenges he encountered. In fact, it was those challenges which played a part in the family’s decision to seek the services of The Baddour Center. Of course, that information was very valuable in thinking about skills he could be working on while he is here, so that if and when he does move out on his own, he’ll be well prepared.

Once all the information was gathered, the resident assisted in formulating his personal plan. The beauty of a PCP plan and the reason it should prove successful is due to the fact that the resident is responsible for setting his/her own goals. I’d like to leave you with some of the comments made by residents, staff, and family members who have participated in a PCP meeting:

Mary Phelps, a 17-year Baddour Case Manager, has attended both the old annual staffings and the new PCP meetings. She states, “The residents don’t feel as if they’re being singled out in the new meetings. There is no intimidation factor. The atmosphere is much more laid back. The residents have an opportunity to express the goals they want to accomplish and know that their team members will work diligently to help them reach those goals.”

Deborah Dancy, Fed Ex Pre-Print supervisor, stated, “The meetings I’ve attended have been awesome! It’s great to hear the residents talk about what they want to achieve, without having words put into their mouths. I look forward to going to more!”

After 68 PCP meetings, there is no question the new process has been embraced by residents, families and staff. The meetings have been positive experiences for the residents and their teams. In fact, several family members have requested copies of the data collection sheets to laminate and frame and hang in their family member’s room. Person-Centered Planning has given real meaning to the catch phrase...It’s all about me!” It truly is a new way of thinking and has allowed us all to be more open to being guided by the residents and to trying what might be possible. 

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Notify us at shill@baddour.org. We’ll add you to the electronic mailing list!

Seizure Disorders Workshop

Patricia Ofili, Intern
Education & Research Division

This Spring, The Baddour Center had the pleasure of hosting a symposium facilitated by Dr. Georgia Montouris, an Associate Professor of Neurology at the Boston University School of Medicine. As the Director of Epilepsy services for the Boston Medical Center, Dr. Montouris provided a comprehensive presentation about the types of seizures and seizure disorders, followed by seizure treatment options.

Types of Seizures

According to Dr. Montouris, seizures are divided into two types based on the electric activity that takes place within the brain. The first type is the secondary generalized seizure which means the seizure starts in a particular region of the brain which in turn encourages various clinical symptoms to develop. Dr. Montouris provided a few examples of this. For instance, if a seizure were to happen in the motor area of the brain we would see movement in a limb or the face. On the other hand, a generalized onset seizure typically involves electric stimulation of the entire brain which incurs a variety of reactions. The following is a brief overview of the kinds of reactions a person may have:

Name of Reaction	Description
Absence (petit mal)	15 seconds of daydream state with amnesia for events
Tonic	Rigid state of the body
Clonic	Jerking movements
Myoclonic	Brief muscle contraction of limb or trunk of body
Atonic	Immediate “drop” of the head or trunk
Tonic clonic (grand mal)	Convulsive activity

Although we generally think of a “seizure” as being a state in which a person loses consciousness, falls, and trembles, this is not always true. In some seizure types, the person remains upright and/or conscious. With simple partial seizures the person maintains total awareness. Complex partial seizures, unlike the simple partial, do alter consciousness and the state of awareness of the individual. The seizures typically last 5-15 minutes and are accompanied by reflex actions that may make the person seem to be aware (e.g., walking or clapping). Those who experience a complex partial seizure usually emerge feeling drowsy, confused, nauseous, and/or suffering from a headache

Epileptic Syndromes

Epilepsy is defined by the presence of two or more recurrent, unprovoked seizures. Epileptic syndromes, as indicated by Dr. Montouris, are defined by a series of characteristics: a) Seizure types, b) EEG findings, c) Neurological status, d) Age of seizure onset, e) Family history, and f) Prognosis.

According to literature about the causes for epileptic syndromes, nearly 75% of the etiology is unknown. The remaining 25% of known causes indicates that structural lesions (i.e. tumors, abscesses, tissue scarring, mechanical injury from birth, anoxia, hemorrhages, and/or parasites) are a notable cause as well as metabolic disorders (i.e. hypoglycemia, hypoxia, hepatic failure, or drug toxicity). Another suspected cause is genetics (i.e. tuberous sclerosis, Sturge Weber, Neurofibromatosis).

Seizure Disorders Workshop

continued from page 9

In addition to epilepsy, provoked seizures are typically caused as a reaction to conditions such as hyponatremia, hyperglycemia, or drug withdrawal and may be treated by treating the underlying condition. However, some people continue to have seizures after the cause has been resolved.

Comorbidities in Patients with Epilepsy

Now that we have established what epilepsy and epileptic syndromes are, we can address the challenges of identifying and treating this medical condition in relation to other existing health concerns, also referred to as comorbidity. Comorbidities can be found within children, adolescents, adults, and the elderly. According to Dr. Montouris, the following is an estimated breakdown of the populations at elevated risks to develop epilepsy:


- 26% of children with Intellectual Disabilities
- 13% of children with Cerebral Palsy
- 50% of children with both disabilities
- 10% of patients with Alzheimer's disease
- 22% of patients with stroke

Treatment

Individualization of therapy is the best approach when treating epilepsy, epilepsy syndromes, and the possibility of comorbidity. It is advised to obtain a precise diagnosis of the disorder in order to evaluate the underlying cause. Once that is accomplished, studies that utilize EEGs, MRIs, and labs results add verification of the initial prognosis. Next, an AED (Anti-Epileptic Drug) may be chosen based on the seizure type, syndrome, age, childbearing potential, and additional medications. This decision should be followed by a discussion about the diagnosis, findings, and rationale for the treatment with the patient and family.

In the event that AEDs are not successful (because they don't control the seizures or because they have excessive side-effects), surgical and non-surgical options are available to help curb the seizures. Surgical options include VNS (Vague nerve stimulator) implantation, a lobectomy (50-80% chance of seizure freedom based on lobe location), and a corpus callosotomy- "split brain surgery." Additionally, some people find success with the Ketogenic diet (a diet high in fat and adequate proteins), but it is very difficult to stick to this strict regimen.

Epilepsy is a delicate condition that not only affects the quality of life for the individual, but for their families as well. Treatment requires a team approach that includes the patient, their family or caregiver, as well as the epileptologist, neurologist, primary care physician and mental health provider.

Dr. Montouris' presentation was one of the most informative we've had in our symposium series. Many attendees commented on her ability to explain very complex material. They also appreciated her down-to-earth, approachable style. We certainly left the session feeling better educated, and sorry that she's no longer a part of the Memphis medical community. 

Parental Advocacy in Adulthood

Brooke Walters, Intern & Shannon Hill, Director
Education & Research Division

*Editors' Note: One of the projects we've extracted from our study of service needs over the past few years relates to the continuing role of parents as advocates. Extensive research has been done in the area of advocacy in intellectual and developmental disability (ID/DD) over the years. In searching for a research base to build upon, we have found very little. Though a moderate amount of early research focused on parental advocacy, much of the current research focuses on self-advocacy in adults with ID/DD. While self-advocacy is becoming the topic of interest among the ID/DD research world, the much needed topic of parental advocacy in an adult's life is being neglected. We did encounter a striking paper, though, written in 1982 by Susan M. Daniels. Advocates are often thought of as being opinionated and forceful. It's an unfair categorization, but this particular paper does come across quite forcefully. Still, we thought that the problems she exposes remain quite salient. So, we've written this edition of Journal Scan a bit different than we usually do. We're not summarizing her positions. We think our readers can decide for themselves how to solve their problems. Instead, we're outlining the problems she raised and attempting to relate them to the practical challenges we face today. The citation for the original article is: Daniels, S.M. (1982). From parent-advocacy to self-advocacy: A problem of transition. *Exceptional Education Quarterly*, 3, 25-32.*

According to Daniels, "parents have a special understanding and caring for their children, a unique ability to perceive the child's needs, and maybe even a biological need to nurture their [dependent] offspring." These qualities may change over the lifespan, but they do not disappear. Therefore, parents remain strong advocating forces in the lives of their adult children. However, once they move from the strongly centralized force of the educational system, they often find themselves alone in carving out a path to meet their child's hopes and needs.

Complicating the challenge of blazing one's own trail are the complex emotions associated with transition to adulthood. Issues such as independent living, social integration, and sexuality face all families during this time, but they can be particularly troublesome for parents of young adults with intellectual disabilities. Daniels' 1982 essay addresses the conflict in being a parent advocate for an adult while, at the same time, letting them be adults. Most of her ideas were ahead of their time and she was often considered controversial in the area of ID/DD. She advocated for greater risk acceptance, community integration, and independent living, and sexual/reproductive rights. Although her positions are now mainstream in the political world of ID/DD, they remain very poignant on an individual level for the parent thinking about the specific needs of his or her own child. Like many advocates, her language is strong; she has definite opinions about what is right and what is wrong, which she seems to apply to all people without distinction. Still, the issues she brings up are modern conflicts as well, and the way a parent resolves them will certainly influence how they advocate, as well as whether they advocate at all.

Daniels addressed four areas in which these conflicts tend to arise. The first is determining how much help to give while still encouraging the adult child to attain independence. According to Daniels, it is often difficult for parents to see their children as capable of independent living, and to recognize which skills will be needed in the future. When something is difficult, how much time and energy do we invest? How important is cooking? Washing clothes? Driving? It all depends on where you see the person living in the future, what kinds of supports you think will be available, and how much you believe he or she can learn it. Although this point remains valid today, we must mention the fact that educational programs and independent living supports are vastly more available than they were thirty years ago. The challenge to advocates is to stay abreast of them and to fight for those the person or family needs.

The second conflict area relates to protection from vs. integration into peer groups and community. Fear of what might happen and a multitude of practical limitations can play into this conflict. As childhood gives way to adulthood, this conflict becomes more salient. The built-in social opportunities of school disappear. It is no longer just about friend-


Parental Advocacy

continued from page 6

ships with peers who have disabilities and those who do not. Now it also becomes about times and places. Integration is perhaps less scary in the school realm, where there are teachers and principals and parents involved. In the adult world, friendships are usually unsupervised. Do you trust the new person who has shown an interest in taking your adult child to the movies? Can you trust your adult child to discern between good intentions and bad? But then again, can you stand to watch them sit in their bedroom eating potato chips, alone? Like the other conflicts described here, the availability of social supports, social skills training programs, social programs, etc., for adults has grown tremendously in the ensuing years. Still, social isolation remains one of the most common and troubling issues of adulthood.

The third area relates to romantic relationships and sexuality. It can be difficult for parents to recognize their child's sexuality, or to see them as potential mates, sexual partners, or future parents, so encouraging or supporting normalized development in this area can be one of the hardest things a parent can do. However, it is an important area of life for most people, whether they have disabilities or not. The challenges of advocacy include how to meet people, the logistics of arranging dates, social skills, sex education, etc. If the relationship does become serious and the couple wants to marry, new challenges may emerge. For example, the couple may find themselves facing a decrease in service eligibility and financial entitlements. Government bureaucracy can be hard for anyone to navigate, so people with ID will likely need strong advocacy backing to assist with such issues.

The final conflict addressed by Daniels relates to realistic goal setting. As with the issues of independence, it can be difficult to support goals the parents think are beyond the person's skill set, and difficult to know where to turn for help. What should a parent do when the adult child sets a truly unrealistic goal, such as landing a recording contract in the absence of any real singing talent? What about scary goals, like going to college? Or unhealthy goals, like stopping seizure medications? The rise of person-centered planning has really assisted in this realm. The challenge for parent advocates is in finding the right facilitator. A good PCP facilitator can truly make a difference.

In sum, parenting is difficult across the lifespan; no one should assume the parent's role as advocate stops upon high school graduation. Parents face some really hard practical and emotional issues as their child with a disability transitions into adulthood. The issues raised by Daniels are alive and well today, but in the thirty years since her essay was published many resources have been developed to assist in the balance between the need to protect vs. the desire to encourage normal adult development. Daniels' essay laid out some strong do's and don'ts for parent advocates. Our position is a little different. We think, and our emerging research supports, that parental advocacy skills are not judged by their ideology, but by other internal factors. In short, parents who are open to discussion, who think positive things about themselves and their children, and who seek information about the latest innovations and services available (both in their home communities and across the nation), tend to perform well as advocates across the lifespan. 

Congratulations

Amy, Gene, and Gale

Medal Winners!

Special Olympics National Games

Lincoln, Nebraska

July 2010

3G Network Activities

Carly Gardner, Research Assistant & Shannon Hill, Director
Education & Research Division

Editors' Note: The 3G Network (Good People, Doing Good Things, for Good Causes) is a program designed to encourage staff to acknowledge positive behaviors among the residents, while encouraging residents to reach out to help others in the community. Baddour staffers write "ABRs" (appropriate behavior reports) when they see someone doing something nice or helpful. Each Saturday, the Education and Research Division hosts an ABR party to celebrate that week's achievements with games, dances, prizes, and other random fun. One ABR is drawn from the lot, and the winning person is invited to go on the monthly community volunteer trip. The writer of the winning ABR is also rewarded.

As usual, the June ABR parties were tons of fun. The first week, we played "Punch-a-Bunch," a board game in the Price Is Right style. People won all kinds of prizes, ranging from soda money to "fancy jewels." Joe, pictured on page 14, won a trip to the library. He checked out a book on dolphins and volunteered to write a report about it. Wait ~ did you notice that sentence? He VOLUNTEERED to write a book report. That was so awesome, I just had to print it. See page 14!

The winners of the volunteer trip drawing, Kathleen, David, Brian, and Nicole, travelled to the local nursing home, the Senatobia Convalescent Center. The specific 'volunteering purpose' of the trip was to give the residents of the Convalescent Center what they often need most- attention and positive regard. When we first arrived, we introduced ourselves to the staff and presented them with a card that we had made for them to portray our thanks

continued on page 14

Accomplishments

Shannon Hill, Director
Education & Research Division

This quarter we've had several people accomplishing major things!

First, Direct Support Professional (DSP) [Judy Duncan](#) of the Greenwood House became the first DSP in Mississippi to attain national certification by the National Alliance for Direct Support Professionals (NADSP). As you may have read in previous editions of this newsletter, the NADSP is working diligently to ensure people with disabilities receive quality care through workforce training, professional growth opportunities, and reduced turnover. It is their belief that the creation of this new certification process will be a giant step in attaining those goals. The process requires DSPs to complete 200 instruction hours, 3000 hours of work experience, and a portfolio demonstrating competency in eight work areas. Additionally, they must write a letter expressing their commitment to the field of direct support and its code of ethics, and gather letters of recommendation from the people they serve and/or their families. According to Judy, this has been a rewarding process of hard work and she plans to continue on to the next level of certification, which is specialization. Congratulations, Judy!

In other news, two of our Education and Research alumni completed their last steps for their Ph.Ds. this quarter. We are very proud to announce that both [Amanda Surdock](#) and [Ashley Durkee](#) may now be addressed as "Dr.!"



3G Network

continued from page 13

for allowing us to visit. We then made our way around the common room and introduced ourselves to each of the residents there. We were able to meet approximately 40 residents that day, most of whom were extremely glad to see us. Conversations were had with many, and even a few sightings were made of former TBC employees. We were also able to join the residents during their table bowling time and tell them about TBC's upcoming production of Wipe Out. Kathleen, David, Nicole, and Brian all had a great time at the nursing home. Although they were a little shy at first, they warmed up to the residents and were able to spread some joy and caring around the Convalescent Center. Everyone at the Senatobia Convalescent Center was very hospitable and we hope to go back very soon on another volunteer trip.

For every resident winner, we had a staff winner as well. Word seems to have gotten around to the DSPs that we're willing to deliver lunch. DSPs have been racking up the rewards; we've delivered lunches from everywhere from Cap'n D's to Penny's Pantry. ♡



L to R: Brian, Le Le, Kathleen, David, and Nicole visiting the Senatobia Convalescent Center.



Kathleen and David greet residents of the Senatobia Convalescent Center.



Book Report

Dolphins! by June Behrens
Joe, Baddour Center Resident



Dolphins make up hunting and chasing games [like] throw and chase. Dolphins have been taught lifesaving. Dolphins use sound to help them see. Dolphins live in the oceans of the world. They travel [in] herds. Dolphins work and play together. They take care of one another.

Dolphins are sometimes called smaller toothed whales. They have more teeth than any other animal. Dolphins are mammals just [like] humans. They breathe air and drink their mother's milk. Their cousins are whales and porpoises. They are members of the cetacean group. Cetaceans are mammals that went to live in the sea millions of years ago.

Dolphins breathe through their blowhole, a nostril on top of their head. They can close the blowhole and stay under water for up to six minutes. Dolphins live for about 25 years. Most have dark colored bodies and lighter colors on the underside. This coloring helps protect them.

My favorite thing about dolphins is that people can ride them. I hope to ride one some day.