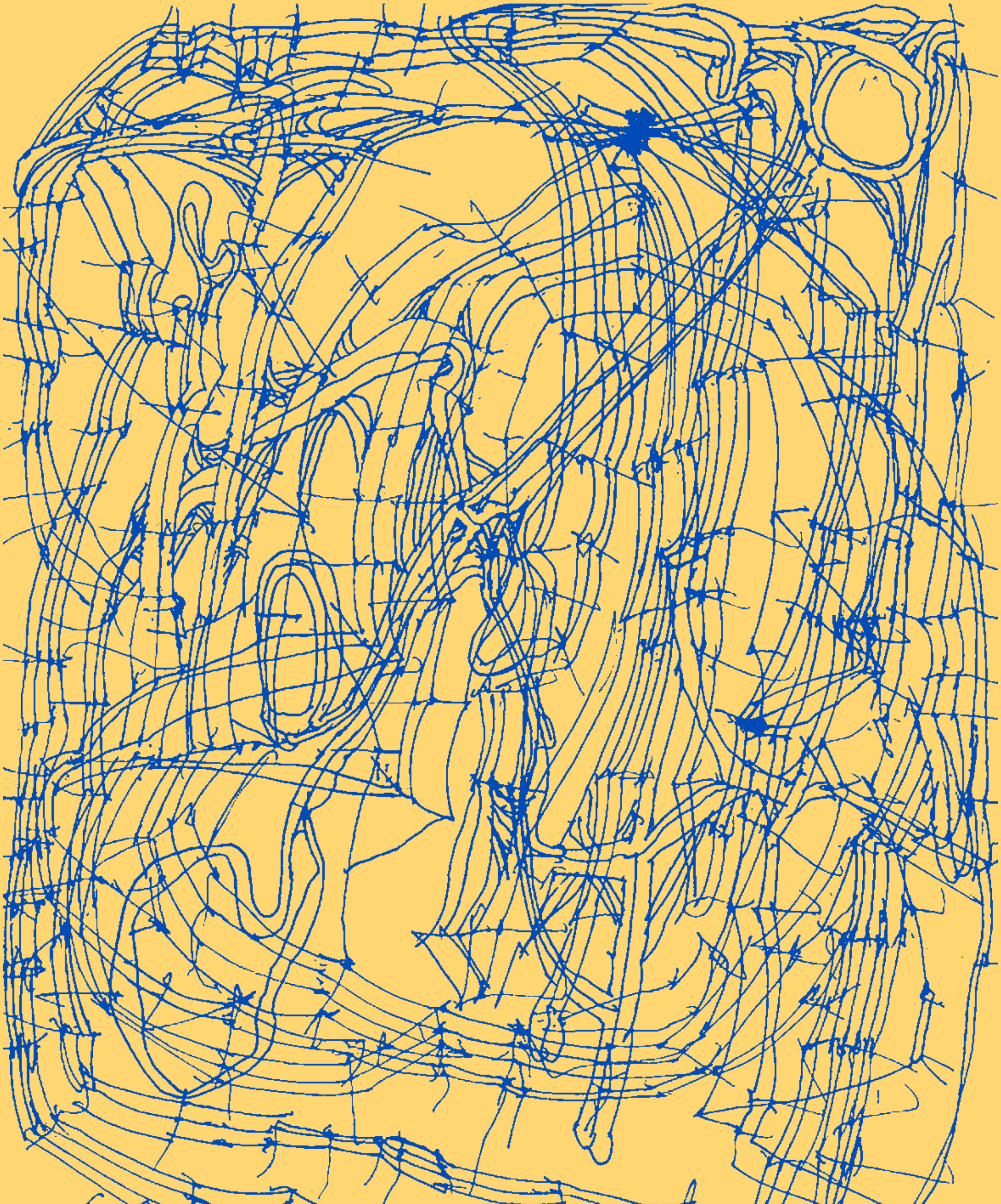
AUTISM NEWS

of Orange County
& the Rest of the World

Spring 2010 *Volume 5, Issue 3*



Cover artwork created by Garrett Sheline

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COVER FEATURE

We are pleased to feature one of our local artists, **Garrett Sheline**. Read more about Garrett on page 15.

Mission Statement

Autism News of Orange County *& the Rest of the World* is a collaborative publication for parents and professionals dedicated to sharing research-based strategies, innovative educational approaches, best practices and experiences in the area of autism.

Submission Policy

The Autism News of Orange County–*RW* is available free of charge. The opinions expressed in the newsletter do not necessarily represent the official view of the agencies involved.

Contributions from teachers, therapists, researchers and relatives/children of/with autism are welcome. The editors select articles and make necessary changes.

Please submit articles in Microsoft Word using font size 12, double spaced, and no more than four pages in length (2600 words). Photos are encouraged and when submitted with articles the permission to include is assumed.

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Editorial

By Vera Bernard-Opitz

Vision for a range of living options for the range of individuals with ASD

The topic of living options for adolescents and adults with Autism Spectrum Disorders has become a highly important and urgent one. The first generation of children with autism that had access to intervention programs has "aged" out of school and, unfortunately, often also out of therapy services. While some individuals with ASD have demonstrated remarkable progress which allows them to lead an independent life, not all have been that fortunate. Adults with ASD in their twenties and thirties and their parents are typically faced with a critical shortage of quality homes and services. One of the leaders in the area of living options, Ruth Sullivan, has called this **"The National Crisis in Adult Services for Individuals with Autism,"** since it affects tens of thousands of families – and not only in the US.

Our focus in this issue of the *Autism News* was motivated by seeing children with autism growing into adults and learning about their day-to-day struggles and those of their families. In addition, the recent plight of more than 200 local parents of adult individuals with ASD has shown that even well-to-do communities like Orange County have not yet been able to provide sufficient services and facilities.

While there is an ardent discussion regarding the pros and cons of various living options, we maintain that a range of options should be made available for the wide diversity of individuals with autism. In addition to considerations of ideology and cost, **policy makers and developers should be guided in their decisions by input from the affected families:**

- What do parents and individuals with ASD consider a good home?
- Would some individuals with developmental disabilities or ASD prefer an urban lifestyle or a retreat in the countryside?
- Would families prefer live-in support (as many Asian countries provide), respite care or would they want separate homes for their children?
- Would parents want a roommate for their son or daughter or should he or she share small living facilities with others?
- Many students, elderly individuals, and cultural groups prefer to live in like-minded communities. Would some individuals with developmental disabilities or autism want to live in a modern larger residential facility with like-minded individuals?
- Would parents want their son or daughter to take public transportation or would they feel safer with a facility-owned transportation system?

The housing ideology for individuals with disabilities seems to be evolving from developing large residential facilities, as was done in the 60's and 70's, to providing group homes, to the current discussion of a range of alternative living options. It has become obvious that simplistic notions of integrating everyone into the community do not do justice to the spectrum of needs. Placing a small group of individuals with ASD in a beautiful home in the community provides no guarantee for their social integration and may actually be isolating. Traditional group homes often have to make special efforts to integrate their residents into the neighborhood. For other adults with ASD it seems equally important to live in communities where living spaces in the neighborhood allow independence and social contacts.

A wide range of living options should be available for our diverse population.

In California, residential facilities are not allowed to have more than 16 beds. If we look outside of CA or the US we see much larger modern rehabilitation centers, which have become aggregations of comfortable small group living units, run by caring and qualified staff within a protected community. Some even have on site clinics, sport facilities or shops and a restaurant. These often are highly attractive for the surrounding "normal" community so that a process of **"reverse integration"** can be witnessed. Perhaps this option should also be considered in future developments.

Simplistic notions of integration in the regular community for all do not do justice to the spectrum of needs.

The current issue of the *Autism News* shows preliminary findings on parent, teacher, and institutional perspectives regarding transitions into living options outside of the parents' home **(Krysti DeZonia, TERI, Oceanside). We also present a range of living options:** from the continuum of services provided by the **TEACCH-program in North Carolina (Dawn Allen)** to the **Weidenhof,** a rural alternative for adults with ASD in **Germany (Peter Sommer)**, to **Noah Homes,** a beautiful residential facility in **San Diego (Molly Nocon)** and last but not least **Promising Futures,** three splendid group homes set up by the mother of Tiffany **(Marti Morrissey)**, also in **San Diego.**

In addition, representatives from different fields share their experience and vision, such as **Janis White from Regional Center of Orange County,** who provides some statistics of needed services and an overview of currently available living options in Orange County.

Boyd Bradshaw, who operates residential group homes, shares his ideas on requirements for such homes. An interesting highlight comes from a mother, who summarizes her expectations for living options for her daughter. **Susan Johnson** discusses an innovative effort by a local housing development group to establish a needs-based community integrating individuals with autism with elderly and low-income individuals. **Peter Gerhardt** raises important issues about sexuality instruction. Another very special highlight is the article by **Jennifer McIlwee Myers,** who describes being married as an Aspie, a future which many parents would wish for their children.

We are grateful for all contributions (including the one by our cover artist **Garrett Sheline**) and hope that this issue generates discussions, especially involving parents and other family members, and possibly even creates new visions.

We thank our donors for their contributions and hope that we will be able to provide ongoing publications. Unfortunately our former sponsors can no longer afford to support the Autism News, so we depend on your generosity. Without further funding this 15th issue of the *Autism News of Orange County* will be the last one.

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A New Way

to Support the Autism News of Orange County!

To continue our newsletter we need your support!

Please donate through the new **Autism News OC Fund at the School of Medicine of UCI** (Go to: Autism News of Orange County). **https://ua-web.uadv.uci.edu/egiving**

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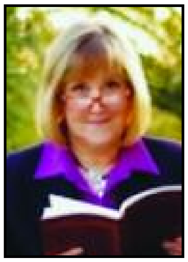
Transition to Adulthood for Students with Profound Disabilities: Parent, Teacher and Institutional Perspectives

By Krysti R. DeZonia



During the past 10 years, there has been an increased research focus on transition services for special education students, in part, as a result of several studies that detail poor post-school outcomes for students who have received special education services during their public school years (Hughes & Eisenman, 1996; Kohler & Feld, 2003; Phelps & Hanley-Maxwell, 1997). These studies revealed that students with the most severe disabilities have poorer outcomes than those with milder disabilities, with few opportunities for meaningful work, varied and integrated social lives, community access, or upward social and economic mobility (Haring & Lovett, 1990). Overcrowded adult service agencies and limited vocational training programs add to the problem. Transition-focused researchers found that federal, state, and local governments did not have coordinated policies and practices that were designed to maximize student learning during transition and, after graduation, in supported employment (Hughes & Eisenman, 1996).

Jimmy flying high

The high cost of special education has resulted in a government and research focus on outcomes for students receiving these services. When outcomes are poor, as they are for students with developmental disabilities post-graduation, the practices and processes used to support and educate these students become a priority for researchers and funding agencies. **Additionally, there has been a significant increase in the numbers of students diagnosed with severe and profound disabilities, in particular individuals diagnosed with autism (California Department of Developmental Services, 2003). This results in a need for more information on teacher training, student support, and cost effectiveness of special education programs.**

Families of students with special needs, and the students themselves, expect that special education transition services will empower individuals by preparing them for meaningful adult lives (Szymanski, 1994). For some adults with disabilities, a meaningful life is defined as full inclusion in their community and opportunities to work, live, and recreate in a manner that is similar to that experienced by those who are not labeled as “disabled” (Cooney, 2002). For other adults with disabilities, often those with more severe disabilities, a meaningful life is defined for them by those who know them best, which includes family members, friends, and teachers (Ferguson, 2000). Oftentimes, a meaningful life for students with severe and profound disabilities is defined as having a safe place to live, being happy, and having constructive ways to fill one’s free time (Hanley-Maxwell & Collett-Klingenberg, 1995).

Ultimately, the goal of this study was to gain a greater understanding of how parents and teach-

ers conceive of adult life for persons with profound disabilities and to compare these conceptions to the institutional formulations of adult life that are contained within the special education laws and institutional practices that surround this student population. Most significantly, this research seeks to add to the scant knowledge we have about students with profound disabilities so that we can find ways to improve the quality of life they experience in adulthood.

Method

Participants

In total, 16 teachers and parents (eight parent/teacher pairs) participated in this study. Participating parents and teachers were obtained from a private, nonpublic school serving large numbers of students with severe and profound disabilities and two school district transition classrooms. The children ranged in age from 16 to 21 and 75% of the children had a primary diagnosis of autism. The remaining two children had a primary diagnosis of Down's syndrome and multiple disabilities.

Instruments

Interview questions were developed to gather information about the adult life parent and teacher participants' envision for their child/student. To gain greater information regarding adult life envisionment, a graphic representation of nine significant life areas was made available as a scaffold for their thinking (see Figure 2). The graphic was voluntarily used by all study participants and was successful in eliciting rich descriptions of parent and teacher thinking.

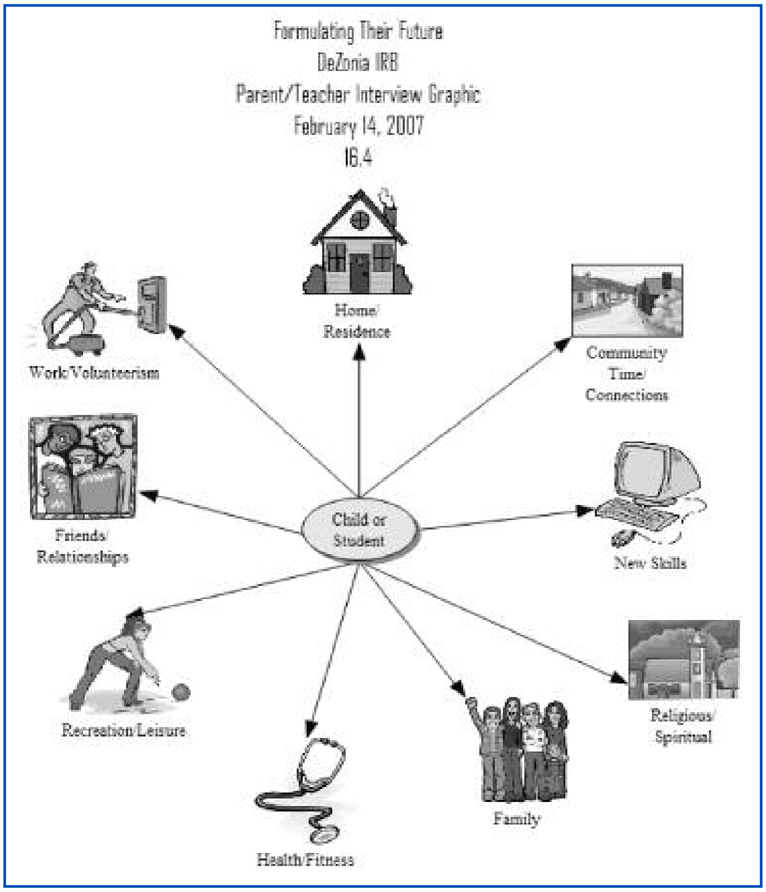
Results

What do parents and teachers believe adult life is actually like for individuals with profound disabilities?

When asked what they believe adult life is like for people with profound disabilities, 75% of the parent participants had a negative opinion about life quality for this adult population (six parents). The remaining 25 % (two parents) had a positive outlook. These parents believed that, because these children are, in their opinion, free from the stresses that non-disabled adults face, their lives are uncomplicated and therefore "happier" than the lives of most typical adults.

> ***I think in fact they are pretty oblivious to the stresses and strains that us typically developing humans have and live with, although I do see that he gets anxious and nervous. But I don't think it's that he worries about money or worries about where his next meal is coming from. I think that they can be pretty happy.***
>
> ***– Parent Paula***

The six parents (75%) who had a negative perspective regarding adult life for this population view it as "hard"; "sad"; "scary"; and of poor quality. They believed that their children are not understood by others in the general community and that this results in isolation, a lack of empathy, and a lack of opportunities.



> ***For the majority of them? I don't think they have much quality of life, the majority, cause I think it takes a really special family to provide all those needs and a lot of times the kids go to places or have workers that really don't connect with them emotionally and if they don't connect emotionally, they really don't grow either.***
>
> ***– Parent Denise***

More teachers than parents have a negative perspective regarding adult life for persons with significant disabilities. **Of the eight teacher participants, only one thought adult life is positive for this student population while the other seven (87%) had negative beliefs that parallel those expressed by parents.**

> ***Actually, I kind of in a way envy people who have profound disabilities. I don't see them burdened with what other people think about the because their self conscious level really isn't there, so on that aspect I feel like they have a higher quality of life than most of us do.***
>
> ***– Teacher Roxie***

The remaining seven teachers used terms similar to those used by parents to describe adult life for students with profound disabilities. Teachers, like parents, believed adults are often lonely and sad, and that adults with profound disabilities get overlooked and warehoused.

Both parents and teachers expressed their lack of knowledge about adult services. Most teachers believed there are an inadequate number of programs for students with profound disabilities. No teachers commented on circles of support, individualized services, micro-enterprise, supported living or other new service continuums more recently available to this student population.

TERI Center for the Arts & Adult Education: Eric creating a masterpiece

Students from the Agricultural program proud of their growing plant

> ***I think, in reality, I'm transitioning them out of public school rather than transitioning them into adult life. I think I probably know more than the average citizen does, but probably not that much more.***
>
> ***–Teacher Jeff***

How do parents and teachers envision the adult life of their child or student 15 years after graduation from special education?

All parents' first responses to this question fell exclusively within the friendship/relationships, family, and residential categories. Parents want their children to have personal fulfillment and comfort; to be as productive and independent as possible; to be with people who love them; and to be part of life, not just an observer. Parents who have strong religious beliefs (three of eight parents) felt that their child will be healed or otherwise taken care of through God's intervention. **Most parents, however, simply discussed their desire that their child has a place in the world where he or she is respected, happy, and loved.**

Where and with whom their child will live was a primary concern for parents when thinking of their child's adult life. This life category, more than any other, was a focus of the talk of all the parents who participated in the study. **Of the eight parents, six want to have their child live at home as long as possible. Only one of these six parents had a concrete plan for what will happen when he can no longer care for his child** (family members have committed to care for his son). The remaining five parents (62%) hoped that someone will come forward from their families or that, over time, they will find a suitable living arrangement for their child. **Two of the eight parents plan to place their child in a group home as an adult.** These parents indicated a desire to continue to have their child live with them in adulthood but cited the difficulty of maintaining their child within the family home as their primary reason

Table 1: Comparison of Parent, Teacher, and Institutional Conceptions of Adult Life for Students with Profound Disabilities

Parent conceptions	Teacher conceptions	Institutional conceptions
Adult life will be hard; scary; of poor quality for their children; parents know what is best for their child	Adult life will be difficult or negative due to stigmatization; lack of skills; inadequate programs	Adult service system is complex; preparation for adult life requires involvement from institutions
Child will have personal fulfillment and be involved in "structured" activities (not otherwise defined)	Students will be actively involved in functional tasks; spend time in the community, engage in leisure activities	Adults will work and live independently within the community
Child will live with family or loved one	Student will live in a community based residential setting	Adults will be financially, personally, and socially independent or institutionalized in segregated settings
Child will not work as an adult	Student will not work as an adult	Adults work in independent or supported settings in the community
Child will have friendships/relationships with people who care about them	Student will have opportunities to spend time with friends and family or people familiar with the student	Not reflected in data reviewed.
Child will be part of life, not an observer	Student will attend a structured adult day program	Adults will achieve maximum integration in our communities; people with profound disabilities have little to offer society

for considering group home placement.

> ***I have a lot of pressure to put Jack in a home. They [friends and family] see I have no life. …In my head I have to think positive about it [residential placement], that's where I put it, but the truth is I'm miserable and I wish that he could stay with me forever, and his behaviors weren't so severe, and I could treat him more like an adult than a baby.***
>
> ***– Parent Denise***

Like the parents, teachers were asked to comment on the adult life they envision for their student 15 years after graduation. **In contrast to parents who were primarily concerned about personal fulfillment and comfort, teachers hope for a future in which their students remain active as adults. Most teachers (six of eight teachers) did not believe their students will work once they graduate from public school.** The remaining two of eight teachers envisioned their students working in a structured setting with high levels of support.

Regarding students' residential life once reaching adulthood, **six of the eight teachers envisioned their students living in a group home setting (75%) while two teachers, based on their knowledge of the parents' wishes, saw their student living in the family home as an adult.** This is in direct opposition to parent envisionments for the same students, with 75% of parents believing their child will still live at home or with family members 15 years after graduation.

How do Parent/ Teacher Constructions of Adulthood Compare with Institutional Constructions of Adulthood for Persons with Disabilities?

An examination of public laws (California Education Code-Title 5 and IDEA 2004) directed at transition to adulthood for students with disabilities provides insight into the social/cultural understandings and expectations of this segment of our population. Table 1 provides a summary of parent, teacher, and cultural expectations of individuals with profound disability once they reach adulthood as revealed in the data sources used for this study.

Fitness, Therapy & Recreation Center: Having a ball

While families are focused on "life quality" pastimes that will result in personal fulfillment for their child, teacher focus is on active engagement in structured activities conducted within institutionalized, adult service settings. Both parent and teacher perspectives are in direct opposition to social/cultural/institutional viewpoints, which assert that adults should be independent and self-sufficient.

Discussion

Five primary findings emerged from the analysis of the interview data of the parent and teacher participants and of the artifacts reviewed:

Movement Research

- **Parents and teachers have different formulations of a student's adult life.**
- **Parents and teachers lack knowledge about adult services available to students with profound disabilities.**
- **Parents' and teachers' thinking is influenced by different factors, with parents more influenced by internal factors and teachers by external factors.**

> ***Ferguson, Ferguson and Jones (1988) note that transition to adulthood is as much a family transition as an individual transition.***

- **Parents need support in order to formulate an adult life for their child that can be operationalized into concrete goals and objectives.**
- **Institutional constructions of adulthood for individuals with disabilities are inconsistent with parent and teacher formulations of an individual's adult life.**

In order to maximize student success in adulthood, the IEP transition plan and individual student goals should reflect the wishes of the people who will be most involved in supporting the student across the lifespan - typically the student's parents. Ferguson, Ferguson and Jones (1988) note that transition to adulthood is as much a family transition as an individual transition. The finding that parents of individuals with profound disabilities need support in order to conceptualize their child's adult life substantiates the critical need to provide life quality planning support to parents prior to team meetings to design transition goals and objectives. Ensuring that family wishes are reflected in student goals should help increase the chances that students will lead a high quality adult life.

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This article is excerpted from a paper presented at the Annual Meeting of the American Educational Research Association San Diego, April 13-17, 2009.

Living Options for People with Autism

By Dawn Allen, Janet Breeding & Beth Olivieri

GHA, Inc., formerly known as Group Homes for the Autistic, is a private non-profit organization headquartered in Albemarle, North Carolina. GHA was developed in 1978 as a result of the dedicated efforts of a group of concerned parents who recognized a need for services for individuals with Autism Spectrum Disorder (ASD). The program's first residence became home to five children, ranging from 5 to 12 years old. As the children grew, the organization grew along with them. Additional homes were opened, staff was hired and trained and services were expanded to meet the needs of older teens and young adults. Over the past 32 years, GHA has grown to serve sixty-four individuals in over 20 programs providing residential, vocational, educational, community and in-home **services.** These services are provided in homes, classrooms, competitive job situations, a working farm, apartments, duplexes and in-home settings.


Group home in a residential facility houses 6 young adult individuals with autism

Moving to a new home is a significant, life altering change for anyone, but for an individual with autism it is even more challenging. Michelle, sister to two individuals with autism, shared that ***"before becoming part of the GHA family (that is the feeling with this group) each day was an uphill battle searching for programs, interviewing and applying for housing. Then, just when you think it all falls into place it is taken away due to a lack of funding, or just not the appropriate environment for an individual with autism."*** GHA is committed to empowering individuals with autism and their families to have greater choice and control over where and how they live.


Supervised living service for five adults with an emphasis on training and supports for daily living and volunteer work in the community

The identification of housing needs of people with autism through records, research or surveys is almost non-existent. There is an objective in the *North Carolina Division of Mental Health, Developmental Disabilities and Substance Abuse Services State Strategic Plan 2007 – 2010* to improve consumer outcomes related to housing. The need for creative housing options is also closely aligned with the United States Supreme Court's Olmstead decision, which provides individuals the right to live in the most integrated situation appropriate to their abilities.

The North Carolina Division of Mental Health, Developmental Disabilities and Substance Abuse Services presently has a person who oversees housing initiatives as part of its Best Practice Team in each of the seventeen Local Management Entities throughout the State. This effort is applauded by the autism community, however, once again individuals with autism are treated as part of the entire developmental disabilities population. Individuals with autism, their parents and advocacy groups are expressing concern regarding the overall lack of planning for the unique housing needs of the ASD population.

Living options are so much more than bricks and mortar – a variety of factors including location, climate, smell, space, proximity to noise, etc., may contribute to a situation resulting in a negative impact for the person challenged with autism spectrum disorder.

“Creative housing for the autistic is critical for their success,” stated Michelle. “At GHA, our family is finally listened to and strongly encouraged to participate in the planning of my siblings’ needs.”

GHA’s focus is to address the need for autism-specific services in partnership with appropriate entities. We are committed to ensuring that there are a range of options and a service continuum available for individuals with ASD. The need for collaborative advocacy efforts requires significant time and effort in addition to the challenge and commitment of supporting people and managing services. The continuing need to defend costs also contributes to an ongoing struggle. Often in planning with case managers as well as local and state authorities, there is no recognition that the needs of individuals with autism are any different from individuals with varying other disabilities.

Carolina Farms is a development of four group homes for seventeen residents, located on a beautiful working farm in a rural area

> *GHA currently serves sixty-four individuals in over 20 programs providing residential, vocational, educational, community and in-home services.*

Frustrated family members often convey to GHA’s screening team that there is poor planning and a haphazard process for finding housing options for individuals with autism. In their attempt to manage services for their family members, they often feel their loved ones’ unique needs are not clearly understood. “It is critical that individuals with autism not be categorized with individuals with varying disabilities,” shared Michelle. ***“Autism isn’t ‘one size fits all.’ Each individual is extremely unique*** *and their success in life is critically dependent on the countless hours and exhaustive planning that goes into having one successful day. So many times, our family ‘heard the talk,’ while no one ‘walked the walk.’ That is, until GHA developed unique housing options and support services for my brother and sister,”* she added.

> *The need for creative housing options is closely aligned with the United States Supreme Court’s Olmstead decision, which is the right to live in the most integrated situation. appropriate.*

The development of supports and services at GHA is an example of how collaborative partnerships can provide living options for individuals with autism. We are currently working with **five different living options** that range from a traditional six-person service to an independent situation that involves subsidized housing with minimal wrap-around supports.

The smaller (2 - 3 persons) situations have proven to be very successful for the residents, but the associated work is made more difficult by constrained finances. In addition, the ever-changing regulatory situation, including tremendous administrative burden and unfunded mandates, further complicate matters. However, when you look past the bureaucracy and see the individuals receiving support, it makes the investment in the success of these services well worth the effort.

Fifteen years ago, GHA began providing services in smaller situations and we currently support more than 10 individuals who previously failed in larger, congregate living situations. Some of these individuals experienced multiple

We are currently working with **five different living options** that range from a traditional six-person service to an independent situation that involves subsidized housing with minimal wrap-around supports.

failures with other providers who attempted to provide appropriate housing and service supports, but the effect was the "square peg in the round hole" as they were "placed" into existing services that could not accommodate their unique challenges. Some of the individuals had been "housed" within one of the State Developmental Centers, either for stabilization or for long-term institutionalization, as there did not appear to be any other suitable alternatives. One family we worked with was fearful of considering a change due to past failures that would always haunt them.

We are committed to ensuring a range of options and a service continuum that crosses varying needs and ages to ensure that there is no service gap.

Successful living situations are based on several factors, including the ability to more effectively manage the number of support staff, living with fewer housemates, more efficient management of both internal and external stimuli, and utilization of highly individualized schedules and structure to provides consistency in the lives of the individuals. In addition, environmental changes/adjustments can be made quickly, which often diffuses situations that otherwise can result in an escalation of extremely challenging behaviors. ***"My sister is a shining example of just how well an individual with autism thrives in a two-person household setting,"*** said Michelle. *"A farm house setting was too laid back for her and not challenging enough, while a setting with seven other housemates proved to be extremely difficult, if not impossible for her to be successful. She was much higher functioning than the others in the home and would actually lose skills.* ***Getting her into an apartment with one roommate has been the most wonderful thing for her! She is happy again! She is thriving and looks forward to facing each day."***

One of the goals for all of the individuals supported is to focus on their talents and areas of interest, as opposed to placing emphasis on their deficits. For instance, if an individual is fixated on a particular object, then support staff makes every effort to utilize that fixation to motivate learning a host of other skills. This can be accomplished much more readily in a smaller living situation. There is also a focus on accommodating sensory sensitivities, such as eliminating fluorescent lights, which may be more difficult to do in a larger setting.

In North Carolina, the development of smaller living options often requires months of administrative preparations. This includes working with local communities, zoning boards, and a team of engineers within the Division of Health Service Regulation. These relationships ensure compliance with building codes, location and exterior requirements as well as design and equipment restrictions. Following approval of the construction, the applicants must navigate the complex maze of licensing. All but one of GHA's living options is licensed by the State of North Carolina. In addition, there must be collaboration with the responsible Local Management Entity (LME) for each individual supported. This body is charged by the North Carolina General Assembly with monitoring the services provided, as well as with oversight of finances for individuals with developmental disabilities.

> ***One of the goals for all of the individuals supported is to focus on their talents and areas of interest... For instance, if there is a fixation on a particular object, then support staff makes every effort to utilize that fixation to motivate learning a host of other skills.***

It is important that each individual with autism be afforded respect, dignity and the opportunity to achieve their personal goals. Fran, mother and guardian, of Wendy, age 41 and Chris, age 36, shared that "after years of improper placement and an 'in-home' service that included total neglect and waiting list after waiting list, we finally found and were accepted into the GHA family. Thanks to the collaborative efforts of GHA and our family, my two adult children are realizing their dream for independent living and are successfully achieving their goals." We want to ensure good practice in development of housing alternatives, and pursue replication of housing models that are successful. GHA is committed to continuing its goal of ensuring that individuals with autism have choices about where they live, with whom they live, and who supports them.

> GHA is committed to continuing its goal of ensuring that individuals with autism have choices about where they live, with whom they live, and who supports them.

For further information, please visit our website: www.ghainc.org

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This article is solely based on the experiences of GHA, Inc. and due to limited time and space detailed explanations are not included.

Editor's note: Dawn Allen, Chief Executive Director of Group Homes for the Autistic (GHA) in Albemarle, received the 2008 Professional of the Year Award. A belated congratulation!!

a few comments from our readers...

"Publications like this provide a great service to the community."

"Would like to get ANOC on a regular basis."

"It's a wonderful resource for patients, families, and service providers. This is not only educational, but a great way to link into other support systems and programs."

A Very Special Place for Individuals with Autism in Northern Germany:

The Weidenhof

By Peter Sommer

Adults with autism have found a very special home located in the valley of the Elbe River in Northern Germany. Two sites, called Seerau and Elbufer, offer 35 individuals with autism a permanent home within a rural setting.

The Weidenhof was founded in 1982 by a couple from Hamburg, Helen and Werner Blohm, who started a foundation that supports the center. They had not been able to find a suitable home for their daughter, who had autism and required life-long specialized attention within a small facility. At the time, most German rehabilitation centers were large communities. The Blohms wanted a home where individual attention to the needs and interests of the residents was provided and where staff would be highly sensitive to the personality of all group members.

Both Wiedenhof sites have become renowned as model homes within as well as outside of Germany. The well-trained staff matches activities to the interests of the residents, for example, assigning individuals with a high activity level to gardening or wood work, while individuals with repetitive tendencies are given the opportunity to work in the weaving department. Others who like collecting objects can be involved in collecting eggs in the morning and packaging them. Individuals with sensory needs often enjoy weighing and packaging tea leaves or candle making. The activities offered are designed to be functional from the perspective of the individual with autism, such as getting wood from the forest, chopping it and finally making a fire in the fireplace. Besides facilitating daily and leisure activities, a guiding principle at the centers is relating to the residents as partners, to understand their conflicts and to help solve their problems.

Since its beginning the Weidenhof has continually developed and adjusted to the needs of the residents. Besides four main groups, two additional homes have been created. There are now also two single apartments outside of the premises. In addition, two training apartments have been created within the Weidenhof, where training in independent living is practiced.

The educational and social training aspects and a fixed daily schedule as well as enjoyable outings are important components of the Weidenhof. Since the homes are located on a large site, a gar-

den as well as additional facilities such as a therapeutic workshop, a ceramic center, a center for weaving and an art center have been established. Individuals with autism are assigned to specific activities based on their interests and talents with opportunities to change to a variety of activities in a flexible manner.

The items the residents produce are sold at the shop on the premises at Seerau as well as at markets in the immediate neighborhood. This exchange helps the community understand and respect the Weidenhof residents as well as contributes to the confidence of the individuals with autism in their work.

Peter Sommer
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Cover Artist: Garrett Sheline

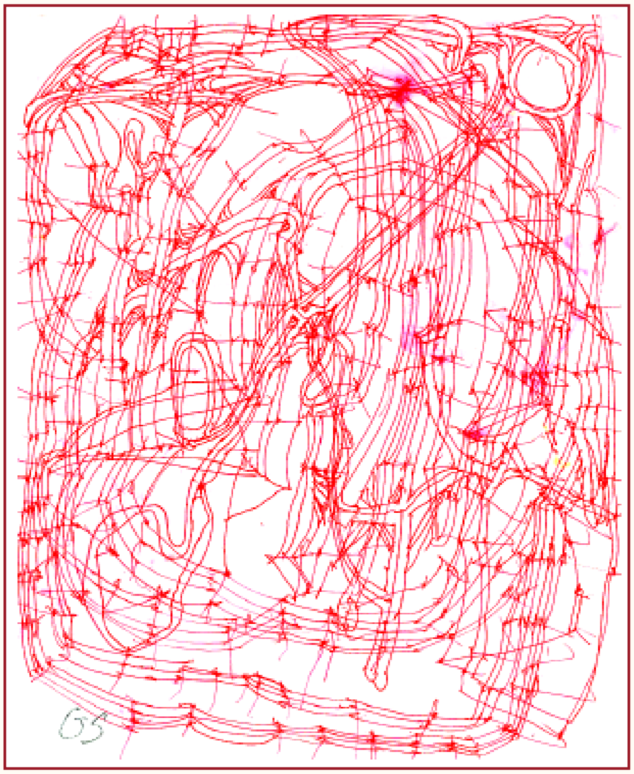
Garrett Sheline is a fun-loving 8-year-old who displays a big smile and caring personality every day. His initials are GLS, but should have been GPS as he is very in tune with the path he is traveling and all of his surroundings. One of his most remarkable fields of expertise is the very intricate Orange County Freeway system. He can advise you on the best route to many destinations. However, his true love is drawing trains and railroad crossings (with the hope of a passing train). Garrett loves spending hours designing an intricate railroad or freeway system. What is amazing is that just 2 years ago he was struggling with his fine motor skills - today his penmanship is flawless.

Besides drawing, Garrett's other passions include: music, cooking, swimming, video games and family outings in the great outdoors.

When in the car, he is always on the lookout for trains, windmills and landmarks to remember.

Garrett is an inspiration to all, demonstrating that with hard work and a great attitude you can overcome life's obstacles.

Written by Garrett's mom
To make a donation, please visit our website: www.autismnewsoc.org/donation.php



Noah Homes

By Molly Nocon

In the beginning there was a flurry of activity by concerned parents to try to solve a desperate need to know that our children with disabilities would be safe when we are no longer here to protect them. A group of us from several area churches joined forces and looked for a place we could call a safe haven. **In 1983, Noah Homes opened, and over the next 27 years a vibrant community arose on 11 acres in the rural outskirts of San Diego.**

Today, 70 men and women with intellectual and other developmental disabilities live and work at Noah Homes celebrating life to the fullest in a safe and loving environment. Five homes occupy the main campus and three more in the surrounding community. More than 60 staff members support our residents in their daily living skills. Noah Homes is a thriving campus of activity, an oasis of peace, and the hub of a concept that gives residents the chance to achieve maximum independence while enjoying the support of their friends, family and staff in every part of their lives.

The residents of Noah Homes leave their homes each weekday morning to work in their community at a variety of jobs and activities. Some earn salaries at an array of jobs at restaurants, bookstores, grocery stores and fast food establishments. Some go into the community with job coaches to garden, pass out flyers, and learn janitorial skills, while others do contract work for local industries. As with the rest of the community, work and paychecks are an important part of everyday life for our residents.

Weekends are an opportunity to enjoy all that San Diego has to offer. The choices are abundant and include Padre games, Seaworld, the San Diego Zoo, movies, sports practice, bowling, Special Olympics and worship.

Every day at Noah Homes is a day of learning and ongoing support from a dedicated staff in areas of personal care, independent living skills, problem solving and participation in leisure and social activities.

The staff at Noah Homes are all trained and certified by the State of California Department of Developmental Services as Direct Support Professionals. In addition, Noah Homes has health care and behavioral consultants on staff as well as House Managers, Casa Supervisors, and Residential Administrators certified by the State of California. Depending on their position, staff members are required to complete 8-20 hours per year of continuing education coursework.

Noah Homes Campus with Memorial Garden

Noah Homes is licensed and regulated by the State of California, Department of Social Services – Community Care Licensing and vendored by the San Diego-Imperial Counties Regional Center to provide services.

Noah Homes operates Level II and Level III homes. Both homes require 24-hour-a-day staffing. Residents in Level II homes are fairly independent; they may need some staff prompts and support for personal care issues, and many work in the community at paying jobs. Staffing requirements are one staff person for every six residents. Level III homes require a higher level of personal care for residents, assistance at meal times, and occasional assistance with walking or transferring. Staffing levels for 6-12 residents require the presence of 2-3 staff.

The philosophy of Noah Homes is one of supporting residents' ability to be as independent as possible, and to live as family units in their homes. This comes at a cost to Noah Homes since the State of California reimburses residential rates at the lowest level of care in each home. Noah Homes, Inc. is a non-profit corporation and accepts SSA and SSI and the residential rate from the State of California as payment in full. These two sources cover 70% of the operating costs. The rest is realized through grants, donations and special events.

We have found that the chance to offer a helping hand is something most people take great pride in doing in all walks of life. The same is true of people with disabilities. When a wheelchair-bound individual is rooming with an ambulatory individual, both inevitably grow in their desire to assist each other with daily living skills. While the person in the wheelchair needs help to reach the bookshelf, his or her roommate may need help reading their paycheck. Both feel wanted, loved and rewarded for their caring natures, and ultimately take great pride in their ability to help others. Gradually both residents become more independent, and enjoy life more as a result.

A day at the Padre game

Valentine's Day party at the Community Center

While the 27-year history of Noah Homes has proven that this partnering method is both positive and successful, the State continues to reimburse for the lowest level of care of the individuals rooming together. This creates a financial hardship for the organization, but creates a living environment that is the envy of other residential care facilities.

In 1998 a Community Center was built on the campus with a great room and offices that put all of the administrative staff under the same roof for the first time in 16 years. **The Walter Fitch III Community Center has become the activity center of the campus and hosts daily and weekly activities from campus bingo parties to exercise and dance programs to community meetings, as well as fundraising events.** The residents can interact in an extremely social campus, visit friends in other houses independently, or choose to stay close to home and enjoy the privacy of their comfortable and familiar surroundings. Each house offers a certain rhythm of activity and as new residents are accepted to Noah Homes, the staff carefully assesses not only the needs of the potential resident, but how that resident's personality will blend in with the existing family unit.

While we do everything possible to admit all who come to us, we must adhere to standards that will ensure a successful transition to a group living environment. For many people, this is their first time away from home in 40+ years. People may find themselves waiting several years for the right placement at Noah Homes, while others get lucky and find themselves a match for immediate opening. We take pride in the statistic that once placed at Noah Homes very few leave unless we are no longer able to meet their needs. **Noah Homes opened in 1983 with six original residents, and four are still here today.**

We have also started exploring Noah Homes' ability to accept more residents with a single diagnosis of autism, and have done several respite weekends to observe the interactions of our current, mostly Down syndrome population with these individuals. The initial feedback from staff and managers has been positive, and we are moving forward in that direction. **San Diego Regional Center estimates 25,000 individuals with autism are coming out of the school system in the next 10 years, with nothing in place to help their transition to adulthood.** We are hopeful that our movement in this direction will help us gain the needed knowledge to meet the residential care portion of their quest to live independent lives to their full potential.

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Preparing for the Unique Housing Needs of People with Autism in Orange County

By Janis White

In Orange County, as in the rest of the nation, we are preparing for the unique needs of housing for people with autism, as they age up within the school system. Regional Center of Orange County (RCOC) currently serves 3,300 individuals with autism out of our total client population of 13,301 individuals over the age of three. Looking at the high percentage of young children, our services will need to dramatically increase over the coming years as new children enter the Regional Center system. The Table below shows that more than 1,200 clients with autism are currently older than 15, reflecting the urgent need to plan for life beyond school. We are preparing now as the first RCOC students are exiting the school system and parents are asking, where will my child live when I can no longer take care of them?

> ***Currently almost half of the children ages 5 to 9 served by RCOC have a diagnosis of autism.***

Age:	Autism/Total number served	% with Autism
3-4 years:	273/678	40.27%
5-9	946/2019	46.85%
10-14	809/1,813	44.62%
15-18	478/1,449	32.99%
19-22	279/1,230	22.68%
23-29	224/1,634	13.71%
30-39	131/1,531	8.56%
40-49	92/1,411	6.52%
50+	58/1,536	3.78%
All	3,330/13,301	25%

Several options are available, and within each of those options, preparation is taking place to address the unique needs of people with autism. In Orange County, some of the current options are as follows:

1) Living at Home

First of all, there is always the option for a person to continue to live at home with his/her family. Families are given support as needed to address behavioral excesses and to help the individual find a job as well as learn independent living skills in anticipation of moving out in the future.

2) Supported or Independent Living

A second option is Supported or Independent Living. Here the person lives in an apartment that is typically shared to aid in paying rent, a situation similar to other young people who are setting out to live independently. The apartment is set up to address the needs of the person with autism. Everything is in its place; a schedule can be posted to give predictability to the day and the events that will occur. There is also staff support in this situation based on the individual needs of the person with autism.

3) Adult Family Home Agency

A third option is the Adult Family Home Agency (A.F.H.A.). Here an agency finds a match between the person with a developmental disability and a family in the community. In this way, the person with autism lives in a family home and the family is given monetary compensation to provide support for the person.

4) Traditional Group Home

A fourth option is the traditional group home. This is a home in the community that typically serves six people. The preference is for each person to have his/her own room,

> ***We must be prepared. We cannot wait any longer.***

which is set up in an individual manner. To aid in the transitioning process from the family to the new home, close approximation to their room at home is often helpful. Staff is available 24 hours a day and provides support, meals and activities.

The October 2009 edition of the *Autism Adovate* focused on residential options for individuals on the spectrum. One contribution pointed out that individuals with autism should be at the center of the design[1]. The author noted that when designing a place for a person with autism to live, it is important to emphasize the following:

1. ***Sensory balance*** – keeping the details simple with a predictable layout and open flexible spaces.
2. ***Universal design*** – a layout that is environmentally friendly, paying close attention to lighting intensity, temperature changes, textures, smells, and visual transitions as well as colors and noise patterns.
3. ***Socialization*** – include community-building spaces that incorporate individuals into a neighborhood. Designing to help individuals to connect with others is important to the growth of a person with a diagnosis of autism.

5) Communal Living

Although this type of residential option was used in the past, society has shied away from it recently believing that it did not provide an integrated setting. Now families have begun to request this option with the idea of combined living, working, rehabilitation and social opportunities.

Currently in Orange County there are several non-profit housing organizations that are working hard to prepare for the future of people with autism, among them Community Housing Resources Inc. (CHRI) and Acacia Housing. These agencies are already securing apartments and four-plexes for current and future needs.

Preparation is the key to the future for the housing needs of people with autism. The time to act is now as the number of people with autism served by Regional Centers continue to rise in each age group. Currently almost half of the children ages 5 to 9 served by RCOC have a diagnosis of autism. We must be prepared. We cannot wait any longer.

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Reference

- [1] Raterman, R., "Designing Spaces for Spectrum Populations" *Autism Advocate,* October 2009, 17-20.

Deciding if Residential Care is Right for Your Loved One

By Boyd Bradshaw

I recently received a video created by the parents of a girl with autism. It was a profound story that chronicled their family's fight to find a way to communicate with their daughter. Eventually, using computer technology, they were able to break through her veil of silence. Now their daughter can communicate quite effectively. What hit me the most was that the father in the video stated he'd kept going because there was no way he could ever give up. When asked why he didn't institutionalize her in Canada he said he could never do it, saying "How could you give up your child?!"

I felt a profound sadness because I knew the family who had given me the video, and who have a child with autism themselves, had viewed the film many times before sharing it with me. I operate residential care programs, commonly referred to as group homes, in Orange County, California. These parents had voluntarily placed their daughter with me two years earlier. Now, they were trying to reconcile their experience with the one chronicled in the video.

Choosing residential care is a difficult decision. Especially with children with autism, even behind the worst behaviors sits a glittering gem. Although a child with autism may behave in ways that are astoundingly different from other children, he or she is also an incredibly sensitive person. When these children create a bond with another person, they rely on that relationship to sustain them. The hours, weeks, and years of trying to figure out the smallest parts of his or her life all strengthen the bond. People who don't know the child stare, and often don't have patience with them. Many people try to be compassionate but all they manage to do is to be patronizing.

Various circumstances may cause a family to consider a residential placement. One such circumstance occurs when the family is in chronic crisis, either because the child takes a disproportionate amount of the family's energy to the detriment of siblings, or because the family operates with a lack of sleep or a lack of personal freedom. I am currently working with a parent who recognizes that she has a much better relationship with her son when he is not residing in her home. With frequent visits, this mom finds that when her son does spend time with the family, he is more relaxed AND that she is more focused on enjoying him.

> *"If you are considering residential placement for your child, it is important to remember that residential providers are diverse."*

A good residential option can also be beneficial to the child. In my 18 years of experience, I have observed that the most frequent weakness within families is consistency. In a good residential care program, consistency is much easier to achieve. In the home, consistency falters after eight hours of work, after cleaning the home, trying to get the laundry done and food on the table. Consistency waivers when you are trying to get through a grocery store. A good residential care program has the unique advantage of 24-hour staffing. This means that when a staff person begins to falter, another familiar staff person can jump right in. Keep in mind their full responsibility when on the job is to care for your son or daughter. In the normal family environment, parents are juggling many different responsibilities, and getting pulled in different directions. Another benefit found in a good residential care program is an ongoing effort to help your son or daughter learn how to interact and deal with the bigger world. If they have problems in public spaces, instead of avoiding them, staff assists them and helps them begin to understand their limits and how to cope better with those environments.

If you are considering residential placement for your child, it is important to remember that residential providers are diverse. There are some excellent programs out there. Unfortunately, there are also

A nice large yard provides leisure options for the residents of the group home

entities that would not fit the criteria of the good residential program as I have described above. This doesn't mean they're necessarily bad as much as that they may not be consistent or understand your child's needs as well.

To begin to identify the program that would best serve your son or daughter I recommend interviewing the owner of the program. Do not be satisfied by speaking with anyone other than the person who is the licensee of the home. If you speak with anyone else, keep in mind they are only an employee. This means their vision may be constrained by limits placed on them, and that they may not be with the program in the future. Things to ask the owner include but are not limited to the following:

- Don't tell the provider what you want, instead ask what they do. A common mistake parents make is that they tell the prospective residential provider what they want, which results in the residential provider being able to say "yes we can do that ..." For instance, if your son or daughter uses PECS at school, ask the provider what communications systems they support – then look for evidence. You would expect a home with a good picture communication system to have picture signs all over everything. In a home that uses sign language, you would expect to see staff signing.
- Ask the owner who will be attending the IEP's. Keep in mind that a good residential care program should be involved in the educational process both to ensure consistency AND to simply be aware of what is going on at school.
- Ask what therapeutic programs are continued from school for the children?
- Ask which doctors they use (primary care, as well as psychiatry and other specialties) and which dentists?
- How is the residents' money handled?
- Which consultants does the program use?
- When is bedtime? How is the situation handled if the child does not want to go to sleep?
- Ask the owner specifically what they believe (fill in the diagnosis) is. If the residential provider does not even understand the disability, how can they be expected to understand your son or daughter's needs?
- Ask the owner who their best direct care (Direct Support Professional) staff person is and then ask to speak to them. Ask this staff person what they do.
- Ask the owner about holidays and weekends. If the provider says the child must go home, be aware that this is against regulations unless YOU AGREE to it.
- How many of the staff drive and how do they arrange transportation for activities and outings?
- What transportation is used and where is it kept?

When you look at a residential care program you should look for little things like the following:

- What types of activities do they do in the summer? Do not just ask for the activity schedule – look for it first. It is required that the activity schedule be posted.
- Does the home have toys and games? Look first then ask where they're kept.
- Look around the house to see if there is evidence of the different therapeutic modalities that your son or daughter gets in school or benefits from.
- Observe what activities the children are involved in during your visit.

Another benefit of the residential option is that a good residential care program provides the individuals it serves with opportunities to grow. For example, a common issue with individuals with autism is their socialization. Being outside their family unit puts them in the position of having to use more socially appropriate interpersonal skills. Sometimes families get used to being attuned to the individual's nonverbal behaviors. As a result, they facilitate the navigation of the child through most situations. While this is not harmful, it will be much more difficult to act as the liaison between your child and the community as he or she becomes an adult. Unusual accommodations or situations are much less acceptable as the individual ages. In addition, some behaviors that were tolerated by others during childhood may be perceived as threatening behavior from an adult. A good residential care program facilitates your son or daughter learning the necessary social skills to be more successful in adulthood.

This article was written not to advocate for residential care, but as the basis for understanding some of the benefits of a good residential program and how to find a good program. Hopefully, the message presented in the video "How can you give up your child?" can be recognized as incomplete. A better question might be "How can you best help your child and your family?"

It reminds me of a personal lesson I received in my driveway recently. I was talking with some elderly neighbors who walk past my home daily. Chatting about the family losses this past year, they inquired if we were going to replace the service dog for my son, which had drowned. I told them although we cherished the dog and he'd done wonders, fortunately, he was no longer needed. I then proudly rattled off my son's exciting progress over the past year. They oohed and ahhed, giving me the desired feedback and pat on the back. Then, just when I was basking in my current glory, they asked what our plans were for our son's future. As a parent, I immediately stumbled into how we didn't know but we would cross that bridge when we came to it. Ever so politely, Nickie then softly noted that they'd been close friends with a family who placed their child in residential care, and it turned out to be the best thing that could ever happen to the child. They felt the young man had matured through living outside the home. Yup, eighteen years in this field and I, too, have a hard time planning for my own son's future.

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Meeting the Need

By Susan Johnson

Background on Advocates for Adults with Developmental Disabilities

In 2005, a handful of parents in Irvine first met around a dining room table to discuss the inevitability of their own death, and to plan for what would become of their children who had a variety of developmental disabilities – from autism and Down's syndrome to severe seizure conditions. It was their desire to provide a plan for their own children that could also serve others and be used as a model for communities nationwide. Today the core group has grown to include additional parents and interested parties, and is called Advocates for Adults with Developmental Disabilities (AADD). To help push the agenda forward, AADD recently partnered with Community Housing Resources Inc. (CHRI), a nonprofit agency dedicated to providing housing opportunities to people with disabilities.

Advocates for Adults with Developmental Disabilities (AADD) is championing a simple, clear plan for the future: sustainable and inclusive residential communities in which citizens with developmental disabilities -- and others with similar needs -- can live safe, productive and independent lives.

A recent Southern California Association of Governments study projecting needs for 2006 - 2014, determined that Orange County will need at least 17,733 housing units for *"very low"* income residents. Sadly, the report makes no mention of the *"very very low"* income units that are needed to house citizens with developmental disabilities. These citizens aren't even on the radar screen as plans evolve for affordable housing.

What can be done about that? AADD believes the key is "shared solutions for shared needs."

The residential and community needs of adults with developmental disabilities are shared, to a surprising extent, with other special needs populations, including seniors, physically disabled and low-income populations. A new approach to serve and house these populations can be more cost-efficient than existing models.

Our goal is to help city planners, county and state leaders, federal government housing and social services agencies, private service providers and the general population understand that these seemingly disparate groups actually share many needs, including:

- Affordable, accessible housing
- Easy access to reliable public transportation or para-transit services
- Ready access to such essential life services as:
    - Medical care and oversight
    - Restaurants and cafeterias with nutritious, affordable meals
    - Continuing education and libraries, etc.
    - Leisure activities, including movies, recreation, sports facilities, and adaptive physical exercise facilities
    - Retail stores, including groceries, pharmacies, and clothing stores
- Employment and/or volunteer opportunities
- Independent living assistance, instruction and services

We believe our vision is in keeping with the current economic and societal realities – starting with the hard fact that Orange County is one of the nation's 10 least affordable metropolitan housing markets.

An adult with developmental disabilities who is receiving an $870 monthly Supplemental Security Income (SSI) check would need 149% of that amount to rent a one-bedroom apartment in Orange County.

Unfortunately, too many Californians with disabilities face similar predicaments. In 2008, the state was home to more than 601,700 non-elderly adults with disabilities who are receiving SSI benefits.

Time for a new model

Economic realities have derailed the old model of creating and funding separate systems to house and service seniors, physically disabled residents, adults with developmental disabilities and other low-income households.

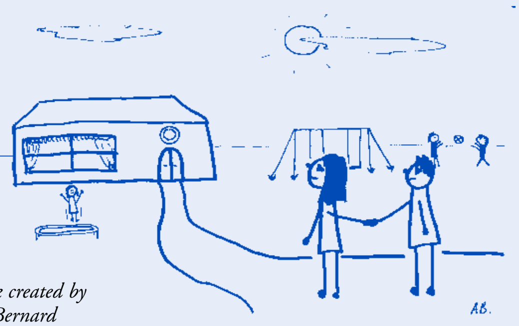
We're not alone in thinking this way. Our vision is echoed by the Urban Land Institute (ULI), an internationally respected group that describes its mission as providing "leadership in the responsible

HIGHLIGHT

A Mother's View

What I am looking for in a living environment for our son

1. A group home with individuals he either knows or is compatible with, who can play games with him and participate with him in joint activities.
2. Staff that lives with the residents and understands and respects them. The live-in commitment of the staff should last at least a year.
3. A home that is part of a community of homes at a minimum, and part of a greater organizational community, if possible.
4. An oversight board that can include parents, representatives of a charity and other individuals who monitor the operation and staffing of the home(s). The board should be designed to outlive the parents of the residents.
5. Staff that makes sure the residents have meaningful and fun jobs and/or activities that allow for interaction outside the home to broaden the residents' interaction skills.
6. A schedule that incorporates trips or overnight outings.
7. Close proximity to where we or other close relatives live.
8. If possible, his own bedroom. ♥



Artwork created by
Andra Bernard

use of land and in creating and sustaining thriving communities worldwide."

In 2007, members of ULI's Orange County Young Leaders Group completed a pro bono study for AADD that determined that, *"there are multiple populations that are dependent upon the same amenities."* That finding led to ULI drafting a housing and services design that could better meet the needs of the aforementioned populations.

ULI's panelists concluded that *"through proper design, a synergy can be created"* that would benefit the physically disabled, seniors and developmentally disabled populations.

The ULI panel described this vision as "an all-inclusive location that allows for families and caregivers to have access to scarce resources for special needs." The ULI study made it clear that the "clustering" approach being suggested isn't intended to be "an island for segregation." Rather, it is envisioned as "an established environment and home in which individuals with specific needs can be served … in a sustainable model that contributes to the community at large."

> ***"The needs and abilities of citizens with developmental disabilities vary widely."***

Or, as ULI's report states: This is an innovative design that, while cost-efficient compared to existing housing and service models, emphasizes "the development and growth of the citizens within it."

The cluster concept

Clustering services to be shared – instead of duplicated – makes economic sense. Funding sources for one group could be combined, in some instances, to develop combined housing and services to benefit other groups as well.

Our vision of "clustered" housing with necessary services is in sync with a growing recognition among urban planners that the "old ways" won't work in the current economic climate.

Services for these special needs populations could be provided in a central hub building(s), with the housing located within walking distance. Currently, each population has its own social services delivery system. All would benefit, for example, from the creation of a single 501(c)(3) nonprofit organization to provide cohesive oversight and coordination of services. This single point of entry to services would be responsible for oversight, follow-through and accountability, improving the likelihood of more productive lives.

The prospect of shared facilities is limitless: a cafeteria for low-cost meals; a fitness center offering adaptive P.E. for the disabled, stroke victims, elderly etc.; common recreation areas for use by the disabled and the elderly; and a day facility for the developmentally disabled as well as the elderly. The hub could contain multi-use training/conference rooms; space for volunteer organizations; a walk-in health clinic; and provide a transit pickup/drop-off zone.

Synergy, benefits, needs

The disabled, elderly and low-income residents can provide a ready workforce for the for-profit sector, as well as a significant volunteer base for community service. Because their needs and interests frequently overlap, creating communities responsive to their needs provides opportunities for multi-generational interactions that are likely to enhance individual lives and to create a more vibrant community.

The needs and abilities of citizens with developmental disabilities vary widely. Although they share many needs with other group, the housing initiative is particularly important to adults with developmental disabilities because:

- They are more likely to remain low income for life and require permanent low-cost housing.
- They are more likely to remain single.
- Most will never have a driver's license or a car, so they are unable to transport themselves to medical appointments, grocery stores, banks, and other needed errands.

- Many are hard-pressed to use telephones and computers, and even if they have this ability, many lack the skills to communicate effectively with banks, insurance companies, Social Security etc.
- Most will need support from social service agencies for basic life skills.
- Without access to a supportive environment, many are destined to become housebound with a poor quality of life.
- Most have limited budgets and struggle to stay healthy, prepare meals, pay their bills and find meaningful work.

But…they can provide a ready and stable workforce with the proper support.

How about funding?

Housing funds are in short supply. It will be necessary to create an agency that can use multiple funding sources – for example, blending housing funds available through federal Section 8 and 211 housing. Though it is difficult to do, successful projects typically blend federal, state, local and private funding. Utilizing all sources of funding available makes it more likely that the housing stock can be sustained and continue to serve the desired populations.

Funding rules also require that life services be included for housing occupants – which makes it increasingly important that quality of life issues (which are monitored by funding agencies) be included. Simply creating housing isn't enough; quality of life also must be addressed.

What's next?

We are working with civic, business and government leaders to pursue construction of sustainable and inclusive residential communities that will give citizens with developmental and intellectual disabilities the opportunity to live productive and independent lives.

Our hope is to provide a plan and vision for Orange County so that public housing agencies and service providers will join with us as we forge partnerships to work toward a common goal: to provide appropriate housing and services for this deserving population.

We, as parents or caregivers of those with developmental and intellectual disabilities, have a unique responsibility to provide a voice for our loved ones, many of whom can't speak for themselves.

There is a lot of work to be done, but we believe that with your help it can be accomplished.

Want to get involved? E-mail Advocates for Adults with Developmental Disabilities at aadd.housing@yahoo.com. ♥

a few comments from our readers...

"This is a very informative, well-balance publication, which is extremely helpful to families and providers of children with autism and related disorders."

"What an incredible mag-journal this is!"

"I love getting the newsletter."

"High quality, informative, fills a niche."

"Very informative. I share it every month with the teachers I support. They appreciate the information."

"This is a great resource for families dealing with Autism."

"Important tool for sharing information with the community in Orange County."

"Excellent journal for best clinical practice in Autism."

Sexuality Instruction and Autism Spectrum Disorders

By Peter F. Gerhardt

Although generally difficult to talk about in an open and honest manner, sex and sexuality are central to understanding ourselves as individuals and are integral to our individual determination of quality of life. Contrary to some preconceived notions about sexuality, instruction it is not designed to titillate, arouse or excite and it does not focus primarily on the physical act of having sex. Comprehensive sexuality instruction, instead, focuses primarily on who the individual is as a sexual being and what that may mean in his or her life. Sexuality education involves instruction beyond just basic facts and knowledge and includes issues such as personal safety, individual values, gender-role identification, physical maturation and an understanding of the complex social dimension of sexuality and sexual behavior. In short, sexuality education, while complex, should be considered an integral element of a truly effective education for learners with an autism spectrum disorder (ASD) assuming that the goal of such an education is to be a safe, competent, and confident adult to the fullest extent possible.

Workshop at the Regional Center of Orange County

Definition of Sexuality

Human sexuality presents us with very complex subject matter starting with, the definition of sexuality. Sexuality, as defined by the World Health Organization (2004) is:

> *[ ] a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behavior, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors.*

Similarly complex is the process of sexual development which has been described as a "multidimensional process intimately linked to the basic human needs of being liked and accepted, displaying and receiving affection, feeling valued and attractive and sharing thoughts and feelings." (Murphy & Elias, 2006, p. 398) What both of these definitions boil down to is that sexuality, at its core, is simply part of being human. Avoidance of any discussion of sexuality and/or sexuality instruction as it pertains to learners with ASD con-

> ***But make no mistake: teens will encounter information about sex as part of daily life, whether it's from the media, overhearing locker room talk, watching the physical actions of couples at school or in the community, or being the subject of insensitive, sexually-oriented teasing by others.***

stitutes, in effect, a tacit denial of their humanity, which, I think we all would agree, is unacceptable.

History

For much of our history the very concept of individuals with any disability label being viewed as sexual beings was, by and large, anathema to the thinking of the time. The Eugenics movement (1880-1940) resulted in the wholesale sterilization of individuals with a developmental disability in an effort to reduce the number of such individuals being born. (Sobsey, 1994) Beyond the obvious moral and ethical challenges of such a practice, the logic behind the movement was seriously flawed (i.e., most children with a developmental disability are not born to similarly diagnosed parents but, rather, to neurotypical parents) and, thereby, unsupportable on any level. Up until fairly recently, the predominant method of addressing sexuality in learners with developmental disabilities was denial and suppression (Watson, Venema, Molloy & Reich, 2002). Not surprisingly neither one was, nor could be, considered an effective approach. Learners with ASD are, by definition, sexual beings and to deny them that status is to deny them appropriate access to a critical part of their life, their status as an adult, and their ability to be safe from harm.

The Components of Sexuality Education

Perhaps surprisingly, sexuality education starts very early in life (differences between boys and girls; using the boys room or girls room, etc.) and continues well into adulthood (dating, marriage, and parenting). Comprehensive sexuality education consists of instruction in three distinct (yet interrelated) content areas:

1) Basic facts/accurate information
2) Individual values and
3) Social relationships.

Effective sexuality education for learners with ASD is complicated by the language and communication problems and social deficits associated with the disorder. And while sexual feelings and interest may be high, a primary information source available to neurotypical teens, (i.e., other teens), is often not available to learners on the spectrum (Volkmar & Wiesner, 2003). This, in turn, often results in a situation where the information is not being taught in school, not being addressed by the family, and not being provided by friends resulting in little, if any, appropriate skill development. But make no mistake: teens will encounter information about sex as part of daily life, whether it's from the media, overhearing locker room talk, watching the physical actions of couples at school or in the community, or being the subject of insensitive, sexually-oriented teasing by others (for instance, the girl who develops large breasts earlier than her peers is often the subject of unkind remarks from classmates).

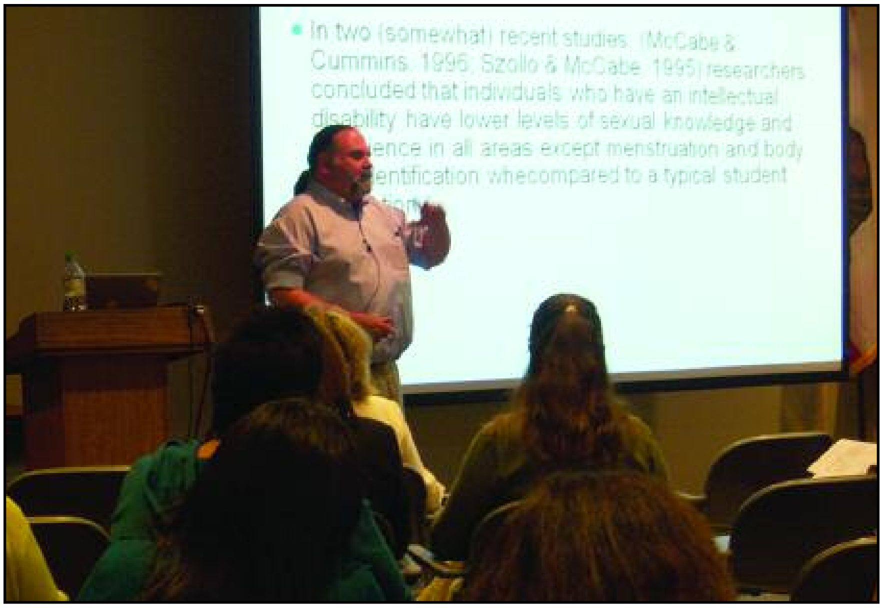
In light of the social challenges experienced by even the brightest learner with ASD, direct training and education about sexual issues needs to be provided, commensurate with each individual's receptive and expressive abilities. This direct social skills instruction should be two-pronged, on one hand, discussing the complexities of relationship building and, on the other hand, more concrete discrimination training as to who can, and who cannot, help in the bathroom, with menstrual care, at the doctor's office, etc.

General Instructional Considerations

In general, the three basic goals for sexuality instruction mentioned above - sharing basic facts/accurate information; developing individual values and teaching appropriate social relationship skills - should form the structure of any program for learners with ASD. Age and functioning level will affect how information is shared, but adults should use care not to restrict education because of their own preconceived notions about what these learners

What most children with ASD should learn:

- Circles of comfort (who may touch you or ask you to undress)
- Good touch/bad touch
- Bathroom and locker room independence
- Reporting of past events such an inappropriate touch

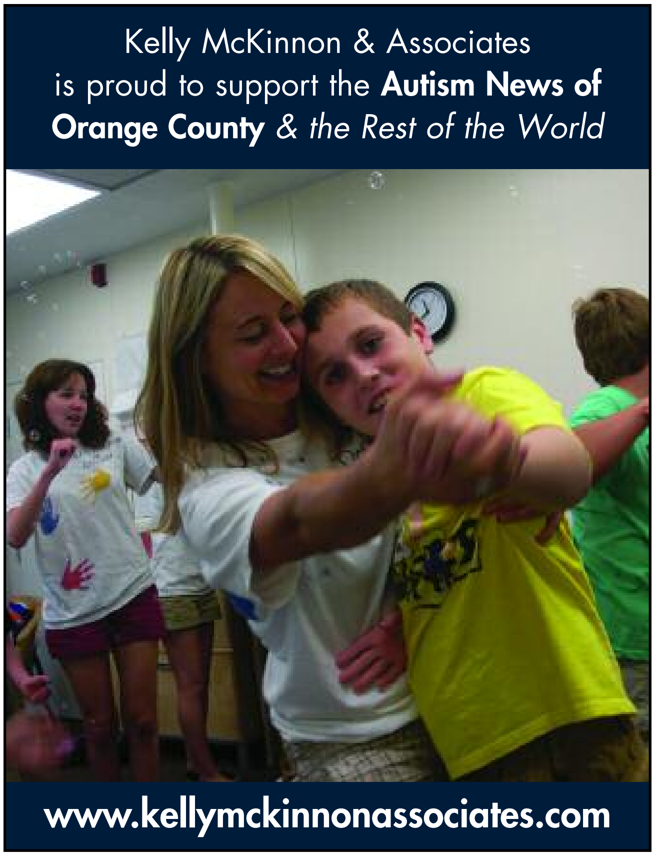

In two (somewhat) recent studies (McCabe & Cummins 1996; Szollo & McCabe 1995) researchers concluded that individuals who have an intellectual disability have lower levels of sexual knowledge and ence in all areas except menstruation and body entification whecompared to a typical student

Peter Gerhard presenting a workshop on Adolescence and Autism: Sexuality and Life Issues

“need” or “want.” Other guidelines include:

- **Think ahead and be proactive**
    - Waiting until something inappropriate happens is not an option. For example, training in appropriate menstrual care should start prior to onset of a young woman’s first period if it is to be most effective (and potentially, less challenging).
- **Start when children are young**
    - Don’t make the mistake of waiting until the individual expresses interest in sex for education to begin. Teaching children about personal safety issues such as good touch/bad touch, consent and personal boundaries should start at an early age.
- **Be concrete and factual**
    - Be concrete and factual in presenting information, but also calm and supportive in all your interactions. References to the “birds and bees” as an introduction to sex or comparisons of the vulva to “petals on a flower” will, in all likelihood, be misunderstood. Much of the information is factual, based on biology. Use visuals whenever possible.
- **Break larger areas of information into smaller, more manageable blocks (task analyze).**
    - For some individuals discussing the biological underpinnings of pregnancy may be quite appropriate while for another a more simplistic explanation may be sufficient.
- **Remember that sexual behavior is social behavior**
    - Always remember that sexual behavior is social behavior and, therefore, the social dimension of sexuality needs to be addressed when and wherever appropriate. “Hidden rules” regarding sexual behavior are pervasive. Masturbation, not often thought of as having a social component, does indeed and it includes such social rules as: 1) don’t masturbate in front of others; 2) your bedroom is the appropriate place for masturbation; and 3) close the door to your bedroom if you want to masturbate, etc.
- **Revisit skills regularly**
    - Keep in mind that sexuality education needs to be consistent and the skills learned may need to be monitored to make certain they are retained. Once a young woman learns who can/cannot help her with menstrual care, our hope is that this skill is rarely needed in real life. However, important skills such as these may have to be revisited at different times across her life to assure their maintenance.

Sexuality education with learners with ASD is often regarded as a “problem because it is not an issue, or is an issue because it is seen as a problem.” (Koller, 2000, p. 126). In practice this means we generally ignore sexuality as it pertains to learners with ASD until it becomes a problem, at which point we generally regard it as big problem. A more appropriate and, ideally, more effective approach is to address sexuality as just another, albeit complex, instructional focus, the teaching of which allows



learners to be safer, more independent and more integrated into their own communities, resulting in a more positive quality of life. As noted by Koller (2000), the question no longer can be if sexuality education should be provided, but rather how it will be offered.

The article was reprinted with slight changes and kind permission from Autism Asperger's Digest, Nov-Dec 2006.

Dr. Peter F. Gerhardt is President of the Organization for Autism Research, and has over 25 years experience working with adolescents and adults with ASD in educational, employment, and community-based settings. He has authored numerous articles and book chapters on adult issues, school-to-work-transition and problematic behavior.

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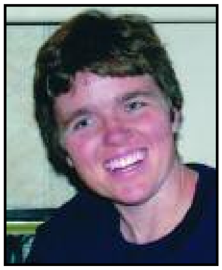
Tiffany's Mom

By Marti Morrissey

(Left) For many years Tiffany was featured on the cover for The Autism Research Institute, San Diego



(Right) Tiffany as a happy adult

There was a time when I felt the worst thing a mother could possibly face was having a child with autism. Facing these challenges has proven to be the purpose of my life and given me more joy than I could ever have known as a "typical" mother. After more than thirty years of learning and struggling financially as well as emotionally, I find myself directing an agency that successfully serves over sixty families challenged by autism and other severe communication and behavior disorders.

Promising Futures Inc. provides residential, transportation and day program services in San Diego County. Our day treatment program is focused on active treatment plans that enrich the lives of the individuals we serve while providing prevocational experiences. Many referrals come to us of clients with no work skills and few (if any) communication skills. Because of their inability to compete in the work force, many have had precious unsuccessful day program experiences. Our success is measured by the reduction of behavioral episodes, skill development and reports from the families we serve and we are happy, that over 80% of our clients meet their annual objectives.

A Promising Futures home for adults with autism

My daughter Tiffany was born in 1973 when professionals knew little about autism and the mother was still seen as the cause of the child's autism, and was often labeled a "refrigerator mother." Services were limited, but we were fortunate to find a small private program in San Diego that served young children with autism. This program equipped me as a young mom and taught Tiffany communication through sign language and pictures. While she made progress on one side, tantrums and aggressive behaviors developed that were almost life shattering and made a regular family life impossible. Tiffany's father left when she was six years old. Raising her and her older brother Todd, who struggled with the split in our family, made me face the reality that I might not be able to finish this task. Too many times I felt I would not survive the constant needs, stress and physical limitations placed on me without a support system.

I had worked for agencies that provided residential services for disabled individuals for almost ten years. **I felt I could develop a residential model for a community-based program that would teach more, love more and provide a quality environment. My hope was that families would feel blessed to have their child placed there.** There were many doors opened to establish Promising Futures' first two homes. The financial struggles were monumental, eating up most of my personal resources. The young children placed in the first two homes progressed and succeeded on all expected levels. I probably never would have started a third home because of the financial challenges with the first two homes. My own daughter was still not placed in a home. She had been on a "waiting list" for eight years. (I put the request on her individual service plan every year for eight years). I never wanted to be her provider and felt that another provider would be a better solution for Tiffany.

After two failed placements with other providers, both of them tragic for Tiffany, I opened our third home. Tiffany was the first resident placed in this home and after twenty-three years of care, I felt a great liberation. I knew she was safe, well cared for and I still had a big part in her life. The first five years were not without trials, but Tiffany has learned to live without being totally dependent upon me alone. I often see families trying to provide all of the necessary care for their adult children with autism. This is a huge burden, especially when carried for many, many years. Most families want some separation from their adult or adolescent children, but services are often unavailable or limited. Total dependence upon the family is not a goal, but rather the opposite. Our children with autism should have the ability to access independent living arrangements when they are not in a crisis. Health crisis or the death of a parent can cause an immediate crisis in the life of a child with autism. I wanted my daughter to adjust to living independent of me, while I monitored and supported her.

My own daughter had been on a "waiting list" for eight years.

It has been ten years since Tiffany began living in one of our six bed group homes. **She has made tremendous gains in terms of her self care (showering/tooth brushing), independent living skills (cooking/cleaning) and YES even her behavioral problems have decreased.** She is always well behaved for me when I have her for visits. She knows that if she acts like a two-year-old, she goes home immediately. I can spoil her rotten now. She gets almost anything she asks for but she must NOT tantrum or hit. She understands this and I enjoy her visits as much as she does running up my Visa account.

The structure of each of our homes has provided Tiffany with the environment she needs to succeed. The staff keeps our clients active in the community with monthly dinner outings at non-fast food restaurants, beach outings, concerts and shopping. I am the one without a social life now. Tiffany loves to go shopping and loves the "routine" party schedule. Each individual has five or six measurable objectives that provide teaching throughout the year. Programs are designed for the success of the individual and broken down into small teaching steps if necessary. This rich, fun environment has provided not only my Tiffany with a desirable future but the 17 other parents enjoy the same peace I feel. We have monthly "family parties" and parents often express their gratitude and appreciation for the services we all know are too rare.

View from the front of the home

It's always easier to look back on a challenge and say "It's over and I am glad I experienced it," but it truly did make me a better person. Looking at my beautiful, healthy grandchildren, I still long for the little girl who never was because of autism. One of my many rewards on earth is my precious granddaughter, Victoria Tiffany, who allowed me to have the tea parties, snuggle feasts, fancy dresses and baby doll parties that I missed with my Tiffany. Facing life's challenges does have rewards.

The staff keeps our clients active in the community…

I am the one without a social life now.

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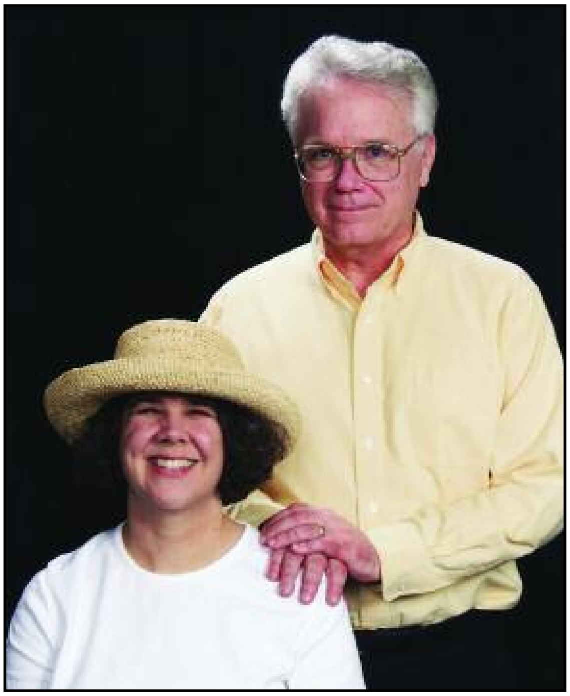
Marriage and Asperger's Syndrome

By Jennifer McIlwee Myers

I'm an adult with Asperger's Syndrome who has been married for sixteen years. As such, I get asked a lot about how people with Asperger's or high-functioning autism can have a successful marriage.

Many of the things that make marriage successful for people on the spectrum are the same things that make marriage successful for neurotypical people. Extensive data shows that people rate their experience of their relationship in proportion to how much the partners have in common. Interests, values, level of sociability, likes and dislikes don't have to be identical, but people who have a lot in common get along better at every level, from the first date to well into the marriage.



Jennifer McIlwee Myers with husband Gary

For people with Asperger's, this often means common interests and behavior patterns. My husband Gary and I met in a science fiction and fantasy book discussion group – a room full of bookish, geeky types who just loved to spend three or four hours debating the use of symbolism in *The Lord of the Rings.*

After some years in the group we started hanging out together because there were activities and interests that both of us enjoyed. You can't get to know someone's interests in a club or bar; you need an activity or group that allows for conversation and observing people over time.

The first time Gary and I went to the movies together in 1992, it was not a date; it was just two friends seeing a movie. In this case, the film was *Bram Stoker's Dracula.*

When I got to Gary's apartment to pick him up, he asked me in so he could show me a presentation he had put together. He had all of the laser discs of all of the major versions of *Dracula* lined up across the front of the entertainment hutch, and he had a small notebook in which he had written down the location on each disc of a short scene that he felt epitomized that particular version of *Dracula.*

He had put it all together, showing each movie clip in chronological order, to make up a presentation he called "Dracula Through the Ages." It was intended to allow us to view this newest version of the story in the context of the development of the Dracula narrative in Western culture.

Well, of course this floored me, and I was completely smitten. It rang all of the right bells. It not only showed an interest in something I loved, but was also presented in a fun and friendly way.

- ***That last sentence is important. Many people with Asperger's gather a lot of information on their particular interest and will make either a formal or informal presentation at the drop of a hat. This can be a total turn-off when it is intended to show off, and can be a total bore when it is used regularly as a means of communication. People, including potential dates, do not like to be subjected to one-sided lectures on model trains or historic sidearms.***

The second key to dating and mating with Asperger's is that while common interests and common ways of behaving are great, they won't help a person who is rude or obnoxious. A person who lectures constantly, doesn't listen, and who always has to be right will not charm anyone.

When I was in my twenties, I came across an article that told me that in a marriage, you could either be right all of the time or you could be happy, but not both. I didn't fully understand it at the time, but it turned out to be the truest and best advice I have ever received.

Don't get me wrong; I love to be right. I love, love, love to win arguments, I enjoy knocking down other people's poorly supported and badly thought out ideas, and I just really like being the one who "wins" the fight. I have often been willing to act against my own best interests just to be *right!*

But the price of being right all of the time is terribly high, and most of us with Asperger's take a long time to learn that. We have many good qualities, but we are, on the whole, not a mellow people.

It is absolutely possible to win every fight with your boyfriend or girlfriend; all it really takes is the willingness to keep arguing no matter how long it takes. Sooner or later the other person will get tired or hungry or just plain sick of the argument and will give in just to get the darn thing over with.

As an aspie, I've been willing over the years to go to the mat over some really stupid arguments. With various opponents and for various reasons, I've successfully argued that I am right about which way the toilet paper is placed on the spindle, which is the best place to go for a haircut in Pasadena, what "angel hair" pasta should be called (the actual name is vermicelli), in what color ink checks should be written, how floor space in a dorm room should be allotted, what radio station one should set one's alarm clock to, how to wash dishes, how to make a bed, and whether Apple should have ever abandoned the Apple II line in favor of the Mac line (no, they shouldn't have, of course, and it was a very important issue for me to win a fight about in 2007 – a couple of decades after it mattered at all).

I have argued myself blue in the face over a whole ton of meaningless, minor, or pointless causes and alienated perfectly nice people in the process. I have made friends with common interests into enemies, I have bored rooms full of people, and I have worked myself up into serious digestive trouble over these petty, silly arguments.

- ***You can't sustain a successful marriage very long unless you can learn to let things go. My fellow aspies and I often have a hard time seeing that there can be multiple "right" answers, or no particularly "right" answer to a question. We certainly have difficultly learning that one activity (like making the bed) or one item (like computers) can come in more than one flavor without it being a disaster.***

If you can't handle the fact that you are a Mac and your sweetie is a PC with good humor, you are not going to be able to make it as a couple. If you complain every time your spouse makes the bed, does the dishes, or vacuums because you think s/he did it *wrong,* you are going to wind up doing the housework just the way you like it in your own lonely apartment with no partner to mess things up.

- ***The third key to dating and mating with Asperger's is to treat your spouse, family, and friends with respect, decency, and goodwill. If you assume that the person you love is out to get you, then your marriage won't last – if you ever get that far. If you feel it is okay to be rude to your spouse because "we're family, I should be able to relax at home" or to ignore your spouse's needs because "I told you I love you when we got married, I shouldn't have to say it every day" then you will wind up losing your sweetie to someone who says kind, nice, and/or romantic things more often.***

These are serious problems. I've seen the effects of incorrect assumptions and it is sad: when one husband of my acquaintance simply lost his wedding ring (he's a bit absentminded and tends to lose things) his wife was furious, saying that he wouldn't have lost it if he really valued it and that it was totally disrespectful to her. She had no goodwill for him; nowhere in her mind was the idea that maybe he was just a bit clumsy and it had nothing to do with how he felt about her or his marriage. It turned into a major disaster, even though they could easily have afforded to get a new ring.

That's what happens when one partner doesn't consider that their partner has basic goodwill. In aspies, this can happen when a spouse forgets that the other only eats pizza of a certain kind or wears only clothes made of specific fabrics. Bringing home dinner as a surprise or giving a gift that transgresses that aspie's specific rules for buying can mean an explosively angry aspie.

So basic goodwill, with the assumption that the partner, being human, will make mistakes and that this is not horrible, but instead merely a bit inconvenient and possibly annoying, is vital. The aspie (or other) partner who has no tolerance for disappointment and frustration will wear out his or her partner very quickly.

- ***Basic goodwill also includes respect, politeness, and kindness. Some people assume that once they are married, they don't need to make any attempt to "woo" their spouse.*** This isn't just an aspie problem, but it is important for aspie couples too.

What made me able to be different was that my parents both modeled and insisted on basic politeness and kindness. My mom cooked dinner every night, and every night, before he got up from the table, my dad thanked her for making dinner. Every night.

Not only that, I was required to be polite and kind. If I had a meltdown and yelled at my mom, I had to apologize. If I had a fight with my dad, we both had to apologize for letting ourselves get too angry. I was taught that you don't just apologize when you "feel" like apologizing; you apologize because it is the right thing to do.

For example, the rule I was taught was that if you accidentally trip someone, you haven't done anything wrong and you might not feel bad about it, but you apologize because you have caused someone inconvenience or pain, however inadvertently.

I had to apologize for things I said when I had meltdowns, too. Just because I had been "out of control" didn't mean I didn't have to clean up after myself by "saying sorry."

- ***It is often very hard for people on the autism spectrum to learn the broader concepts of kind and polite behavior, simply because the rules for kind and polite behavior are not intuitive and do not fit a pattern that can be recognized from just a few examples. It was absolutely necessary for me to be taught many specific rules and examples of polite and kind behavior so that over time I could start piecing together a concept of what behaviors a person should do in order to be kind.***

After all, both kindness and politeness are things that only work if they are communicated to the other person or people involved. If I leave someone alone when they are sick because I like to be left alone, what gets communicated is not what I intended – so

Who am I?

A puppy represents me because I am hyperactive. I am also loyal to my friends. Puppies like to play and so do I. They are also social and so am I.

A magnifying glass signifies me because they help you see detail. I am very complex. I like to dig deeper into things so that I can learn and understand things.

A butterfly symbolizes me because I am graceful. They are also unique and so am I. Butterflies also represent change as they develop from a caterpillar to a butterfly and I also experience change.

I chose a book to characterize me because I love to read. I also love to write. Books also have ups and downs and so do people.

I also chose a historical painting because millions of years from now, we will be considered history. History is also a part of art because we learn about other people's cultures. Also, I like to draw.

~ ***Karen Michel***

those of us on the autism spectrum need lots of practice to be able to communicate what we really feel.

I am not sure if others would support me, but I think the "lack of empathy" aspect of autism spectrum disorders is wrongly named. I think the real problem is *lack of information.* It is impossible to feel empathetic or act in a sympathetic way if you can't tell what other people are feeling and don't know what might make them feel better. Constant training from my parents in politeness and kind acts made it possible for me to learn to be empathetic in action and thoughts. I didn't need to somehow "feel" empathetic; I needed to know when other people were hurting, when what I do might be hurtful, and what to do to help. Through lots of examples and coaching, my parents taught me this.

- ***I wish all children could be taught this set of conditions for whether or not to say something:***
  - ***Is it true?***
  - ***Is it kind?***
  - ***Is it necessary?***

There are adults on the spectrum who only ask the first question, and don't realize that anything they say should also be at least one of the second two things: kind or necessary.

Conclusion

The requirements for a successful marriage for people with Asperger's are very much the same as the requirements for anyone to have a successful marriage. The difference is that we are unlikely to figure these things out on our own, and we need a lot of support to learn them. Parents and family members can make it more likely that an aspie will be successful in a relationship as an adult if they spend that aspie's childhood teaching them about appropriate, kind, and respectful treatment of others. It also helps a lot if someone lets the aspie know that winning every fight and always being right are sure ways to lose out when it comes to relationships with other people.

Jennifer McIlwee Myers

Weddings and Asperger's Syndrome

By Jennifer McIlwee Myers

While some people with Asperger's may decide to have a "normal" wedding, most choose weddings that are a little different. There have been Star Wars weddings, Star Trek weddings, Renaissance weddings, Civil War reinact-ment weddings, and myriad others.

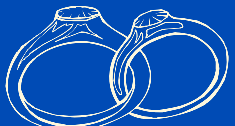
Gary and I, on the other hand, simply had the perfect wedding. We had been engaged for about a year, and one Thursday night I asked him if he would like to do something about getting married. He said that would be a good idea and he would pick me up the next day on his lunch break.

So that Friday, Gary picked me up and we drove down to the county courthouse and got married. There is no requirement that you have witnesses or guests or anything like that if you get married by a county clerk at the courthouse.

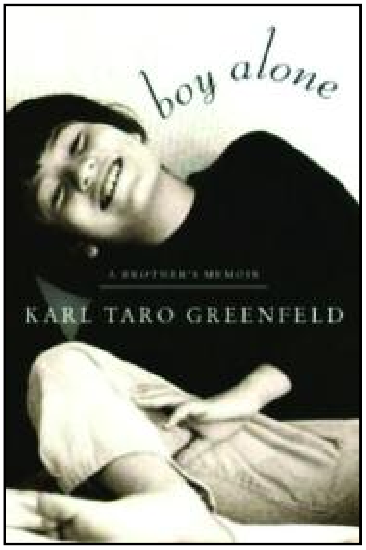
Once we got married, we had a quick lunch and Gary drove me to my appointment at the DMV. I took the opportunity to change my name on my new license, and then he dropped me off and went back to work.

Gary's colleagues noticed that he had taken a longer lunch than usual and asked him about it, so he told them he had gotten married, at which point his boss insisted that he take the rest of the day off and go home to me.

And that's how I got married.



Book Review



Boy Alone (2009) by Karl Taro Greenfeld, is a new book about how a brother and his parents, a Jewish father and Japanese mother, deal with Noah, their son with autism who is now 42 years old. The book describes their struggles, trials, frustrations, challenges and discoveries while dealing with Noah and his progression to middle age.

The parents, Josh and Foumi, moved from New York to Los Angeles in hopes that a new program at UCLA would provide a cure. They encountered both good and bad doctors, and had difficulties getting placement for Noah when he became too difficult to handle (around 13 years of age). The housing they found for him ranged from group homes to institutions to live-in care takers or host homes.

In an interview in *Time Magazine,* Karl Taro Greenfeld said, "My father and mother are in their 80's and will go on as long as possible caring for Noah... will I always be there for Noah, as my parents have been?" His answer, "I wish I could say, yes, definitely, I will be there. But I honestly don't know."

The question really is, who will take care of the developmentally disabled person after their parents pass away? Many of the siblings have emotional issues in administering a special needs trust or being a guardian for their developmentally disabled sibling. How can the parents provide for the care their child needs before they pass away, and thus achieve peace of mind?

There is hope and a solution. You can visit the website www.proxyparentfoundation.org for more information on Proxy Parent Foundation, a non-profit 501(c)(3) organization which is affiliated with the Planned Lifetime Assistance Foundation Network of California (PLAN).

Reviewer

Joseph DeCarlo *is the father of a 34-year-old son with autism, "Joey", who functions with the capacity of a 6-year-old. Joey lives at home and attends a Regional Center of Orange County funded program True Project Independence. Mr. DeCarlo can be reached at joe@jdproperty.com.*

HIGHLIGHT

Senate Select Committee on Autism & Related Disorders

The Senate Autism Committee has been established in order to promote policies and legislations to better assist individuals with Autism Spectrum Disorders (ASD) and their families.

The Committee is focused on addressing four important issues that are related to this disorder: that children are evaluated and treated at an early age; that private health plans are doing their fair share to provide medically necessary services; access to adequate employment opportunities; and the development and expansion of appropriate and affordable housing.

The Senators who comprise this Committee have appointed 12 Autism Regional Taskforces that consist of consumers, families, advocates and autism experts. These Taskforces, which represent some of the foremost leaders in the field of ASD, are working with the Committee to provide recommendations that will improve the outcomes for individuals with ASD, and their families, during the current economic crisis.

Janis B. White, Ed.D. Chief Operating Officer Regional Center of Orange County, has initiated the Task Force for Orange Country and coordinates four focus groups. About 50 local autism specialists from different professions are currently involved in developing recommendations. Results are expected in September.

For further information, please see http://www.senate.ca.gov/autism.

"Social Skills Town Hall"

PART II

AUTISM SPECTRUM OF SUPPORT
A S O S

Presented by
Dr. Alexander Gantman
Monday, May 17
at 7:00pm

Dr. Alexander Gantman of UCLA has generously offered to meet again with our A.S.O.S. group on Monday evening, May 17. This will be a follow-up to his presentation last October when he introduced us to his work in the area of social skills training for adolescents and young adults with Autism Spectrum Disorders, and the UCLA "PEERS" study (Program for the Education and Enrichment of Relational Skills).

THE MEETING WILL BE HELD AT:

7:00pm, May 17, 2010
St. Andrew's Presbyterian Church
Newport Beach, CA

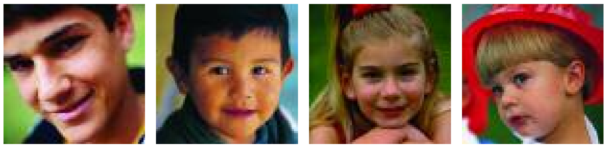
Social skills addressed by Dr. Gantman and PEERS include communication skills, choosing appropriate relationships, dealing with social rejection, resisting peer pressure, introductory dating etiquette, and social skills relating to vocational settings.

The Help Group UCLA
Autism Research Alliance

PEERS is conducted under the auspices of The Help Group – UCLA Autism Research Alliance. For information, call (310) 206-7284 or visit www.semel.ucla.edu/socialskills/programs/.

For questions regarding the May 17
A.S.O.S. meeting, please contact:
A.S.O.S. (Autism Spectrum Of Support –
formerly OC Asperger's Support Group)
Phone: (714) 227-8819
E-mail: ocasupport@gmail.com
Website: www.spectrumofsupport.org

Do You Have a Child with Autism?



Help international researchers discover genes that contribute to Autism. Participate in a UCLA study sponsored by the Simons Foundation Autism Research Initiative.

Who can participate?

- Families who have one child 4-17 years old with an autism spectrum disorder (ASD) or a suspected ASD and no other children with ASD

What is involved?

- Questionnaires, interviews and gold-standard psychological assessments (including ADOS and ADI-R)
- Blood draw and short physical exam

Participants receive

- Written summary of test results
- $200 per family

Participation in this study is strictly confidential and will not affect any services you may be receiving.

For more information call
UCLA at 310 794 2215

UCLA CART
CENTER FOR AUTISM RESEARCH AND TREATMENT

Pegeen Cronin, PhD
Info@autism.ucla.edu
www.autism.ucla.edu ◆ www.simonsfoundation.org

UCLA IRB # 03-07-098-13
Expiration Date: July 22, 2010

APPROVED • JUL 23 2009
UCLA Medical Institutional Review Board

Thank You For Your Support!

We very much appreciate the support for ANOC and thank the following donors:

Supporter ($1,000-$2,999)

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REACT Foundation

Contributor ($500-$999)

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S.H. Annabel Chen

Your support is urgently needed to help ANOC continue. Please visit our website at **www.autismnewsoc.org** for more information.

Thank you!

RCOC and Comfort Connection Family Resource Center

The Regional Center of Orange County and Comfort Connection Family Resource Center have developed a FREE Recreation Resource Guide, which lists many activities including sports, arts and camping. There is also a section with additional opportunities outside of Orange County. You can obtain a copy of this guide by visiting the Family Support link at www.rcocdd.com or by calling Comfort Connection Family Resource Center at (714) 558-5400.

REGIONAL CENTER OF ORANGE COUNTY

COMFORT CONNECTION FAMILY RESOURCE CENTER

FAN
Family Autism Network

The **Family Autism Network** is a model program, utilizing trained volunteers to meet the needs of the underserved families affected by autism in Orange County. FAN increases access to existing resources.

For further information, please visit the following website: www.faninfo.org

Tax-deductible donations

to ANOC are possible through the Autism Fund at the School of Medicine of UCI. Support is possible at the following levels:

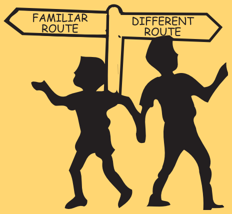
Benefactor: $5,000 and above
Sustaining Member: $3,000 - $4,999
Supporter: $1,000 - $2,999
Contributor: $500 - $999
Friend: $25 - $499

Please visit ***https://ua-web.uadv.uci.edu/egiving*** *for more information or to make a donation today!*

SOME EXAMPLES OF AUTISTIC BEHAVIOR
ALGUNOS EJEMPLOS DEL COMPORTAMIENTO DE PERSONAS CON AUTISMO

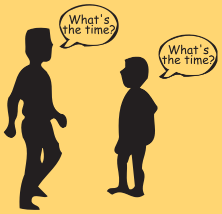

Avoids eye contact
Evita el contacto visual


Lacks creative “pretend” play
Carece el juego creativo



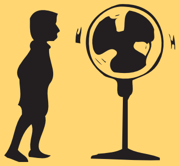
Does not like variety: it’s not the spice of life
No demuestra interés en variedad


Laughs or giggles inappropriately
Risa/reír inadecuadamente



Copies words like a parrot (“echolalic”)
Repíte las palabras como un loro
(“en forma de echo”)


Shows indifference
Demuestra indiferéncia


Shows fascination with spinning objects
Demuestra fascinación con objetos que gíran

Shows one-sided interaction
Demuestra interacción que es unilateral


Shows preoccupation with only one topic
Demuestra preocupación/interés en solo un tema/asunto


Displays special abilities in music, art, memory, or manual dexterity
Demuestra capacidades especiales en musica, arte, memoria or destreza manual


Shows fear of, or fascination with certain sounds
Demuestra miedo de/ó fascinación con ciertos sonidos

Some Examples of Autistic Behavior
Algunos ejemplos del comportamiento de personas con autismo

- Difficulty with social interactions.
  Tienen dificultad para socializar con otras personas.
- Problems with speech.
  Tienen problemas con su lenguaje.
- Disturbed perception.
  Tienen una percepción anormal de los sucesos que acontecen a su alrededor.
- Abnormal play.
  Su forma de jugar es anormal.
- Resistance to change in routine or environment.
  Se resisten a cambios en sus actividad rutinarias ó a su medio ambiente.


Does not play with other children
No juega con otros niños