

Best Practices for Serving Adults with Autism

***Results of the study on services and supports
for adults on the autism spectrum across
the United States***

Full Research Report

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Table of Contents

Background for this study	3
Methodology	5
Description of Target Population	6
Recommendations	7
For all individuals	9
For individuals living with their family	13
For individuals living outside family home	14
Program level recommendations	16
Staff level recommendations	19
State level recommendations	20
References	26
Appendix I: Summary of observations for program visited	27
Appendix II: Project participants	52
Appendix III: Organizations contacted via phone or email	53

Background for this study

Not many years ago autism was a low-incidence disability—one person in 10,000 received the diagnosis. As a result, little research was done on the causes of or treatments for autism. Since most diagnoses were of children enrolled in special education programs under the Individuals with Disabilities Education Act (IDEA), adults usually went undiagnosed unless they had been identified by special education systems. In adulthood, things became more complicated for individuals with autism. Not only is there no adult service mandate like IDEA for children, but autism and Asperger Syndrome are much less frequently recognized as diagnoses warranting any services for adults. Thus adults who may have been identified as being on the autism spectrum as children have generally entered adult programs designed for individuals with cognitive disabilities or mental illness. Such services do not take into consideration the unique behavioral, communication, and sensory challenges presented by autism. These challenges greatly impact behavior, and do so differently in every individual. After serving children and young adults with autism for over 25 years in educational settings, we know that individuals with autism require highly specialized services and supports that address these considerable challenges. We also know that independence and post-school employment depend greatly on the quality and stability of services and the relevant knowledge, expertise, and commitment of support staff.

Further, we are at a critical juncture in the advancement of services for adults with autism. There has been a dramatic increase in the prevalence of autism over the past 15 years. Autism is the fastest growing developmental disability. Growing at a rate of 10 – 17% per year, these diagnoses are surpassing cerebral palsy and Down syndrome (Autism Society of America, 2005). The rapid rise in the number of children diagnosed with autism has most states scrambling to address educational programming, yet few have begun to address the needs of adults. As much as 90% of the costs are in adult services (Jarbrink & Knapp, 2001).

The national growth in individuals diagnosed with autism is well reflected in Delaware's statistics. Until 2004 in Delaware, there were typically three to six students on the autism spectrum entering adult services each year. In 2004 there were 13 graduates of the Delaware Autism Program, in 2005 there were 21, and at least 25 graduates per year are projected by 2011.

Delaware has long been in the forefront of meeting the needs of children and adults on the autism spectrum, with a statewide educational program for 25 years, and the Special Populations program for adults in operation since 1989. However, our state must continue to uphold appropriate services and begin planning today. Unless proper planning occurs now, it is likely that future graduates of the Delaware Autism Program will enter programs that were not designed to address the complex needs of adults with autism. With increased public awareness about autism and a greater number of diagnosed individuals, it is reasonable to expect that the number of adults needing services will go beyond the graduates from the Statewide Delaware Autism Program. Newly identified adults may have received educational services under classifications other than autism as much as 25 or more years ago, or may not have been identified for special services at all. Yet, as adults, these individuals may manifest

communication, behavior, and social problems that affect their ability to live independently and hold a job. The rising numbers of adults, the expanding diversity of their needs, and the growing cost of adult services are making it imperative that we ensure that services in Delaware reflect “best practices,” that is, services that are appropriate, flexible, highly individualized, and have a good cost-benefit ratio.

We must make a special note here about individuals with Asperger Syndrome. In 2005, Delaware’s Department of Education recognized Asperger Syndrome as part of the autism spectrum. Previously, this disability was not recognized nor are specialized services generally available within the educational system. There are many adults and increasing numbers of graduating students who are just receiving this diagnosis and who are applying for services. But these individuals are not generally eligible for any adult services because they do not have cognitive disabilities. At the same time they may not have the functional skills needed to live, work, and function independently in the community. All too often these adults place an undue burden on the social welfare system, frequently with costly emergencies, when in fact many of them have marked strengths which allow them to perform very capably at home and in the workplace, provided they have the proper support.

The effectiveness of IDEA mandated educational and related services programming and the application of best practices in the educational setting has produced many young adults who can, with coordinated and timely transition services, enter the DDDS Community Service program rather than the more intense Adult Special Population Program. Although these young people require less intense and less expensive services, they continue to have needs for supports that are unique to individuals with autism. Therefore, the capacity of the DDDS programs designed primarily to meet the needs of individuals with cognitive delays and/or physical disabilities must be enhanced to meet the growing needs of adults with autism and to ensure that skills gained in school are maintained and enhanced throughout adult life.

If we do not provide effective adult services and supports, we will be failing a generation of individuals by wasting considerable financial resources; years of time and effort invested by these individuals and their families; and the tremendous dedication of many staff who prepared them for a life of independence and productivity. We cannot simply terminate the supports for improved communication and behavior, management of sensory challenges, and social and community integration and not expect marked deterioration in skills. Individuals do not “grow out” of autism, nor does it just go away on its own. The much-improved behavior and skills seen in the current generation of students completing DAP will inevitably erode without maintenance. Both young and older adults on the autism spectrum need ways to maintain the skills they have, and to continue to learn.

There is a growing recognition in this country of the importance of continuing education, and the term “lifelong learning” is becoming more and more common. Similarly, while young people on the autism spectrum must transition and begin to meet the challenges of young adulthood, they too need ways to maintain the skills they have and continue to learn.

In the spring of 2004, in recognition of this situation, Delaware’s Division of Developmental Disabilities Services agreed to fund a study by the Autism Society of Delaware to formally identify best practices for adults with autism on a nationwide basis, to review

services in Delaware, and to outline the steps required to ensure that best practices are adopted statewide.

Methodology

The Autism Society of Delaware contracted with Dr. Susan Peterson to conduct the study. Dr. Peterson is a clinical psychologist with 20 years of experience working with students and adults with autism. A behavioral psychologist, she has extensive experience in both writing programs and teaching communication. Dr. Peterson was supported by the Executive Director of ASD, Theda Ellis, who has extensive experience in adult services, training, and systems change. The project was also guided by the Adult Services committee within ASD, chaired by Karen Bashkow, parent of a teenager with autism. Additionally, there was a consulting committee consisting of Marie-Anne Aghazadian, parent of an adult son with autism and director of the Parent Information Center of Delaware, Dom Squittere of the Delaware Autism Program, Michael Partie of Therapeutic Options, who has extensive experience in working with adults with autism, and Dr. Donald L. Peters, Professor Emeritus of the University of Delaware, and the former director of the UD Center for Disabilities Studies. Dr. Peters, a named professor in early childhood studies, has extensive experience in developing new approaches to research and service.

Starting in September of 2004, the study began with a formal literature review. Not surprisingly, little was found that was specific to effective services and supports for adults with autism. During this period, Dr. Peters worked with the team to develop a different approach. We made contacts with autism provider agencies through the ASA chapter network, and conducted a web search through the Association of University Centers on Disabilities (AUCD) and through Centers of Excellence on Autism around the nation to learn where research related to adults and autism or services related to adults and autism was being conducted. We also contacted the membership of NARPAA, the National Association of Rehabilitation Programs for Adults with Autism. This allowed us to obtain information on a large number of programs providing services and supports for adults with autism. We contacted or attempted to contact all these programs and scheduled phone interviews. From September 2004 through February of 2005, Dr. Peterson and ASD staff carried out 24 telephone interviews with key staff in these identified program sites. The interviews used standard questions, and were used to identify programs to be visited. We looked for programs that, reported unique or comprehensive approaches to supports, were identified by other programs and individuals as exemplifying best practices, and served sufficient numbers of individuals that approaches might be transferable to Delaware.

Site visits were scheduled at eight sites in seven states between November, 2004 and February, 2005. During visits, the team spoke with staff members at all levels, with parents of adults being served, and with some adults as well. We asked questions about what programs struggle with and what components work best for them. Dr. Peterson participated in all site visits. In addition, at least one of the following individuals also participated in seven of the eight visits: Theda Ellis, Karen Bashkow, and Marie-Anne Aghazadian, parent of an adult son and Director of the Delaware Parent Information Center. Visit summaries for the eight site visits can be found in Appendix 1 of this report. The visits and interviews were supplemented by a review of written program descriptions and other relevant literature.

Following the site visits, project participants met a number of times to review the findings and draft recommendations. Others assisted (please see Appendix 2, the list of project participants and those who assisted). Feedback was also solicited from the members of ASD's Adult Issues Committee. All available information was reviewed from our varied perspectives and experiences of the participants with services in Delaware. Each program displayed a number of exemplary practices, but none of the programs exemplified all of what is construed as "best practices" as applied to Delaware's needs. Our reviews and interviews tried to focus on where each program was exceptional or doing something uniquely innovative.

Description of the target population

The adults who will need to be served and supported in the coming years are from two differing populations. On one hand, growing numbers of young adults are completing Delaware's Statewide Autism Program and have been preparing for this transition over an extended period. They have had a variety of work experiences; and they have received individualized communication, recreation and leisure, self-help, community, and social skills programming. While many of these individuals do not speak, almost all have at least some basic communication skills that allow them to make simple requests and to follow basic directions. Often they have had some experience living (part-time) in one of the Delaware Autism Program's teaching homes. Many have a history of moderate to severe aggression, property destruction, and self-injury, although the vast majority of these problems are mild or rarely exhibited by the time of transition to adulthood. While these individuals have a range of functioning levels, they tend to have moderate to very significant needs for support. These young graduates can often demonstrate impressive performances on the job and in the community, but it must be stressed that these performances have taken place within the context of the high degree of structure and support provided within the Delaware Autism Program. Once they enter adult services, the appropriate type, level and quality of supports must be in place for this group to continue to function as well as they do while in the educational program.

It should be noted that Delaware does not offer an entitlement to adult services or assure any adult with a disability that services will be in place when they graduate. Further, as students graduate without severe behavioral challenges, they will most likely enter community programming designed for individuals with traditional developmental disabilities (mental retardation). The concern is that the good behavioral status seen in exiting students greatly reflects the strong systems of supports they have been receiving, and that skills will deteriorate and behaviors will decline when educational supports are replaced by the greatly reduced support level available in the adult system.

The second population is perhaps even more diverse. This group consists of adults who range in age from 21 through their 50's, 60's or beyond. While in school, they may have had a variety of educational classifications, such as learning disability or social-emotional disturbance, or they may not have been identified at all. Whatever their educational history, what they have in common are impairments that put them somewhere on the autism spectrum. Many are diagnosed with Asperger Syndrome. Most have relatively high cognitive functioning. Their adaptive skills, e.g., skills needed for independent living and working in the community, may be surprisingly

limited in at least some areas, such as appropriate social skills. These individuals differ from those described previously in other ways as well. They generally do not have a history of effective programming or instruction in life skill areas. As opposed to students coming out of the Delaware Autism Program, where the transition has been planned, these individuals may develop significant needs quite suddenly, through the loss of natural supports such as death of an aged parent or loss of a job long held. Alternatively, they may have had no assistance with transition, and are often found at home, having failed to obtain or maintain employment. These individuals may also have to cope with the issues involved in being newly identified with an autism spectrum disorder. Even young adults who may have had appropriate services in school and functioned relatively well frequently find it much more challenging to make friends, keep a competitive job, and maintain their independent living skills once out of the structure of a school program.

These individuals currently do not qualify for services through the state developmental disabilities program. Nor are they typically eligible for mental health services based on Asperger Syndrome. Currently the only state agency that provides services is the Division of Vocational Rehabilitation, and that agency is struggling to address the employment needs of this group. These services are short term and staff have little experience or education in meeting these needs. The vocational rehabilitation system was not designed to meet the needs of these individuals who need specialized lifelong support.

RECOMMENDATIONS

As we completed the interviews and visits, and began to analyze the information, we came up with the following assumptions and developed a list of Delaware's strengths.

Foundation and underlying assumptions:

The unique needs of individuals on the autism spectrum and their growing numbers require an expanded service/support network with more options. Specifically, we are basing our recommendations on the following assumptions:

- *The growth in numbers of people with autism has been documented and projections indicate further growth, which levels off in the future.*
- *Individuals on the autism spectrum have unique needs, especially in the areas of communication, behavior, socialization, sensory issues, and the interaction between all of these, regardless of their level of intelligence.*
- *The entire spectrum of the disorder needs to be recognized within the service system. Each individual has a unique set of strengths and needs.*
- *Families (and individuals) have different expectations, resources, values and priorities from each other, and the same families (and individuals) may differ on these dimensions across the individual's lifespan.*

Delaware's strengths:

Delaware has its own values, experiences, and history, including legislative commitment

to children and adults with autism. Additionally, Delaware is a small state, which facilitates training and program dissemination. Our “best practices” will have a unique Delaware flavor because in Delaware we have:

- *A history of parent sophistication, advocacy, and family-based concern*
- *A strong statewide educational program since 1981*
- *A specialized statewide program for adults since 1989*
- *An active University Center of Excellence, the Center for Disabilities Studies within the University of Delaware, which offers specialized disabilities training and program evaluation.*

Individualized Choices and Preferences

All of the recommendations, which follow, are intended to be as pragmatic as possible, with the goal of identifying ways to adapt current program models (keeping what works!) to best practice models so that adults with autism can experience meaningful and productive lives in their home communities.

One of the hallmarks of recent developments in the field nationwide, and one that is certainly embraced by Delawareans, is the notion that individual preferences and needs must be honored. This extends from issues as small as the color of paint the individual wants on the walls of his or her bedroom, to those as large as where a person prefers to work or live and with whom. Often a person will be able to express these preferences and needs. Much of the time, however, this will be more challenging due to communication limitations. In some cases, preferences can be determined through careful observation of the individual’s responses. Often a family member will serve as a key representative in expressing these issues, since the family will play an extremely important life-long role in many individuals’ lives. In many cases, a group of concerned individuals who know the individual well, including but not limited to the family, will collectively assess and express these issues. Whatever the means of determining the individual’s needs and preferences, it is equally important to recognize that this will be an ongoing process because these issues will not be static, and will change over time.

In recognition of these factors, a fundamental feature underpinning all of the recommendations which follow is that they are meant to represent OPTIONS that are a) flexible; b) developed for the individual; and c) responsive to changes in individual and family needs over time. We have provided many examples, but certainly the options presented here are not an exhaustive list. The key idea is that the services and supports are to be designed around the individual, as opposed to the individual “fitting” into the available service that may most closely meet his/her needs.

Working Assumption

This report, strongly supported by the Autism Society of Delaware, has only one specific working assumption. That is:

We assume that each individual will spend approximately 40 hours per week engaged in meaningful activity outside of the home, with at least 20 hours of this being gainful employment. This is regardless of where an individual may live, or what he or she may do across the day

While most of those we interviewed would agree with the notion of spending 40 hours per week meaningfully occupied outside the home, not all would necessarily agree with the employment priority. We chose it for the following reasons: Individuals and their families in Delaware have a 20-year plus history of strong vocational preparation and achievement. Families and staff have witnessed, and individuals have experienced, the pride that comes from these achievements, the satisfaction that comes from coming home to relax after working for a significant portion of the day, and the respect that is extended to individuals who do all they can do to provide for themselves.

Recommendations

The recommendations in this report are divided into three sections. First are recommendations for individuals and what should be happening at the individual level. The second set of recommendations address what should be happening at the programmatic level, meaning the support provider's level, and finally, we have recommendations for the system, or state level. We believe that best practices can only be implemented across a state with both a systems and an individual approach. The intent is that best practices become embedded through a systems approach rather than the charismatic leadership approach that is the prevailing model for developing and implementing best practices.

A. Recommendations for all individuals

1. Individualize supports for the person with autism that strongly consider his or her desires and needs as well as the family's values and needs. This calls for an individual budget and a well considered support plan.

Planning needs to start with each individual's needs. This is the opposite of many typical strategies, which involve developing a budget to serve a group of people based on an overall estimate of needs. The first step in planning for the individual is to identify who should participate in the planning process. Key players should include the individual him- or herself, family members, and current staff members who know the individual well. Other participants may be drawn from among concerned individuals who are willing to commit to the planning process, potentially including friends, neighbors, co-workers, and advocates. An already-identified circle of friends fits the bill perfectly for planning purposes. Once participants are identified, it is important to follow some systematic process to identify the individual's needs. Examples include the Essential Lifestyle Plan, which Delaware currently uses, or the Positive Futures Plan, used by the Institute for Applied Behavior Analysis (IABA). IABA may also do a functional assessment if there are significant behavioral concerns. The Positive Futures Plan is used to develop a preliminary service plan with an attached budget, which then is sent to the funding agency.

2. *Provide professional support for trouble-shooting and problem solving, on the job site, in the home, or in the community; for behavior support, behavior development, expressive and receptive communication, sensory adaptations, and socialization.*

Delaware's history with the use of professional support leads us to strongly emphasize the importance of its continuing availability in adult services. Among the programs we visited, we saw differences in the relative emphasis placed on behavior vs. communication vs. sensory adaptations vs. socialization. The focus on communication and behavior issues, while strongly supported in the literature (e.g., Holmes, 1998; R. Koegel & L. K. Koegel, 1996; Quill, 1995), is also based in experience with students in the Delaware Autism Program (DAP) and with these same individuals as young adults. For example, DAP has a strong emphasis on functional communication (DAP is where PECS, the Picture Exchange Communication System, was first developed). Virtually every student completing the DAP has at least some basic functional communication skills, meaning that they can successfully indicate basic wants and needs, and follow critical directions, whether at home, at work, or in the community. This is a record that few educational programs for students with autism can match.¹

As to providers of such supports (specialists vs. trained generalists vs. direct support workers) there was great disparity among our visited sites. We found an emphasis on the use of staff with 4-year degrees and some additional training, as opposed to specialists such as speech pathologists, behavior analysts, and the like. Funding is probably part of the reason for this. Most providers of adult services are not in a financial position to have such specialists on staff. At the same time, there is no substitute for this expertise. Use of specialist consultants who would work with selected full-time staff members may be one answer. Such specialists should be available on a routine, periodic basis (e.g., twice per month) and on an as-needed basis.

Sensory processing is another critical area that is often neglected for adults on the autism spectrum. They may be hyper- or hyposensitive to a wide variety of stimuli. For example, an individual may be very uncomfortable when wearing tight clothing, such as a shirt and tie, and perhaps has had a long history of outbursts when required to wear this type of clothing. Putting this person in an office setting that requires typical office attire is a recipe for disaster. In this

¹ We choose the terms *behavior support* and *behavior development* to express what is needed in the behavior area, from a wide array of potential terms. By *behavior support* we mean to emphasize the notion that for adults, support is often a more practical and respectful goal than *behavior change* or *behavior modification*. *Behavior development* is meant to convey the notion that developing alternatives to problematic behaviors is the key to finding solutions. "Positive behavior support" shares many characteristics that we mean to convey with these two terms, but it is often associated with school-wide programming for school-age students. The specific elements we are seeking include the use of a data- or evidence-based approach, use of powerful individualized positive reinforcers, careful identification and teaching of specific functionally equivalent alternatives, and, perhaps most important for adults, environmental adaptations. Both DAP and the Special Populations programs have strong records of implementing these elements and seeing the positive results that occur.

case, one of the many available job settings which allows for more casual clothing is going to be more suitable. In other cases, it may be possible to provide an adaptation which works. If, for example, a young woman works best while listening to music, she can work in a quiet setting without disturbing others if she uses headphones.

While we all preach socialization and the development of social skills for individuals on the autism spectrum, this area takes on new importance for young adults once they leave school. Many times, the only friends an individual may have are those he made in school. Schools often provide structured socialization activities (dances and the like). Once these supports are no longer available, individuals who have not developed alternatives will suffer. In fact, this is known to be a very serious problem for adults with Asperger Syndrome, and is related to a greater incidence of depression and even suicide in some individuals (Attwood, 1998).

3. The range of support options available should include one-to-one support. Matching individuals with a compatible support person as well as compatible roommates is a priority across programs and systems.

Staff support ratios must be individualized. Needs may vary for the same individual depending on the setting he/she is in. One-to-one support may be needed, at least temporarily, when new skills are being taught, and/or the individual is entering a new home or workplace. Since constant one-to-one support can foster dependence, it is usually helpful to begin to fade support as soon as possible. It is critical to note that when fading begins, it needs to be done in a systematic and gradual fashion. It may not be possible to fade support on the first attempt, but over time a gradual reduction in support and increase in independence can often be achieved.

Virtually everyone interviewed emphasized the importance of finding compatible staff to work with individuals. In fact, it was clear that the more atypical or challenging an individual, the more important it is to try to identify staff they will be compatible with, and the bigger the positive impact of matching these people. Unfortunately, there is no recipe or “test” for identifying these potential matches. Providers sometimes find it useful to ask prospective staff members about their leisure interests and hobbies. Often it is a matter of trying out different staff members with different individuals, until there is a good fit.

Finding compatible roommates is critical to the happiness of anyone who lives with other adults. It is helpful if the individuals have common leisure interests, tastes, and other preferences. We do assume everyone will have his/her own bedroom, so personal hobbies and decorating preferences can be easily accommodated. But some individuals will have issues that will tend to create conflict if not well tolerated by their roommates. Someone who immediately puts away any items that are out of place in the kitchen will only antagonize a roommate who likes to get out all the pots and pans before beginning to cook! One strategy employed is to have a prospective new roommate visit several times for dinner or the like, to see how things go.

The development of natural supports in the community must also be encouraged. As clusters of potential natural support providers are identified (e.g., a group of fellow employees or neighbors within an apartment complex), it is a good idea to provide them with 4-8 hour mini-

workshops to give them some basic orientation and information. This has been a very successful strategy for the Judevine Center.

The availability of a range of support options is just as critical when we look specifically at the area of employment. Division TEACCH uses the following models: individual, or standard placement, which has one individual working with intermittent job coach support; shared support or “dispersed enclave” which has several individuals working in different positions dispersed throughout a business, with the support of one job coach; a “mobile crew” option which consists of several individuals moving from site to site doing similar jobs (e.g., house cleaning, landscaping) with one job coach; and finally, a one-to-one model of job coaching for an individual. While this is certainly not an exhaustive list of the possibilities, it gives a sense of the range that may be developed.

4. Provide effective individualized transition planning for alternative living and employment situations as needed.

A major feature of autism is difficulty with transitions. Thus, the saddest stories are about crisis situations, involving the death or sudden illness of a parent that required a change in the individual’s placement on an emergency basis. Such situations exemplify the wrong way to transition someone! Transitions needed to be planned and carried out gradually, and it does not work for too many factors to change at once. Another problem with transitions was reported for the St. Louis, MO area by Judevine Center. The staff there noted that students leaving the school programs may have job placements in their last year of school but are required to give them up and cannot transition with the job. Needless to say, this makes for challenging transitions to adult services!

In the area of employment, the positive side of difficulty with transition is that individuals on the spectrum may show better job retention and more resistance to boredom from repetitive work than their non-identified peers. We heard anecdotal reports from employers to this effect. On the other hand, the fact that transitions that do take place are difficult means that they need to be handled with great care. For the individual, preparation can include visits to prospective living or employment settings, spending small amounts of time with prospective staff in non-stressful activities, and providing information about transitions and transition schedules in a form which allows for repeated access by the individual, such as in written or picture form. Staff should also prepare themselves by learning what they can ahead of time in ways that do not directly involve the individual. At CSAAC the job developer works on a new job by himself for two weeks before transitioning an individual into the position. This way, he knows exactly what is required, as well as having developed relationships with the co-workers and supervisor. Such preparation eases the way for the individual when he arrives. Another very successful approach for transitioning staff is to have a new staff member observe or work side by side with a departing staff member.

In the state of North Carolina, the Department of Vocational Rehabilitation recognized the specialized expertise required for the transition from school to employment in a different way. Rather than having the DVR staff handle these transitions, the department contracts with Division TEACCH to provide them. In this manner, the specialized assessment, sometimes

extensive period of job development and initial intensive training can all be handled within Division TEACCH, thus allowing eventually for a seamless transition into TEACCH job coaching support.

5. Provide support to access community medical and dental care.

Often a routine visit to the doctor or dentist can be anything BUT routine for individuals on the autism spectrum. The lack of understanding about what is happening is compounded by communication problems, fears about pain, and the inevitable intrusions into personal space. The additional range of sensory issues, such as distress over the buzzing of a dental drill, or the sharp smell of an antiseptic, can also provoke intense reactions. It is critical to first identify an understanding doctor or dentist, hopefully with experience with this population, or, lacking that, someone who is willing to learn. Preliminary visits in which no care is provided, but the individual is allowed to become familiar with the strange setting, may be very helpful. Sensory supports such as listening to music on a headphone may be necessary during the procedure itself. And it may be very helpful to plan a highly reinforcing activity to take place immediately after a successful doctor or dentist visit. All of these accommodations may require staff support and potentially consultation with a behavior and/or communication specialist.

6. Support and teach individuals with autism to access transportation, including the DART (regular) bus and DAST (special transport).

Individuals need to be able to access transportation as independently as possible. Effective transportation use means access work sites, as well as all community activities, including leisure activities, domestic errands, continuing education, and religious and spiritual life. As parents age, it may become necessary for the adult son or daughter to travel to them rather than vice versa. All options must be pursued. Assuming the individual is within walking distance of a bus line (which must be a priority, see Recommendation C. 1) they may be able to learn to take the bus independently. Even when staff support is needed, taking the bus is a good option because it diminishes the need for dedicated vehicles with all of the complications they entail. DAST can also be used for individuals who can ride without additional staff assistance but whose skills do not allow them to utilize the bus system.

B. Recommendations for individuals living with their family

The most cost effective service is to provide supports to individuals who live in the family home. When appropriate services and supports are provided, families are able to maintain their loved one for many years before residential services are required. Families should not be expected to be caregivers 24 hours per day, seven days per week. This creates undue stress on the caretaker, and does not promote independence for the individual.

1. Individuals and their families must have home and community access to the professional supports listed in Recommendation A.2 above.

As a practical matter, there should be no difference in where the individual is living when it comes to receiving these types of supports. Living with family does involve a different set of

strengths and challenges, however. Among strengths, it is frequently found that families have had a long time to develop strategies that work. They may also be more tolerant of behavioral challenges. On the other hand, some problems may be more entrenched due to long histories. In these cases, one of the primary functions of professional supports in the home may be to help assess what can be tolerated and what needs to be changed; and ultimately, when it may be necessary for the individual to begin to transition to another living situation. To the extent that professional consultation makes it possible for the individual to live more successfully with their family; thus, prolonging the interval before they need to move out, professional consultation can be very cost-effective.

2. Families must have in-home support staff so that they can keep their adult son or daughter living at home with them. This includes support before and after the workday, as well as weekend support. The goals of staff support will be to help the individual participate in daily living skills, community activities, including those with peers, and special family activities such as weddings.

Several providers in this study do support some individuals living with their families. They found this option to be quite cost-effective because in these cases staff is needed only for specific times of the day or on weekends. Only rarely was support required around the clock. When this level of support was required for an extended period of time, it was usually deemed necessary to bring the individual into a staffed living situation. As an example of the average amount of support required by a family, the Autism Services Center in West Virginia has found that families average about 32 hours per week of in-home support.

C. Recommendations for individuals living out of the family home

The group home is the option of choice for many families, but individuals with high levels of functional and communicative skills, who want alternative options, are entering adult services as well. There should be options that acknowledge these levels of skills and desires for a home with fewer individuals.

1. There must be a range of options that includes apartments, townhouses, and homes. Location of housing is key, including accessibility to public transportation and community resources (e.g., shopping, banking, etc.).

Options are needed so that individual preferences and needs can be accommodated. Apartments and townhouses can provide a natural community. Individuals can meet their neighbors at the mailbox or while entering the building. The location of housing is critical. Location near bus routes and/or within walking distance of community resources is especially valuable in that it eases transportation complications. With the right location, the most independent individuals may well be able to access many community resources without staff assistance.

A different set of considerations is important with regard to group homes. There are always potential issues with acceptance by neighbors. The following are some pointers we heard from programs we visited:

- 1) Autism Services Center prefers corner locations because they enhance staff parking and maximizing distance from neighboring homes. They also suggested that the houses chosen should be among the best in the neighborhood.
- 2) Several programs recommended that individuals living in a home be active within the neighborhood doing volunteer work such as neighborhood clean-ups.
- 3) Judevine staff recommended that “welcoming, diverse” neighborhoods be chosen.

Opinions differed on whether it was best to rent or buy the homes.

2. Adults should be able to live alone or with no more than two roommates with whom they are well matched and compatible.

Having their own apartment is viewed as a hallmark of independence by many young adults. Further, living alone may be an even stronger preference for some individuals on the autism spectrum than for those in the general population. If there are to be roommates, a total of two or three individuals seem to be optimal in terms of sharing space without getting in each others' way. Two or three individuals living in a home or apartment generally will also require the presence of at least one or two staff members much of the time, and more than six adults in the same living unit begins to appear crowded. At that point, people begin to be disturbed by competing stimuli and simple lack of space. Compatibility can be measured in two ways: 1) two or more individuals may literally share similar interests and general activity patterns, or 2) individuals may not literally be compatible, but if at least one or two are very tolerant of potentially disruptive behavior by a roommate, then the twosome or threesome may still be compatible overall.

3. There should be flexible staffing options ranging from: 1:1 to 1:4 staffing; use of roommates without disabilities who have specified duties, drop-in support, neighbor support, or an individual living with a host family.

Following are specific examples of options seen just to give an idea of the range of possibilities that can exist: At the Jay Nolan Center, as well as at the Institute for Applied Behavior Analysis (IABA), many of the individuals who require 24-hour support have a live-in, non-disabled roommate. These roommates generally work with the individuals for an evening shift from Monday through Friday, but are off-duty the rest of the time. Since they live in the same unit, they may provide informal support at other times. Usually the individual has a daytime staff member who shows up in the morning, helps with the morning routine, and goes with them to whatever their daytime schedule calls for. On the weekend, there is a variety of schedules. One option is a staff member who works 48 hours, including sleeping over Saturday and Sunday nights.

For those who live alone in an apartment, Judevine described a novel “support neighbor” concept. An individual gets free rent and utilities in a neighboring apartment in exchange for specific duties. The target individual’s apartment always has a 2nd bedroom so that someone can stay there in case of a crisis or when the support neighbor is out of town. The support neighbor is paid extra for any non-routine duties, such as time involved when there is a crisis.

D. Program level recommendations

We encourage the development of local programs with small administrative structures to support adults in ways that are individualized, flexible, and responsive to individual preferences and family concerns. Programs must be responsive to local needs. They should not rely on decision making, budget restrictions or staff decisions made by out-of-state administrations.

An attribute of seven of the eight programs visited is that they were local with lean administrative structure and strong leadership. We found that local providers are positioned to be most sensitive and responsive to local standards, staff issues, expertise, and funding opportunities. In part due to Delaware's small size, we have several providers based out-of-state, thus requiring out-of-state administrative oversight. This makes it more challenging for effective family input and consumer choice to be considered in delivering services. Because of our small size, providers based within Delaware will naturally have small administrative structures. The same advantages of small size that currently allow for statewide consistency in programming for birth through 21 can then also come into play for adults.

1. Small and mid-size providers can and must ensure supports that are family driven and organized around a strong "individual/family centered" philosophical orientation. This is best accomplished by including family members at all levels of program development, governance, and oversight.

Family members are in the best position to remain focused on the highest priority: the well-being of each individual. When involved at all levels, they can work to keep this at the forefront whenever policies are made and implemented.

2. Providers must have practices that are evidence-based, with goals set for their use, and regular review of progress toward attainment of these goals.

Practices must be consistent with current knowledge in the field and based upon data. There must be a system in place for regular review of progress. The Institute for Applied Behavior Analysis (IABA) in Los Angeles has such a system with two levels of data-based review taking place. One was a team-level review, and one was a review of the program of a specific individual. In each case, there was a list of quality standards, each of which had operational definitions. Each was reviewed and marked as achieved or not achieved. This particular system is available for purchase by users outside of IABA, and the reader is referred to the IABA visit notes in the appendix for a reference to learn more about this system, which is called the ePSR or e-version of the Periodic Service Review.

Data collection is frequently seen as an unpleasant, challenging task. Data collection systems need to be designed with the involvement of the staff that will be using them. They need to be portable, quick and easy to use, and provide data in a form that can readily be summarized and analyzed. It is also important that staff see that the data they collect is actually used when decisions are made.

Delaware's status as a small state with a major university and university center for excellence provides creates the potential for research to help develop new evidence-based practices. With the newly funded Edelson Chair of Adult Services, housed in the College of Human Services, Education and Policy, there is a great opportunity to be innovative and expand knowledge.

3. Providers should establish a range of options for employment that include varying levels of paid and unpaid employment options.

Because autism spectrum disorders are so individualized and uniquely manifested across individuals, employment opportunities must also be widely varied and specifically targeted to the local economy as well as to the individuals. Assessment tools must be enhanced to consider communication, social skill, behavioral, and sensory needs. The job match is just as critical as the match between the individual and the job coach. Placing a person with sound issues in a noisy dish room will not be a successful match.

This study defines a day as having eight hours of meaningful activity. For a few, this might mean a 40-hour work week; however, our review of programs indicates that it will more frequently mean a 20-hour work week with other activities also in place. The goal for most will be to make a good job match, build hours, work tolerance, and hopefully a career. We also recognize that for some, employment will be more limited.

Employment options should include full time competitive employment with support, using the supported employment model of follow-along services for adults with Asperger Syndrome or high functioning autism. Long term supports needed for this group might include follow-up contact at work, and a support group or social club where individuals can meet and address work issues, learn appropriate social skills, and have fun. This promotes a full life, alleviates loneliness, and gives these individuals a place to seek support and assistance.

For other adults, all supported employment options will be needed, including expanding the use of supported employment models from the single job and job coach to greater use of the clustered placement model with one support person working with two or three individuals at a work site, and potentially to work crews. Work crews could readily accommodate individuals with good work skills but poor social skills, and they can be used as transitional sites—giving experience and building resumes while also teaching both job skills and job-keeping skills. Work sites must be developed that allow individuals with behavioral challenges to be accommodated, and that will use environmental approaches to alleviate behaviors. For example, jobs that are physically demanding and that require good gross motor skills such as working in warehouses, can be ideal for certain individuals. At all times, the needs of the individuals being supported must be taken into account.

Finally, while our emphasis is on work, some individuals may not have the capacity to work in the work settings that are typically available. This may be less due to cognitive or communication issues than to sensory issues. Working in the community must benefit the individual, not create additional pain or frustration. For these individuals, we must seek

alternatives that allow them to grow and learn, but do not require sensory processing that can be overwhelming.

Volunteer jobs are important, and provide a meaningful way to participate in the community. For some individuals, there will be a mix of paid employment, volunteer employment, and leisure time activities during the work week. The intent should be to expand hours as work is more available, as skills grow, and as the individual asks for more work.

These types of support call for creativity and entrepreneurial approaches that have been developed across the country. They may be offered by traditional programs, through new providers, or through self-directed support corporations, which should also be a part of a systems change approach. As individuals and families determine what they want, they should negotiate with providers to meet their needs rather than to rely on a slot-based system.

4. Providers should develop a community-based option for individuals currently served in sheltered workshops. Individuals needing this option include those who have one or more part-time jobs or do volunteer work, or are between jobs. This replaces the sheltered workshop or day habilitation center model that currently exists. One such option is a “clubhouse” model, which provides access to sites developed within community colleges or the like, for various recreational and adult education programs. These options also free funding currently used for “bricks and mortar” to provide more individualized supports.

The best practice programs across the nation used available funds to provide one-to-one or two-to-one support, and did not pay for large buildings for day programs. The one exception has a very low-rent space with job samples developed that were clearly tied to community jobs (newspaper stuffing, computer stations, shelf-stocking, etc) where individuals spent time when not at their job. With these levels of support, very creative programming can be done throughout the community that is not based on using a facility. Individuals can develop their own communities within the local community college, the local YMCA, the library, and so on, creating their own structure.

5. Providers should create a range of support options for employment that include varying levels and ratios of staff support, drop-in support, and natural support for competitive employment.

This has been covered in other recommendations. Because of the unique nature of the disability, the range of employment and employment supports should be broad, flexible, and have the capacity to change as the individual’s needs change.

6. A range of support ratios to participate in these activities should be available, including flexible staff and the use of volunteers and friends.

As noted in recommendation D-3, the range of employment options requires a range of support options. The best practices programs offered one-to-one support for individuals at the severe end of the spectrum across their day, as well as one-to-two support at specific job sites. There must be flexibility built into the system to increase or decrease support as needed. In

Delaware, we are more inclined to work with individuals with more severe autism. With the numbers of young adults with a greater skill level increasing, there should be more options across settings and disability level. First, it is critical to maintain the skill levels that these young adults have achieved, so it is important not only to provide adequate support, but to have staff that are trained about autism and its characteristics, the use of communication systems, behavioral supports, social skill needs, and sensory issues. It is our recommendation that staff support ratios remain high, paying for them by reducing administrative overhead and day program buildings, utilities, equipment, janitorial, and all the other associated costs. By using funding for staff, greater program flexibility is built into the system which allows greater use of community supports such as neighborhood centers, churches, the YMCA, and other regular gathering places.

Staff should be deeply knowledgeable about the individuals they support, and they should be cross-trained to support more than one individual. This allows the person to feel comfortable because they always know who will be supporting them, and in cases of vacation, sick leave, and unexpected absences, there is a backup person (or preferably two) who can assist.

Friends and volunteers who have known the person over time can also be included as part of the support, particularly as individuals develop their own communities at work or in other places. While many adults with autism will always require paid support in the workplace, many others will not. Building on friends and volunteers expands the base of support available.

E. Staff recommendations

1. Use recruiting and hiring practices that are cost-efficient. Provide prospective staff with information so that they can opt in or out of continuing the interview process (show an introductory video; invite them to dinner with the individuals, etc.).

2. Emphasize careful matching of staff to individuals and positions.

3. Establish hiring and staffing practices that promote the development of meaningful relationships between individuals and staff.

4. Provide staff training that includes basics on autism and philosophy, plus orientation to procedures specific to individuals with whom the staff member will be working.

5. Develop staff utilization policies that encourage cross-training and horizontal job mobility as well as promoting from within.

Basic staff training need not be overly cumbersome or lengthy. In fact, many of the sites told us that they have found it most cost-effective to reverse the typical process and provide new staff with observation and orientation experiences prior to investing time in training. Thus a new staff member may first spend up to a week observing individual(s) with whom they will be working, on site with their current staff. This is then followed by training. In this manner, the new staff member has more informed questions, and can use the training to prepare for their

specific job assignment as opposed to a general, abstract assignment. And the cost-effectiveness results in the possibility of new staff members who would not be a good fit recognizing this and opting out (or being directed elsewhere) before there is a significant investment of staff time. Another cost-effective strategy, utilized at the Institute for Applied Behavior Analysis (IABA), was to develop a series of self-contained training modules for staff to study on a flexible schedule, within certain timelines. IABA also has staff start by overlapping shifts with trained staff before they ever work solo.

F. State level recommendations

There need to be more options for families who want to remain in control of their adult child's supports, including family consortiums for living arrangements, individual budgets, supports brokers, self-directed support corporations, and fiscal intermediaries. The state also needs to set a strong policy about service and supports, and provide concentrated technical assistance to state agencies and community providers who support individuals with autism.

1. Create an autism services office. The mission of this entity will be to promote individualized and need-specific service development, assure accountability to state agency and program providers, provide technical assistance to local programs, identify and coordinate funding sources, and build capacity within local programs. The office may be housed in one state agency, or may be a separate non-profit, but it should provide leadership and support to all state agencies that provide services and supports to adults with disabilities. The office should be staffed by experienced professionals who can both provide for and arrange technical assistance to programs, families, and individuals.

This entity will also be charged with developing additional academic training for line staff and professionals statewide, through formal classes and curricula, the internet, etc. One of the first missions of this entity will be to develop and begin to use a meaningful philosophy, which will then be used in developing new providers, recruiting and training staff, developing support options, etc. It may be possible to contract with a nonprofit provider for some of these functions.

An Office on Autism would be charged with providing leadership, establishing a statewide philosophy, and enhancing current capacity within and across state agencies and the provider network. This office would also provide technical assistance and support to generic programs such as Unemployment, Social Service, and the Court System –particularly when addressing the needs of individuals on the spectrum who may not be receiving state services. Likewise, it could provide training, technical assistance, and trouble-shooting supports to the DDDS network of case managers and provider agencies. As more students transition into adult services across the state, current providers will be called upon to provide services and supports and will need training and technical assistance to do so. The use of a circuit rider consultant (meaning someone who supports community programs on a regular basis) can be a very effective way of enhancing local programs.

In Delaware, we need to call upon state agencies to expand their collaborative agreements to coordinate and share responsibility for providing and funding supports for adults with autism spectrum disorders, to expand services to address the needs of individuals with Asperger

Syndrome, to expand services to address the needs of those who are dually diagnosed, to participate in joint employment efforts, to jointly seek technical assistance, and to provide leadership to address the needs of this population. Currently most adults receive services through the Division of Developmental Disabilities Services and (DDDS) their community provider network; some adults receive more limited services through the Division of Vocational Rehabilitation (DVR), and a few may receive services from both agencies. This calls upon agencies to review current policies and practices to accommodate the employment needs of adults with autism spectrum disorders. For example, in Delaware, the Division of Vocational Rehabilitation only supports the individual job coach model. Best practices often has a clustered placement, with one job coach supporting two or even three individuals at a job site. This promotes independence, yet also assures that adequate supervision and support is in place. We would call upon DVR to re-think their supported employment policies to come in line with other models of employment service that meet the needs of individuals with more severe disabilities. Likewise, we would call upon the Division of Substance Abuse and Mental Health to revise their eligibility criteria to address the mental health requirements of this group. Advocates are working on these issues, but a Office on Autism could serve as a planning and implementation organization.

Another priority for this office, for the state, and for the provider community is to develop and maintain a philosophy. No matter what their size, the programs visited that we considered to be *best practices* had unique and meaningful philosophies. Even more significant, the staff at all levels was able to articulate those philosophies. The philosophy reflected the individual “personality” or priorities of each program. For example, Bittersweet Farms uses the term “MAPS” for their philosophy. The letters stand for “Meaning and Motivation,” (teach the meaning of the activity, use motivation); “Aerobic Activity,” “Partnership with Purpose,” (share the work with the individual); and “Structure and Support” (emphasizes visual schedules, sequencing, and communication. A philosophy like this certainly fits the setting for Bittersweet Farms, and it is easy to see how a staff member could refer back to this for practical guidance in planning activities. These kinds of philosophies serve to maintain program consistency over time. To the extent that a clearly-articulated philosophy helps prospective staff identify whether or not they are a good fit with the organization, it adds to efficiency in hiring.

There must be family involvement and oversight no matter where the office is housed. It is important that such an office be overseen by a council composed of parents, experienced professionals, and advocates, whether it is housed at the state level or in a private non-profit.

2. Augment the state’s rate setting process to support the unique needs of individuals with autism.

The Division of Developmental Disabilities Services has been actively working to develop funding rates and mechanisms based on individual need. One of the challenges is to adequately understand all the supports that adults with autism need, which can be significantly greater than other individuals in the DDDS system. As previously noted, adults with autism require significant clinical services, including behavioral supports and adequate data systems and oversight, communication systems and speech therapy, sensory supports, and medical oversight. When these supports lag, skills that have been developed through the educational system can

quickly dissipate, leading to deteriorating behaviors and a need for crisis intervention and even greater level of supports. Embedded in this recommendation is the earlier recommendation regarding transition. These supports must be noted, understood, planned for, and budgeted prior to the individual entering the adult system. When done effectively, as Delaware has generally done through its Special Populations program, transition can be smooth, skills can be maintained, and behavior can continue to improve. With more individuals entering community programs that do not have these supports in place or a clear knowledge and understanding of them, lost skills and deteriorating behavior become more likely.

3. Expand the definition of eligibility to include Asperger Syndrome.

Adults with Asperger Syndrome typically have academic and work skills that can lead to a life of independence. It is their issues with social skills in the work place and difficulties with functional life skills that interfere with their successful achievement of independence. Appropriate supports at work and at home can be both cost effective, eliminating the need for Social Security or SSI, and result in an independent and productive life.

Currently adults with Asperger Syndrome are not eligible for most adult service agencies serving individuals with disabilities because this disability is not considered to be a cognitive or a mental health issue, despite the fact that it is a lifelong disability requiring supports. This will most likely require legislation to assure ongoing funding.

Effective programming will require additional knowledge about Asperger Syndrome itself, as well as appropriate services and supports required by these individuals. This is not always clearly known or understood, and is not typically available in the service provider or mental health network. While this situation is not anyone's fault, due to the fairly recent recognition of Asperger Syndrome as a diagnosis and part of the autism spectrum, it will require some in-depth planning to address on a statewide basis. It also calls for a closer working relationship with mental health organizations to expand their services to address the mental health needs of adults with autism spectrum disorders due to the high co-morbidity of Asperger Syndrome and mental health.

4. Develop and implement practices and financial incentives that encourage small, "homegrown" providers to start providing supports. The biggest challenge to small providers is likely to be the substantial start-up investment required, so this is where incentives will be needed across state agencies serving adults with disabilities.

Small non-profit programs with lean administrative structure offer these benefits:

- parents can and should serve on the board and have a greater say in guiding services and supports
- control is local and does not depend on funding, clinical, programmatic or administrative decisions that are made out-of-state without regard to profit motive, immediate need, and time constraints
- there can be an immediate response to local conditions and individual needs and crises
- local fundraising can enhance program supports rather than support other more distant programs

Start-up for non-profit service organizations, just as for business, is expensive. State payment can be very slow; thus there is a need for the state to assist small programs in the planning and development phase, and to provide adequate “up-front” funding while the program is developing and in early implementation stages. Further, the costs of supporting adults with autism can be higher due to the need for greater clinical services, greater staffing ratios, the requirement for more training and better trained staff and the increased salaries that requires. The state can also develop financial incentives that reward programs that meet quality indicators, and reward community programming and employment over traditional services such as sheltered employment and day services.

5. Use the “support broker” model and a personal budget to build supports around the individual’s needs base.

The family support movement of the past decade has shown over and over that flexibility and decision making are the keys to consumer and family satisfaction. Models around the nation have found that the use of individual budgets and support brokers can actually save money, and provide more individualized, flexible and appropriate supports rather than just supports that are readily available. There will never be a time when every adult with disabilities has all the funding s/he wants or needs; however, when individuals and families can use funds to meet the needs and desires that are most critical to them, they can make choices about what their priorities are and use funds targeted to those priorities. Support brokers are able to negotiate services and supports, and can terminate them when they do not work effectively, thus alleviating the barriers and constrictions of the current practice of annual contracts. For accountability purposes, individual budgets and reporting are also much more transparent than large contracts to provider agencies.

6. Direct support funds to follow the individual through the use of a range of mechanisms, including fiscal intermediaries, support brokers, self-directed support corporations, family consortiums and other models that allow the individual and/or family to control the use of public dollars being spent.

Again, the emphasis is on flexibility and individual and family preference. Some families will want to develop a self-directed support corporation and direct all funding and services themselves, including hiring and supervising staff. Others will want to hire a support broker who can negotiate services and supports with existing vendors and provide quality assurance. Still others may want to work with other families to develop a family consortium to support a residence or even a small agency, and finally, some will want to use the current service delivery system. Again, this promotes individual and family satisfaction, because it matters less which model is chosen. The critical factor is that the individual and family choose the model that best meets their needs.

The fiscal intermediary provides the mechanism to pay for staff, specific services and supports, equipment, and other needs; and it provides the level of accountability that is required when using either public funds, or even funds that are raised privately. The fiscal intermediary should also become knowledgeable about Medicaid waivers, Social Security, and all other state

and federal funding mechanisms, what the law requires, how benefits are impacted by income, and so on. By housing this information with central or even regional fiscal intermediaries, families have technical assistance available to guide them through funding and programmatic decisions.

Overall, our review of the literature, interviews, and study of exemplary programs indicates that “Best Practice” requires:

- *Integrating activities seamlessly throughout the day and week, across the areas of domestic life, employment, recreation, and social relationships. That is, the person’s life should not be divided into compartments such as “residential services” and “employment services” for which different groups of staff have different responsibilities.*
- *Adopting a common philosophy. There must be a clear, shared philosophy that is embraced by all of the stakeholders of the support program. Staff at all levels must not only articulate the philosophy, but “live” it. This enhances consistency in the quality of services delivered.*
- *Establishing funding that is diversified and sustainable, using ALL resources within the community (e.g., small business loans, food stamps) thus promoting flexibility and program survival. It is integrated and coordinate without the constraints of an elaborate administrative “system.”*
- *Building a local Delaware focus. Our program and providers should be “homegrown,” focused on our local priorities, specific individual’s needs, and directed by a simple organizational structure with minimal administrative hierarchy. Programs must be responsive to local needs and not to distant administrations.*
- *Adopting a family-driven, family-directed approach. The individual, with his or her own perspective and preferences is part of a family and must be recognized as such.*
- *Adopting procedures for effective and efficient use of all resources including fiscal and human resources across persons served.*
- *Incorporating systematic evaluation and accountability. This takes place from the individual all the way to the systems level. It should reflect the local ecology.*

Where do we go from here?

It is our consensus that the following steps should be our first priorities:

- Develop a common philosophy, as referred to early. This philosophy must be one that is embraced at all levels and infused into funding practices.

- Add Asperger Syndrome to the definition of autism for adults, so that these individuals will be eligible for services.
- Fund at least two demonstration projects, to take place over a three-year period. One should be a project to provide in-home support, the other to provide community-based supported employment utilizing some of the innovative, person-centered funding mechanisms we have described above.
- Evaluate options for developing an office of autism to provide leadership at the state level. One goal of such an office should be to provide technical assistance and consultation as well as professional and in-service training. Another goal should be to investigate how to make sure that services are available for all adults with autism.

References

- Attwood, T. (1998). *Asperger's syndrome: A guide for parents and professionals*. London and Philadelphia, Jessica Kingsley Publishers.
- Autism Society of America (2001). *Position paper on The National Crisis in Adult Services for Individuals with Autism*. Retrieved April 26, 2005, from <http://www.autism-society.org/upload/images/AdultServices.pdf>
- Autism Society of America (2005). *Autism Facts*. Retrieved March 4, 2005, from http://www.autism-society.org/site/PageServer?pagename=Autism_Facts.
- Holmes, D. (1998). *Autism through the lifespan: The Eden model*. Bethesda, MD: Woodbine House.
- Jarbrink, K., & Knapp, M.R.J. (2001). The economic impact of autism in Britain. *Autism*, 5 (1) 7-22.
- Koegel, R. & Koegel, L. K. (1996). *Teaching children with autism: Strategies for initiating positive interactions and improving learning opportunities*. Baltimore: Paul H. Brookes.
- Pennsylvania Autism Task Force (2004). *Autism Task Force Report*. Retrieved January 31, 2005 from <http://www.dpw.state.pa.us/General/AboutDPW/SecretaryPublicWelfare/AutismTaskForce>
- Powers, Michael D. (2003). *Asperger syndrome and your child: A parent's guide*. New York: HarperCollins.
- Quill, K. A. (1995). *Teaching children with autism: Strategies to enhance communication and socialization*. New York: Delmar.

Appendix 1:

Summary of observations for programs visited

Contact: Ruth Sullivan

1. Agency: Autism Services Center

Phone Number: 304-525-8014

E-mail:

Date: December 9, 2004

1. We are interested in identifying best practices and current policies in services for adults with autism, including high-functioning adults and those with Asperger Syndrome. Since this represents a wide range of adults and skill levels, please briefly describe your target population.

They serve 80 adults with autism. They appeared to have people across the whole range of severity and cognitive functioning.

2. What are the programs that your agency provides for these adults?

Most of the adults served are in their family's home with support. Support in the family home ranges from 5 hours/week to 24 hours/day. (24 hours/day would be only on a temporary basis). A typical pattern would be support from approx. 4 PM to bedtime and maybe 8 hours per day on the weekend. They also provide staff for these family homes for emergencies, or 24-hour staff if the parents want to take a vacation.

They also have group homes with 3 people in a home.

Also provide employment and other daytime programming.

3. What are the elements of these programs that you can consider to be best programs that you consider to be best practice? What areas do they need improvement in?

They feel their strengths are their 1:1 staffing ratio, and the "seamlessness" that comes from not having to separate day and residential programs (they are allowed to use Medicaid waiver money for job coaching in WV).

4. Do you have any policies in place that promote best practice either through state government, local government, or company policy?
5. How do your programs address the domains of:

- a. Residential The family support option was discussed under item #2. The group homes have 1:1 staffing. Individuals participate in activities such as cooking, cleaning, but there did not appear to be a major training component here. Rather, the focus appeared to be to provide high quality of life, along with a typical pattern of coming and going across the day. There were a lot of checklists for management of the homes, e.g., to make sure the towels were folded properly, kitchen sink left clean, etc. etc. This helps the staff be consistent.
- b. Employment: 20 adults are in paid jobs that may be part-time or full-time. Jobs include clerical work at the ASC office, restaurants, hotel cleaning, YMCA cleaning, a nursery school cleaning. Those not in paid employment have volunteer positions at hospitals, churches, parks, etc.
- c. Social Skills/Support
- d. Recreation/Leisure Time
- e. Behavioral Supports: Positive behavior support explicitly used, with an emphasis on identifying antecedents. However, it was noted that in emergencies restraints may be required.
- f. Communication: no explicit emphasis here. We saw a number of people who appeared to have functional speech, but in one home two men are nonverbal and don't have a way to express their needs and wants.
- g. Sensory
- h. Self-Determination

6. What are the typical costs of your services and how are they funded?

This is an ongoing challenge. As far as the residential homes, they used to have enough funding to supervise them 80 hours per week, now it's down to 40 hours per week. But at least the 80 hours per week they had before allowed them to set up systems that can now be maintained. The manager offices are in the homes themselves, which makes monitoring a lot easier. They actually lose money on the group homes, but make money on the family support option, so that they can afford to continue to run the group homes at a loss.

They have also used grants. They had a supported employment grant, also a special grant to give staff incentives to help find jobs for supported workers. They also have an incentive system for staff to recruit other staff. If someone they recommend is hired, they get an initial bonus if they stay 3 months, and a second one if they stay a full year.

7. What collaborations are in place across other agencies? Support systems? Incentives?

8. What is the transition process from school-age programs to the adult services you provide, and how well is it working?

Sometimes they are serving a child in the family support model, and then they become an adult, and of course this is an easy transition. It didn't sound like they "recruited" new clients by coordinating with the schools because they already have more people wanting service than they can provide for now.

9. What skills do you feel staff should have to work with your target population, and what training, if any, do you provide your staff?

Overall, staff get an 8-week curriculum. New staff get 25 hours of classroom training. Then there is ongoing training once a month. They stress their philosophy heavily in the training, plus habilitation, communication, and positive behavior support.

10. What kinds of services are in place to assure maintenance of successful outcomes over time, and/or intervene early if problems begin to develop?

They use direct observation by the manager staff as their primary form of monitoring.

11. What other resources do you recommend?

Other recommendations: “learn the state Medicaid system” “waivers are re-written every 5 years, and we should stay abreast of this process”. Try to get reimbursement in per diems as opposed to 15-minute increments. Supervisors need sufficient hours to supervise. “70% of costs are going to be staff costs”

Contact: Victoria Obee-Hilty

2. Agency: Bittersweet Farms

Phone Number: 1-877-879-0254 ext. 209

E-mail: vobee@bittersweetfarms.org

Date: January 12, 2005

Visited by Susan Peterson and Karen Bashkow

--We are interested in identifying best practices and current policies in services for adults with autism, including high-functioning adults and those with Asperger Syndrome. Since this represents a wide range of adults and skill levels, please briefly describe your target population.

They serve 41 people with autism in their day program, 20 of these people living on campus and 8 of them in supported living. They serve a range of adults with autism.

--What are the programs that your agency provides for these adults?

Day program in "farmstead model" that provides structured day with choice of programs including greenhouse, woodshop, animal care, landscaping/gardening, kitchen/janitorial, print shop, weaving and arts and crafts. Residential program includes dorm-style living for 15 people, and a "co-op" for 5 (they do more of the chores and their own decision-making about running the house). Also supported living in nearby communities for 8 people (we did not see this).

--What are the elements of these programs that you can consider to be best programs that you consider to be best practice? What areas do they need improvement in?

Our philosophy is very strong. We believe in building a sense of community, in engaging in productive work, that relationships between the people we serve and our staff are very important. Daily structure and routine are important, and visual schedules are used. TV and video use are restricted.

--Do you have any policies in place that promote best practice either through state government, local government, or company policy?

--How do your programs address the domains of:

- a. Residential
- b. Employment: They are just now going to a supported employment for some jobs at the farm. This way those individuals can be paid, and hopefully get better preparation for potential jobs in the community. There are also a couple of jobs in the community (1 moving shopping carts, 1 in recycling, and 1 in cleaning at a camp in the summer).

- c. Social Skills/Support: Sense of community it stressed, primarily between individuals and staff but also between individuals.
- d. Recreation/Leisure Time: Each weeknight there is an activity, e.g., “music night”, “arts and crafts night”.
- e. Behavioral Supports: They are comfortable with the “prosthetic structure” concept proposed by David Holmes, i.e., people with autism may need visual supports, staff supports, etc. and these are like a guide dog or artificial leg in that they may be needed on an ongoing basis.
- f. Communication: No special emphasis here. It seemed most of the people we met had functional speech.
- g. Sensory: No special emphasis here, although the speech pathologist is very interested in sensory needs and there are accommodations such as a quiet, out-of-the-way building for those who don’t like lots of commotion.
- h. Self-Determination: Certainly there is an emphasis on personal choice, but not a strong philosophy of self-determination.

--What are the typical costs of your services and how are they funded?

The residential component is funded as an ICF. Total cost is \$90,000 per year including housing, food, and staffing. Supported living is currently funded on an individual basis using the ISP. At the high end, they have twins living in supported living whose residential program costs \$114,000 per year, per person. For the day program, they get \$72.10 per day, but it costs \$100/day to provide.

--What collaborations are in place across other agencies? Support systems? Incentives?

--What is the transition process from school-age programs to the adult services you provide, and how well is it working?

--What skills do you feel staff should have to work with your target population, and what training, if any, do you provide your staff?

Cross-training is important, including for administrative staff. Initially staff were hired for the day program who knew a farm skill and then they were taught about autism. Bettye Ruth, the founder, used the term “golden” to characterize people who had the unique set of qualities to do the work. They still have very little turnover in the day program. There is much more turnover in the residential program. Many of the staff there are students and naturally move on.

Other training tips: they rapidly learned that standardization was important: one way of doing each task, for the sake of the individuals not getting confused. They now actually have a training module for new staff on how to do laundry, so that they all do it the same way. Prospective staff are shown a video produced by a local physician entitled, “The Direct Care Professional: Is it the career for you?” They also are invited to dinner at the group home. These screening tools are very effective in discouraging inappropriate candidates and saving staff training time.

Once someone is hired, they FIRST spend 2 weeks within their specific department, following others around, THEN they get their three day of training on what autism is, CPR, etc. from Human Resources. This also saves time and promotes more effective learning.

--What kinds of services are in place to assure maintenance of successful outcomes over time, and/or intervene early if problems begin to develop?

Groups have team supervisors. Each person has an ISP with goals. All staff have to record something on the goals each day. The Behavior Support Plans all are written in a standard format with 1) preventive elements, 2) early intervention elements, and 3) crisis management (all is positive behavior support). All data are graphed monthly.

Other: There is an organization for parents to participate in.

Professional staff include a consulting psychologist, a speech pathologist, and a licensed dietician. Dustin, the residential director, also serves as the behavior specialist. Not clear if he had special training or credentials for this second role.

--What other resources do you recommend?

Contact: Pete Dakunchak

3. Agency: Chimes Delaware

Phone Number: 302-452-3400

E-mail:

Date: 1/21/05, 2/1/05, 2/2/05

Visited by Susan Peterson and Theda Ellis

--We are interested in identifying best practices and current policies in services for adults with autism, including high-functioning adults and those with Asperger Syndrome. Since this represents a wide range of adults and skill levels, please briefly describe your target population.

They serve approximately 75 people with autism in daytime programs and about 25 people with autism in group homes and apartments. Only a couple of these people are at the high end of the spectrum.

--What are the programs that your agency provides for these adults?

A range of daytime programs including supported employment, mobile work crews, facility-based programming. Residential includes group homes and apartments.

--What are the elements of these programs that you consider to be best practice? What areas do they need improvement in?

They are proud that they have individuals working out in the community now who weren't before. They implement the behavior plans of the individuals coming out of DAP. They feel they do a good job of assessment (vocationally related) using situational assessments as well as Teresa Wells' Vocational Assessment Profile. They emphasize positive behavior supports (using more reinforcement, more activity, more ignoring of problem behavior). They are very structured. The multi-sensory room is very helpful to many. PECS is used across work and home environments. In the residential area, they are happy to see individuals going into the community a lot, have a lot of choice in activities, and getting some specific training.

--Do you have any policies in place that promote best practice either through state government, local government, or company policy?

--How do your programs address the domains of:

-Residential: Most of the homes have 3-5 individuals living in them. The apartments have 1-3 people per apartment. 2 individuals live alone.

-Employment: 27 individuals are in community employment, working 2-6 hours/day. Mostly, people are transported to and from these jobs from the Chimes

building on Elkton Road. 48 individuals are in the facility-based program there, although 20 of them go out in mobile work crews some of the time.

-Social Skills/Support:

-Recreation/Leisure Time:

-Behavioral Supports: Positive behavior support is the model

-Communication: PECS is maintained for those who arrive using it.

-Sensory:

-Self-Determination: Personal choice is emphasized.

-Other services include a nutrition consultant.

--What are the typical costs of your services and how are they funded?

The funding is 50% Medicaid, 50% state.

--What collaborations are in place across other agencies? Support systems? Incentives?

--What is the transition process from school-age programs to the adult services you provide, and how well is it working?

Mostly, transition is from DAP, and there is very close collaboration here and a gradual transition.

--What skills do you feel staff should have to work with your target population, and what training, if any, do you provide your staff?

For the day program, orientation is 1-2 weeks and includes such training as CPR and PEACE training (crisis prevention and intervention). For the residential program there is an additional 2 weeks of shadowing an experienced staff member.

They pay about \$2/hour more than community services staff, so this is an incentive to choose Chimes. Daytime staff turnover is down.

--What kinds of services are in place to assure maintenance of successful outcomes over time, and/or intervene early if problems begin to develop?

One form of supervision is ongoing direct observation by the case managers and behavior analysts. They also collect a lot of data, but there are sometimes problems getting it in a timely manner. There is also an incident report system.

In the residential setting, the house managers work Tuesday-Saturday, alternating with Sunday through Thursday, so that there is supervision on the weekends.

--What other resources do you recommend?

Contact: Kim Dennie

4. Agency: CSAAC (Community Services for Autistic Adults and Children)

Phone Number: 301-762-1650

E-mail: kdennie@csaac.org

Date: Jan. 26, 2005

Visited by Susan Peterson, Theda Ellis, Karen Bashkow

--We are interested in identifying best practices and current policies in services for adults with autism, including high-functioning adults and those with Asperger Syndrome. Since this represents a wide range of adults and skill levels, please briefly describe your target population.

107 individuals with autism are in residential services. They have individuals across the spectrum, but tend to have the more severe individuals, as many of their first participants came from state institutions.

--What are the programs that your agency provides for these adults?

They provide residential support as well as supported employment.

--What are the elements of these programs that you can consider to be best programs that you consider to be best practice? What areas do they need improvement in?

“It all starts with the funding”. They have an identified funding person who figures out all the add-on funding available before they accept an individual. They have an especially strong record of supported employment.

They have a rule of thumb that there will be at least one “2nd eye” on an individual once every 24 hours.

--Do you have any policies in place that promote best practice either through state government, local government, or company policy?

--How do your programs address the domains of:

-Residential—they have individuals living in single home, condos, and townhouses. Usually 2 individuals in a living unit with one staff member.

-Employment:--90% of the individuals are employed for a minimum of 4 hours/day, 20hours/week. 93% of the individuals employed keep their jobs over time. Wages range from \$6/hr. to \$17/hr. They have two full-time job developers. Strategies stress matching the job to the individual’s characteristics. Locations include 2 people at Art Enablers (a place that supports artists to create their work); two individuals are artist’s assistants, doing prep work, etc. Others are employed at grocery stores, and Home Depot. What was their most challenging assignment? One person can’t be around blonde females. They found him a job at a battery warehouse.

Some nonverbal individuals are sorting books at the library, building boxes, delivering flyers and newspapers. Usually they have two individuals at a job site with one job coach. A couple of individuals are mostly using natural supports: one person packaging DNA testing kits, another working at Petsmart.

Job coaches pick individuals up at their homes in CSAAC-owned vehicles or accompany them on public transport. Only in rare cases do staff use their own private cars.

Job development: Marco (job developer) explained that they visit other locations of successful employers, schools, and community centers. He said “connections are everything.” Once they identify a job; he will work it for 2 weeks to get familiar with it, along with the job coach. THEN they will match a person to the job (the psychologist does this), and then they will work with that person until they have learned the job. The job coach does whatever is needed to get the job done.

-Social Skills/Support:

-Recreation/Leisure Time:

-Behavioral Supports:

-Communication:

-Sensory:

-Self-Determination:

--What are the typical costs of your services and how are they funded?

I wrote down \$60K as a very rough figure of the support costs (need to determine if this is for res. or employment or both). Supported employment is under funded in Maryland, at least by 2/7, because of a calculation mistake in the past. They are trying to extend the autism waiver for kids to adults, because of their long-term needs. ALSO, there is a special study to provide services for 100 adults with dev. disabilities. CSAAC is not using PASS/IRWEs right now. They do use section 8 for housing and “it is a nightmare.”

Problems with funding in Maryland include the problem that autism isn't very well recognized, that there is an assumption that a 3:1 individual to staff ratio is OK. Also there is not much psych/behavioral support. Maryland uses the IIRS (Individual Indicator Rating Scale) to attach dollars to needs. This has a health/medical aspect and a supervision aspect. Elements that CSAAC feels are required, that are difficult or impossible to fund, include ONGOING psych/behavioral support, smaller ratios of staff 2:1 or 1:1, 2 individuals in a home with one staff member, and transportation funding. Currently their individual with the most severe needs is funded for 2.7 hours/week of professional support which is funded at \$22/hour. CSAAC has purposely kept their administrative costs low, e.g., they were housed in an old school building with very low rent until just recently.

--What collaborations are in place across other agencies? Support systems? Incentives? They are accredited by The Council (formerly ACMRDD). They have the support of Montgomery County government, as well as the state. Community colleges have been very supportive. They stay in touch with county politicians. They are part of the Maryland Association of Community Services. The former head of this group now heads the new state office of Dev. Disabilities.

--What is the transition process from school-age programs to the adult services you provide, and how well is it working?

Only one out of 3 of the kids they serve transition into their adult program.

--What skills do you feel staff should have to work with your target population, and what training, if any, do you provide your staff?

Staff turnover varies with economy. Entry level agency direct care staff start at \$9.19/hour, with a \$3,000 bonus for a year of service. There is still a gap between pay for workers in the community and the state institution employees. Staff training includes characteristics of autism as well as a class on behavior strategies and principles (nonaversive techniques only are allowed in Maryland). They do lots of ongoing staff training.

--What kinds of services are in place to assure maintenance of successful outcomes over time, and/or intervene early if problems begin to develop?

They make monthly graphs of individual outcome data, and have kept this type of data for 20 years. The state requires reporting of things like # of blocks used, # of restraints used.

--What other resources do you recommend?

Quality assurance—Kim monitors each house every 6 weeks and checks safety issues. They do behavioral reliabilities at least every 2 weeks (also do in supported employment). They have a board with a committee of parents who go out and survey sites every year.

Interview and visit notes (combined)

Contact: Gary LaVigna

5. Agency: IABA: Institute for Applied Behavior Analysis

Phone Number: 805-482-8309

E-mail: glavigna@iaba.com

Date: phone call: 11/17/04, visit by Marie-Anne Aghazadian and me: 12/15/04

--We are interested in identifying best practices and current policies in services for adults with autism, including high-functioning adults and those with Asperger Syndrome. Since this represents a wide range of adults and skill levels, please briefly describe your target population.

They employ 500 staff. They serve about 120 in supported living and 200 in supported employment. They especially try to serve those who have “bombed out” elsewhere. They certainly have many individuals who are on the autism spectrum but don’t concern themselves too much with the diagnosis.

--What are the programs that your agency provides for these adults?

The youth program also provides in-home behavior respite, intensive supports at home and/or school, early and intermediate intervention. IABA also provides training and consultation. A range of supported employment and other daytime options, all highly individualized. Everyone lives in their own place, whether it be an apartment, a rented house, or a house purchased for them.

--What are the elements of these programs that you can consider to be best practice? What areas do they need improvement in?

Everything is done based on positive behavior supports. They are a for-profit psychological corporation to have freedom in how they operate, not to make a profit. Organizational structure: 3 service directors (e.g., Director of Supported Living) and one administrative director. Below these are managers who report to the directors. 5 managers: 2 in Ventura, 2 in Los Angeles, 1 in the valley. Below these are Supervisors (assist. managers) who oversee about 7 individuals (?). Below these are Senior community support companions, and then community support companions. The support companions are the direct staff.

They are very strong in the supported living arena.

--Do you have any policies in place that promote best practice either through state government, local government, or company policy?

--How do your programs address the domains of:

-Residential: Everyone is either in their own apt or home. They may have one disabled roommate if it is someone they especially get along with. Most situations consist of one identified person. Many of the people who require 24-hour support have a live-in, nondisabled roommate. These roommates generally work a PM shift M-F with them, but are off-duty the rest of the time. Since they live in the same unit, they may provide informal support at other times. Usually they have a daytime staff member who shows up in the morning, helps the person get up and going, goes with them to whatever their daytime schedule provides for. On the weekend, there are a variety of schedules, but one is a staff member who works 48 hours, including sleeping over Sat and Sun nights. Thus you might need as many as three bedrooms for three different people sleeping overnight on the weekends.

As far as what people DO in their homes, the major emphasis is on having a typical pattern of existence. It seems that a lot depends on the roommate. In many cases, it seemed like the roommate did a lot of the cooking and cleaning, etc. while the identified person maybe helped a bit. There didn't seem to be a big training push.

-Employment: Big emphasis on typical daily pattern of leaving the house during the day to engage in a meaningful schedule. For some people (a minority) this means going to work for between 5 and 8 hours. For others, it might mean running errands, taking special classes at the community college (daily living classes), doing some volunteer work in the community, etc.

-Social Skills/Support: Not an explicit program element for this.

-Recreation/Leisure Time: Emphasis on leisure activities that are self-determined and similar to what other adults do.

-Behavioral Supports: Positive behavior supports only. The intensive initial assessment guides the individual's program.

-Communication: No specific emphasis on this.

-Sensory: No specific emphasis on this.

-Self-Determination: Part of the guiding philosophy of the entire enterprise.

--What are the typical costs of your services and how are they funded?

Funding is determined by individual need as identified in the Positive Futures Plan, possibly supplemented by a functional assessment. They develop a preliminary service plan with an attached budget. This is then forwarded to the Regional Center responsible for the individual. A handful of individuals have parent-supported rent or homes their parents are purchasing. Community support companions (the direct care personnel) start at around \$10/hour, based on their experience.

--What collaborations are in place across other agencies? Support systems? Incentives?

--What is the transition process from school-age programs to the adult services you provide, and how well is it working?

--What skills do you feel staff should have to work with your target population, and what training, if any, do you provide your staff?

They feel it is critical to match staff to a particular individual they will be working with. Sometimes this takes quite a bit of time and quite a lot of switching people around.

They train using many modules that are self-contained and staff can go at their own pace. They also always have staff start by overlapping shifts with trained staff before they ever work solo.

--What kinds of services are in place to assure maintenance of successful outcomes over time, and/or intervene early if problems begin to develop?

They take lots of data. They use the Periodic Service Review, which is a data-based staff management system designed for organizations providing these types of services. We saw this in use and thought it could be quite useful. This system is available for purchase.

--What other resources do you recommend?

Check out the Periodic Service Review at epsr.com

Contact: Jeff Strully

6. Agency: Jay Nolan Center

Phone Number: 818-361-6400

E-mail: for Jeff Strully, Exec. Director: Jeff@jaynolan.org

Date: December 13, 14, 2005

Visited by Susan Peterson and Marie-Anne Aghazadian

--We are interested in identifying best practices and current policies in services for adults with autism, including high-functioning adults and those with Asperger Syndrome. Since this represents a wide range of adults and skill levels, please briefly describe your target population.

They serve a range of persons with autism and other significant developmental disabilities. They serve about 50 people in supported employment, 100 in day services. Many were formerly institutionalized. Some are in their twenties and thirties, but many are in their forties, people they have been serving for quite awhile.

--What are the programs that your agency provides for these adults?

Supported living, supported employment, structured day program for those who are not working. No "bricks and mortar" day programs.

--What are the elements of these programs that you can consider to be best programs that you consider to be best practice? What areas do they need improvement in?

Very significant emphasis on empowerment, self determination, community involvement. Proud of the fact that every consumer lives in his/her own home. They feel they could probably do better at getting more paid employment.

Each individual has a circle of support which meets regularly and actively monitors the individual's total program. Some pointers we received about how to effectively maintain circles: meetings should be limited to approximately one hour, take minutes and keep in a notebook so that they can be reviewed by those who may have missed a meeting, be sure to provide for follow-up on action items from each meeting, and schedule meetings far ahead, ideally on a predictable schedule, such as the 4th Friday of each month.

Turnover is much lower than the average for such providers. They feel this is for the following reasons: 1) staff feel responsible for the one individual they work with, 2) staff have a lot of different options for professional development within Jay Nolan, 3) staff are closely matched to the individual, and 4) there is a great deal of flexibility allowed in how staff do their jobs.

--Do you have any policies in place that promote best practice either through state government, local government, or company policy?

--How do your programs address the domains of:

- Residential: Supported living. People live in their own home (apt., condo, or house). A few have a roommate with disabilities. Others have a roommate without disabilities who lives there through the week and has a schedule to work with the person, usually 4-11 at night M-F. Individuals participate in the activities of daily living, but they are not required to do specific chores and there is not a big training emphasis. Quality of life is very important.
- Employment (Daytime activity support): Both their daytime programs are 100% community based. One is LINK, which provides community access for two individuals with one staff member, engaging in recreational activities, attending community college classes, working out at the YMCA, etc. The other is Personalized Day Services, which provides mostly 1:1 support for an individual's schedule of activities. (Jay Nolan loses money on PDS).
- Social Skills/Support:
- Recreation/Leisure Time:
- Behavioral Supports: Totally a positive behavior support model.
- Communication: We asked: "What is the typical way you would handle a situation where someone has severe cognitive deficits and does not talk—how do they communicate at a coffee shop, for example?" The answer was that the individual's staff members know the person and their preferences well, that they work with the circle of support, and that they read the individual's body language.
- Sensory:
- Self-Determination: To quote from the Jay Nolan Centers' "General Information" handout: "Jay Nolan assists people to live in their own homes with whatever supports are needed so they can be active members of their community. Support is provided depending upon each person's unique needs, interests, wishes, and desires. JNCS uses circles of support for each person served. Circles are comprised of a group of the individual, family members, friends, and other community members. Together, they determine how to help that person achieve his/her dreams. Control and power rests in the hands of the circle to make decisions about the person's life. Members of circles of support will brainstorm ideas, have parties, assist the person to find employment, support each other through tough times, recruit staff when needed, support the individual to become members within their own community, and a wide array of other things.

Jay Nolan Community Services, Inc. also offers a comprehensive support living needs/assessment with input from the individual, support people, their family, friends and a review of case history. Once all input is gathered, a recommendation for appropriate support is provided. If JNCS determines that we have the capacity to provide appropriate services, a support plan and personalized budget is created with input by all members of the individual's circle. This includes a "proposed" time line, a transition calendar and other useful information about the individual."

Person-centered approach can be associated with certain issues. Perhaps the individual doesn't want to work, and is well aware that their needs will be provided for even if they don't work. For those who understand, the Jay Nolan staff stress the extras they can get with their paycheck.

--What are the typical costs of your services and how are they funded?

In California, there are entitlements to services in the form of the Lanterman Act. These services are channeled through the statewide system of Regional Centers. Funding for Jay Nolan's supported employment program is \$27/hour, and it is \$13/hour for individuals in the LINK or PDS programs who may work part of the time. They make use of all community options such as Section 8, food stamps, etc.

IMPORTANT POINT about funding for 1:1 vs. small groups of individuals. Jeff Strully stated that if you look at all the costs (e.g., staff turnover, property damage, staff injuries, etc), it is not more expensive to serve people 1:1 vs. in small groups. He emailed a PowerPoint presentation where he describes what they have done at Jay Nolan, and includes some of this documentation.

--What collaborations are in place across other agencies? Support systems? Incentives?

--What is the transition process from school-age programs to the adult services you provide, and how well is it working?

--What skills do you feel staff should have to work with your target population, and what training, if any, do you provide your staff?

They feel the match is the most important. Variables on which they attempt to match staff to individual(s) include athletic/educational/vocational ability, relevant skill sets (e.g., computers, ASL, etc.), demeanor (high energy, low-key, etc.). There is a second interview with the individual and family members to see if they approve of the staff member.

Some helpful interview questions include: 1) "Does the prospective staff member know someone with disabilities, and how do they feel about them?" and 2) "The last time you moved, how did you connect with your new community?" (this last question is designed to learn what skills the prospective staff member has that they will be able to use to help the individual they are supporting make connections.

Initial training includes one day on Jay Nolan philosophy and 2 days on Mandt Training (relationship building for crisis prevention).

They feel ongoing training is key for mid-level staff. They have a low rate of staff turnover. Why? "Staff feel responsible for their one person they support...staff have a lot of different employment options within Jay Nolan...we believe in matching the staff to the individual, and we provide flexibility.

--What kinds of services are in place to assure maintenance of successful outcomes over time, and/or intervene early if problems begin to develop?

Supervisors stay in close touch with all of their consumers, so a lot of direct observation is used. They explicitly reject the use of data for monitoring purposes.

Among other things, Jay Nolan uses questions from a two-page document entitled, "Quality Assurance Tools." This asks a number of questions about the individual's community participation, competencies, staffing and roommate, functioning of their Circle of Friends, etc.

--What other resources do you recommend?

Jay Nolan Center provided us with extensive documentation which is available for review at the ASD office.

Contact: Laura Perkins and Becky Blackwell

7. Agency: Judevine Center for Autism, St. Louis, MO

Phone Number: 314-432-6200

E-mail: bblackwell@judevine.org

Date: 2/4/05 (visit), 11/3/04 interview

Visited by Susan Peterson

--We are interested in identifying best practices and current policies in services for adults with autism, including high-functioning adults and those with Asperger Syndrome. Since this represents a wide range of adults and skill levels, please briefly describe your target population.

They serve about 150-175 adults with autism, at all levels of functioning, including Asperger Syndrome). Level of severity runs the gamut. Level of service ranges from 1 hour per week to full-time support. They have a "zero-reject" model. In the area of employment, they provide supported employment, community based day habilitation which includes volunteer work, and facility-based transitional placement if someone loses a job or otherwise has need for such a service. Residentially, they serve about 50 people. They have one group home with 5 individuals and the rest consists of 1-3 people in supported living situations.

--What are the programs that your agency provides for these adults?

They have 26 group homes. Some of the individuals are also at home with their parents and supported by staff. They also have 33 individuals in supported employment and 18 in the EXCELL program.

--What are the elements of these programs that you can consider to be best programs that you consider to be best practice? What areas do they need improvement in?

Things Becky feels they are especially good at are finding good job placements and staff training. She gave examples of 4 people working at the Cardinals stadium filling catsup and mustard dispensers, and noted that one person who liked the sound of breaking glass and china, particularly porcelain toilet lids, now works successfully at a recycling center where his job includes breaking glass. In the residential area, she stated that matching roommates is very important. For those who live alone in an apartment, she described the "support neighbor" concept. An individual gets free rent and utilities in a neighboring apartment in exchange for specific duties. The target person's apartment always has a 2nd bedroom so that someone can stay there in case of a crisis or when the support neighbor is out of town. The support neighbor is paid extra for any non-routine duties, such as time involved when there is a crisis.

--Do you have any policies in place that promote best practice either through state government, local government, or company policy?

--How do your programs address the domains of:

-Residential: See the support neighbor concept described above. They also have host families (like a foster family). Of the group homes, 9 are owned by Judevine (purchased from a special fund). It can be hard to find a good landlord. They recommended picking “diverse, welcoming” neighborhoods to rent in.

-Employment (day activities):). They have EXCELL, a day program for the most challenged individuals, These people are referred from state institutions or the community. This serves 6-7 individuals in a group with 3 staff. They work on banking, handwriting, etc. It’s more of a classroom type of model, although they do also go into the community. The environment is very calm with dark-painted walls and low lights. The space they are in is in an industrial area and it looks like there may be some developing job opportunities with neighbors.

-Sometimes they find a community college or recreation center that can serve as a home base. For individuals who are living with their families, staff support includes helping the individual shop for family errands, going to sit-down restaurants, and other community activities. They intentionally go to the same neighborhood bank, bowling alley, etc. so that they can develop natural supports over time.

Transportation is in cars or vans owned by Judevine.

They feel they could do better with job development. It’s hard to decide what the right mix of skills is for these staff members. Lately they’ve found that using staff with autism experience and a little marketing background tend to do the best.

They do extensive assessment with the individual and try to match their interests and skills very specifically with a job. One individual wanted a job with, “an elevator, where he could sit at a desk and wear a collared shirt.” They found one and it has worked out well. They also have a guy who likes to “spit and yell” employed at the recycling center.

-Social Skills/Support:

-Recreation/Leisure Time:

-Behavioral Supports: They use ABA with an eclectic approach. They also describe what they do as “ABA within a social exchange context”. One thing I liked is that they have a term: “behavior development” which refers to the fact that the key to resolving behavior problems is to develop alternatives, not to focus on consequences.

-Communication:

-Sensory:

-Self-Determination: We were given a copy of Judevine’s Person Centered Planning Guidelines, which is available for review at the ASD office.

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--What are the typical costs of your services and how are they funded?

They are having severe funding challenges right now. The new governor has proposed closing a state facility, but also has been wiping out funding for some of the community services. They can provide services to people with Asperger's through the state Dept. of Mental Health. There is something called "Senate bill 40" which allows counties to raise taxes to pay for Judevine's services. Missouri is moving toward an autism waiver but apparently does not have one yet. Collaborations: They've successfully pushed DVR to pay for voc. Assessment, job development, and the initial months of support on a job, but DVR doesn't do follow-along. There is a new community waiver that provides \$20,000 a year to keep adults living with their families. There is a utilization review process that evaluates whether money being spent is justified for that person's plan.

Residential services are very hard to get right now. There is only Olmsted money or "extreme health and safety needs."

--What collaborations are in place across other agencies? Support systems? Incentives?

They may do assessment on someone, then have another agency do the job development, then Judevine may pick the person up again for job coaching.

--What is the transition process from school-age programs to the adult services you provide, and how well is it working?

In many cases Judevine is already providing services. They make sure that DVR does the assessment while the person is still in school. Some school districts will hire Judevine to do an assessment of the person's needs, so that makes transition easier. On the visit, it was noted that sometimes the special school district puts individuals about to graduate into a job but the individual may not be allowed to keep it when they move into adult services.

--What skills do you feel staff should have to work with your target population, and what training, if any, do you provide your staff?

Staff training: they do a lot of "natural support" training. This consists of 4-8 hour workshops for targeted groups of individuals, such as at a new job site. They also do these trainings before big family events such as weddings, and find this to be extremely helpful. Basic staff training consists of 2-3 weeks which starts with basic info on behavior analysis and autism, etc. Toward the end they do "bug-in-the-ear" coaching while the new staff person is on the job. They do a lot of parent training. The overall model is "ABA within a social exchange context."

The "thinking set" is critical. Staff get a 3-week program of workshops, demonstrations, and guided practice (with bug-in-the-ear) before starting work. (Only exception is first-line residential staff, who get a 3 day program to start).

Natural support training: They educate police departments, security staff at the local malls. They have a little yellow "crisis card" that staff can hand community members. Extended family

members get this same workshop, which includes the thinking set, behavioral development, communication, and autism info.

--What kinds of services are in place to assure maintenance of successful outcomes over time, and/or intervene early if problems begin to develop?

“We take a lot of daily data” and review it on a regular basis. One form they really like is a behavioral assessment form that has boxes to check off (e.g., for antecedent conditions, they just check the correct box from a list).

--What other resources do you recommend?

“Biggest fear of employers is workmen’s’ comp. Judevine clarifies that their employee is covered by them and that Judevine’s liability Ins. Will kick in if appropriate.

Contact: Mike Chapman

8. Agency: Division TEACCH (supported employment program)

Phone Number: 919-966-8194

E-mail: mikechapman@unc.edu

Date: January 13, 2005

--We are interested in identifying best practices and current policies in services for adults with autism, including high-functioning adults and those with Asperger Syndrome. Since this represents a wide range of adults and skill levels, please briefly describe your target population.

Program is a model program. They have found that very few job sites can tolerate aggressive behavior. The less disruptive they are, the better. They work only with the top 30% of the functioning range. They have about 30 people in their program.

--What are the programs that your agency provides for these adults?

Supported employment. There are four models, and they have people in all of them: individual or standard placement (maintenance ratio is 1 job coach to 12 individuals), Shared support or dispersed enclave (1 coach to 2-5 people, all working dispersed through a business), mobile crew (1 coach to 1-3 workers), and 1:1 model. Range of hours worked per week is 4-56, with mean of 22.5. Average salary is \$6.67/hour, range is \$5.15/hour to \$37,000 per year.

--What are the elements of these programs that you can consider to be best programs that you consider to be best practice? What areas do they need improvement in?

“98% of our people are happy, 86% are still in the same job 1 year later.” We provide very extensive assessment, job development, initial training. Initial assessment takes 40-60 hours, job development can take anywhere from 2 days to 3 years (average is 4-6 months). They provide a lot of visual and physical supports (e.g., picture schedules, reminders of rules, shelving set up to buffer distance for person who doesn't like people in his space. It's Mike's opinion that not every person with autism needs a full-time job. One thing they are very happy with is that DVR contracts with TEACCH to do the assessment, job development, initial intensive training of each person (using a voc rehab counselor trained and employed by TEACCH). If he had it to do over, he would hire an outside consultant to write the policy and procedures manual and create the necessary forms. Paperwork is a big challenge, at all levels of the work.

Only the most experienced job coaches work at the 1:12 “standard” support model, since this takes the most experience and skill.

--Do you have any policies in place that promote best practice either through state government, local government, or company policy?

Program is part of the University of North Carolina.

--How do your programs address the domains of:

- Residential
- Employment
- Social Skills/Support
- Recreation/Leisure Time
- Behavioral Supports
- Communication
- Sensory
- Self-Determination

Addresses employment only.

--What are the typical costs of your services and how are they funded?

TEACCH charges \$44/hour, and it takes an average of 250 hours to get the target individual through the steps of assessment, job development, placement, and intensive training (total of \$11,000). After this, the typical cost for a job coach, including benefits and administrative overhead, is \$36,000 per year.

Funding for the initial three steps, which are done by the Voc Rehab counselor, is provided by DVR. Funding for the maintenance step is from the mental health system in NC. Now NC is moving toward services being provided for by the LME (local management entity).

--What collaborations are in place across other agencies? Support systems? Incentives?

Mike has attended frequent meetings of groups in the business community (Chamber of Commerce, etc.). He feels networking is key in finding appropriate jobs.

--What is the transition process from school-age programs to the adult services you provide, and how well is it working?

Mike suggests starting YOUNG in vocational training. Use the TTAP (TEACCH Transition Assessment Profile) for assessment (this will be published soon). the TTAP is the second generation of the AAPEP and now includes a community-based aspect.

--What skills do you feel staff should have to work with your target population, and what training, if any, do you provide your staff?

“Before staff are left alone they’ve had 1 ½ weeks of training, including 3 days of didactics on health, safety, and characteristics of autism and 3-4 days of side-by-side time with the person they’re replacing. THEN the supervisor checks in several times per day for the first few weeks. There is also ongoing training. Most of the job coaches have college degrees. Average staff members stay just over 2 years. They start at \$12 to \$12.50 per hour plus generous benefits. Another perk is the availability of state cars they can use for job-related travel.

--What kinds of services are in place to assure maintenance of successful outcomes over time, and/or intervene early if problems begin to develop?

Mostly this is accomplished by direct observation and monitoring. They also keep service notes.

--Philosophy?

“Our mission is to provide a stable and predictable work environment” “We feel it’s important to honor the autism”

--What other resources do you recommend?

Appendix 2 Project participants

Karen Bashkow, Chair, ASD Adult Issues Committee and parent

Marie-Anne Aghazadian, parent and Director of the Parent Information Center

Don Peters, Ph.D., Project Consultant, Professor Emeritus, University of Delaware and former chair of Individual and Family Studies and Director of the Center for Disabilities Studies

Susan L. Peterson, Ph.D., Principal Investigator and former psychologist at the Delaware Autism Program

Theda Ellis, Executive Director of the Autism Society of Delaware

Others who assisted:

Michael Partie, Therapeutic Options, Inc.

Dom Squittiére, Delaware Autism Program

Rob Gilsdorf, Legislative Chair, ASD, and parent

Appendix 3

Organizations contacted via phone or email

Name	Organization	State	Phone
Harrel, Micheal A.	Aging with Autism Workshop	LA	1.318.649.2385
Meredith, Carol	ARC of Arapahoe & Douglas	CO	303.220.9228
Baseheart, Sarah	Ask Me! Survey	MD	410.974.6139
Page, Terry	Bancroft	NJ	856.429.5637
Schmidt, Brittany	Center for Disabilities	SD	800-658-3080
Fleming, Laura	Carolina Habilitation Services	NC	919.678.9780
Braswell, Bruce	Dept. of Dis. & Spec Needs Autism Division	SC	803.898.9776
McCool, Thomas	Devereux	CA	805.967.0934
Isler, Vicki	Eden Family Services	FL	239.437.5335
Montgomery, Gary	Eden Family Services	NJ	609.426.1319
Sanders, Kim	Grafton	VA	540.542.0200
Yeater, Dave	Grafton	VA	540.542.0200
Muller, Steve	Homestead	IA	515.967.4369
Reaven, Judy	JFK Partners	CO	303.315.6503
Blackwell, Becky	Judevine Center	MO	314-432-6200
Moss, Bill	Linwood Center	MD	410.465.1352
Fishbein, Herman	Multiple Agencies	MA	508.850.3900
Long, Leslie	NJ COSAC	NJ	609.883.8100
Chambon-Gay, Linda	Rusty's Morning Ranch	AZ	928.634.4784
Benson, Kelly	The Sean Ashley House	TX	713.667.6460
Yuan, Susan	University of Vermont	VT	802.899.2883

