

**Empowering Independent Lives** 

## **FAQ Guide**

# As a parent of an autistic young adult you are likely to have questions



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### Introduction

## Transitioning from adolescence into young adulthood requires a mix of essential socialization skills to function in the community.

Vista has a long heritage of teaching individuals functional skills designed to help them lead more independent lives. To address the needs of autistic children as they become young adults, Vista has introduced an Adult Services Program focusing on the essential living, social integration, and vocational skills needed to integrate into society.

#### During this time, many parents, just like you, ask important questions:

- What happens when my child exits the structured public school system?
- What independent living skills are needed and how can my child acquire these essential skills as a young adult?
- What financial assistance is available for my adult child with Autism Spectrum Disorder?
- How may my adult child develop the necessary skills to get and maintain a job?

#### Our comprehensive and individualized programs are designed to:

- Engage young adults in the development of life skills
- Enable them to integrate into society
- Enrich their lives with a sense of independence

As your child gets older our program will adapt to his/her maturing needs.



#### **Services For Adults with Autism**

#### What programs and services are available for adults on the autism spectrum?

Adults with autism spectrum disorder need ongoing quality services to maintain the gains made during intensive behavioral training programs as children and adolescents. If they did not receive these services as children and adolescents, then they'll need even more intensive skills training as adults. Effective services should be based on Applied Behavior Analysis, which is the only proven method for training individuals on the autism spectrum. Independent Living Skills, Supported Living Services and Supported Employment are services available and funded for qualified individuals by Regional Centers in California.

# What is Independent Living Skills (ILS) training and how may my adult child qualify for this service?

Independent Living Skills (ILS) are services available through the Regional Centers and is a program that provides for the development of skills necessary for an adult client to live independently and maintain him/herself in a self-sustaining, independent-living situation.

The challenge with most ILS programs is that regulations do not require specific educational credentials and training for providers delivering this service. At Vista we te ach and train independent living skills in our "Skills for Living" program but what differentiates our program from most ILS programs is that we have highly tr ained personnel administering our programs and our programs utilize procedures that are based on Applied Behavior Analysis. The application of the ABA approach result in the rapid attainment of skills needed to live independently.

# We've tried it all and still our adult child is struggling to make progress how can you help us?

We have been successful helping individuals advance from their current level of functioning. Progress cannot be guaranteed but your odds are greatly increased when you work with highly qualified professionals, who use the most advanced training procedures based on Applied Behavior Analysis.

It is also important to set realistic goals. Our goal is to empower you and your teen or adult child to achieve the level of independence for which he or she is capable. We believe that each individual is a unique and can achieve significant progress towards being a productive and worthwhile member of their community.



## **Services For Adults with Autism (Continued)**

#### What skills and supports does my adult child on the autism spectrum need?

Your adult child will need skill development in three essential areas: (1) Independent Living, (2) Socialization & Recreation, and (3) Vocational. By way of outside services and support, we believe the most effective method for developing these skills is through a comprehensive life skills training program designed and provided by professionals educated and experienced in the principles of Applied Behavior Analysis.

Of course, the internal support and encouragement of family, extended family and friends is critical while your adult child takes on the challenges associated with building skills in these areas.



## **Transition Planning**

# What will happen when my child on the autism spectrum exits the public school system?

Upon exiting the public school system, your adult child with autism actually has many available options, which include attendance at a college or trade school, entry into the job market, or participation in a structured day program. Residential options include staying at home with family, living in a supported residential group home, or living independently in the community.

These options can be exercised with support from family, but there are also state and federal funding mechanisms which assist with the cost of necessary services to support your son or daughter's choices for securing employment and housing.

# How do I manage my child's transition from adolescence into young adulthood and beyond?

Most parents of children on the autism spectrum are very anxious about the transition from adolescence into adulthood, since many of the services that were available from school districts and other funding sources will no longer be provided.

It is important for you and your son or daughter, if he or she is capable, to identify short and long-term goals for independent living and vocational development, and then to make a plan toward achieving those goals. This would involve an assessment of your child's current level of skills. Your child is likely to require some training to develop the skills he/she will need to live independently or semi-independently and to succeed in college or in the workforce. This is often most effectively achieved through a program that is based on Applied Behavior Analysis.

# Tips for Preparing Your Child on the Autistic Spectrum to Transition from High School to College

- Start the transition process early
- Research education laws
- Think "Big Picture"
- Do the prep work
- Be selective about the college your child chooses to attend
- Start building independent living skills
- Learn to establish friendships and circles of support
- Anticipate obstacles
- Develop a plan for obtaining support services at the college



## **Social and Relationship Skills**

# What social and recreational activities are recommend for my adult child on the autism spectrum?

There is no absolute right or wrong choice for the selection of leisure activities for an adult with autism; rather, each person should be able to choose the activities that he or she most enjoys.

Some people on the autism spectrum need support in developing social & recreational skills to participate effectively in their chosen activities, but they should be encouraged to participate in activities which are most meaningful and enriching to them. Recommended activities are those which foster good fitness and health, community integration, and personal satisfaction.

# How important is it for my adult child on the autism spectrum to learn good etiquette and table manners?

Many people might think that with all the difficulties people on the autism spectrum need to overcome, that social etiquette and good table manners would be nice but hardly essential. On the contrary, we think that etiquette and manners training are essential skills to learn for individuals with Autism Spectrum Disorder.

The main purpose for displaying etiquette and manners is to show respect to others and to help them feel more comfortable with us. When we interrupt others in conversation, fail to say "thank you" when someone does something for us, or talk with our mouth full, other people feel uncomfortable. One the other hand, when we take turns in conversation, say "please" and "thank you" or ask for food to be passed, instead of grabbing it, other people feel more comfortable and they are more inclined to want to be around us.

#### What are the key elements of a quality Life Skills Training Program?

It is very important that any Life Skills Training Program be tailored to the needs of your child. The individual's skills and deficits should be assessed in the broad skill areas of vocational, independent living, socialization, communication, recreation and leisure, and safety. This can only be accomplished through a comprehensive assessment, which involves interviews with you and your adult child, observations of him or her, and the administration of at least one standardized assessment of living skills.

The agency or individual doing the assessment should provide you with an assessment report, which details your adult child's specific age-appropriate strengths and weaknesses, along with a comprehensive plan for improving skill deficits.



## Social and Relationship Skills (Continued)

A quality treatment plan should be based on procedures derived from the principles of Applied Behavior Analysis (ABA), which is the only scientifically proven approach towards improving skills deficits in individuals on the autism spectrum. ABA involves a thorough understanding of behavior and how it is influenced by events in the environment. There are a number of techniques that are based on the principles of ABA like:

- **Positive Reinforcement** when a behavior is reinforced or rewarded, it is more likely to occur in the future.
- **Shaping** using positive reinforcement on small improvements at first and then on greater and greater improvements.
- Task Analysis breaking skills, like riding a bus or meal prep, into small steps and then training each step in the process.
- **Differential Reinforcement** reinforcing a desired behavior and not reinforcing an inappropriate behavior.

The training program should focus on age-appropriate skills. Here are some important skills that an adult on the autism spectrum should learn, depending on the individual's capacity:

Vocational skills

- Searching for employment
- Managing job stress
- Socializing with co-workers

#### Living skills

- · Personal hygiene and grooming
- Washing and drying clothes
- Paying bills

Social and Recreational skills

- Interactive conversations
- Interpreting social cues
- Dealing with dating and sexuality

In an effective plan, training should be provided in a variety of settings, such as home, work, and in the community. Formal instruction sessions may be held, but the use of naturalistic training is preferred for the acquisition of new skills and to increase the likelihood that the trained skills will be used in a variety of settings.



## Social and Relationship Skills (Continued)

# How can my adult child on the autism spectrum learn to socialize with others, so that she/he will be able to develop richer relationships?

The inability to form and maintain social relationships is one of the most common challenges of individuals on the autism spectrum. Developing this skill is vital because social relationships are so central to having a meaningful and productive life.

Fortunately, training procedures that use procedures based on Applied Behavior Analysis have been extremely effective in teaching the skills critical for navigating the social world.

Social skills are trained individually and in small groups. Some of the important skills that we train include:

- Initiating and ending conversations
- Participating in interactive conversations
- Joining in conversations and activities
- Interpreting social cues, both verbal and nonverbal
- Making eye contact
- Taking turns in conversations

An assessment of social skills must be conducted, to assure that the training program developed is tailored for your child, making sure that he or she receives training for the skills that are most needed.

# What do I need to know to prepare my adult child on the autistic spectrum for dating and sex?

Your adult son or daughter will naturally be interested and curious about dating and developing a sexual relationship. He or she will also experience significant anxiety and confusion in these areas.

Establishing a relationship that may lead to romance and sexuality may be particularly difficult for young adults on the autism spectrum, due to serious deficits in judgment and social skills. The skills needed to develop and maintain a romantic relationship can be taught using ABA procedures and include:

- Initiating conversations.
- Maintaining conversations
- Establishing eye contact
- Asking someone for a date
- Selecting an appropriate place to go or meet
- Understanding and dealing with emotional reactions



## Social and Relationship Skills (Continued)

• Beginning to develop intimacy in a relationship.

Discuss issues of dating, intimacy and sexuality with your child, at the level that he or she can understand. Try to be proactive; initiate discussions on sexuality before there is a problem. You may want to prepare yourself by obtaining appropriate materials that are related to your child's level of development. There are resources on the internet that can guide you through these discussions. As an example, we recommend the article entitled, Sexuality Instruction and Autism Spectrum Disorders by Peter Gerhardt <a href="http://www.education.com/reference/article/sexuality-instruction-autism-ASD/">http://www.education.com/reference/article/sexuality-instruction-autism-ASD/</a>.

Since sexuality is a natural extension of a romantic relationship, there are many things that young autistic adults need to know about sexuality, including:

- When is it appropriate to touch the other person and where do you touch?
- How does the young adult protect him or herself from sexually transmitted diseases
- and pregnancy?
- Effective birth control practices.
- If the young adult tries to touch and the other person says no, how can she or he deal with this emotional rejection?

We understand that parents may not feel comfortable or confident to instruct their child in sexual education. We recommend that parents also read *Intimate Relationships and Sexual Health: A Curriculum for Teaching Adolescents/Adults with High-Functioning Autism Spectrum Disorders and Other Social Challenges* by Catherine Davies and Melissa Dubie.

This book outlines essential topics that should be included in a sexual education curriculum, including reproduction, birth control, sexual health, appropriate behaviors, privacy issues, establishing relationships, dating, marriage, parenting, abuse awareness, boundary issues, self-esteem, sexual orientation, sexual values, intercourse, contraception and sexually transmitted disease protection.

If you have not already begun having these discussions with your adolescent or young adult child, it is important to begin now.



#### **Vocational**

#### What do we need to know to help an autistic adult to find, get and keep a job?

- Identify your son's or daughter's strengths and interests.
- Learn to use job search tools
- Make a professional resume
- Prepare for job Interviews
- Have pertinent personal information readily available
- Learn to be a colleague at work
- · Develop social skills
- Find reliable transportation
- Know the job duties and complete them
- Know the Employer-Employee Boundary

#### Is there Job Discrimination protection for an adult on the autism spectrum?

The Americans for Disabilities Act (ADA) is a federal statute providing legal protection for individuals with autism and other disabilities. The ADA establishes that there can be no job discrimination on the basis of developmental problems, as long as the person is capable and adequate to do the job.

## Housing

# What type of living arrangements would be available for my adult child on the autism spectrum?

Considering the maturity level and skills development of your adult child, many options could be open. Sometimes, remaining with family is the best option. Other times, a residential setting with other individuals with similar conditions provides the most supportive environment.

On an increasing basis, independent residential living environments are becoming the preferred goal as individuals with autism are now often building skills of independent living throughout their lives, thereby preparing them to exercise apply these skills as adults in their own independent living situations.

If it is your parenting goal and your adult child desires to live independently, it is important that he or she start now learning the necessary living skills to do so. An independent living skills training program based on Applied Behavior Analysis procedures, is the most proven method for preparing your to live independently.



## **Financial**

# What financial assistance is available for my adult child on the autism spectrum?

Adults with autism have access to a variety of State and Federal programs that provide financial assistance for costs of living and necessary skills training. Such resources include Supplemental Security Income (SSI), Medicaid, In-home Supportive Services (IHSS), and Job Related Services. In addition, Regional Centers in California provide funding for a number of services for adults on the autism spectrum and they collaborate with the Department of Rehabilitation to co-fund Supported Employment Services. Additionally, as of July 1, 2012, private insurance plans in California have a mandate to pay for prescribed Applied Behavior Analysis services for eligible policyholders with a diagnosis of autism spectrum disorder (ASD), irrespective of age.

#### Should I set up a Special Needs Trust for my adult child on the autism spectrum?

We cannot offer specific legal or financial advice, but we can suggest that you consider various options of support for your adult child, one of which is a Special Needs Trust. The basic reason families set up such trusts is to administrate benefits through the trust to a disabled beneficiary who would otherwise lose eligibility for Supplemental Security Income (SSI) or Medicaid (which is known as Medi-Cal in California). Seek out a financial and legal consultant with expertise in Special Needs Trusts to see if this is applicable for your adult child.

# What may happen financially to my adult child in the future when I am no longer around?

We recommend that you consult with a skilled financial and legal professional, with specific training in dealing with cases involving children with special needs.

This is a critical area of concern for all parents of special needs children and causes a great deal of anxiety and stress for most. We all hope our children will be capable of living independently but many parents of children on the autistic spectrum are afraid this may never happen.

It is important that your adult child is taught independent living skills from a qualified professional trainer. This training can best be accomplished with procedures based on Applied Behavior Analysis, the only scientifically proven method for training and building skills for people on the autism spectrum.

Regardless whether your son or daughter will be able to maintain a job or live independently, it is essential that you plan carefully about his or her financial future. A recent study by Easter Seals and the Massachusetts Mutual Life Insurance Company found that 74 percent of parents fear their children with autism will not have enough



## **Financial (Continued)**

financial assets to support themselves after their parents die. Therefore, it is critical for both parents to have Wills that coordinate with other planning documents, such as a special needs Trust.

Also consider establishing a "Third Party Special Needs Trust" in your Living Trust or Will. This Trust would not be under the control of your adult child, and he or she would not be able to

revoke it and use the assets at his or her own discretion. The Trust would have an independent trustee and would continue for the lifetime of the child. The basic reason families set up such trusts is to provide support through the trust to a disabled beneficiary who would otherwise lose eligibility for Supplemental Security Income (SSI) or Medicaid (Medi-Cal in California). We recommend that you consult with an attorney if you are considering setting up a Third Party Special Needs Trust.

It is also important to write a letter of intent that details essential information about your child with autism. The letter of intent offers guidance to courts and other individuals for interpreting care instructions. The letter usually includes information about your adult child's medical history, emergency contacts, living arrangements, education or work situations, recreation and leisure activities, and challenging behaviors, as well as a summary of family contacts and financial information.

# Will medical insurance cover autism treatment for my adult child on the autism spectrum?

As of July 1, 2012, private insurance plans in California will have a mandate to pay for Applied Behavior Analysis (ABA) services for eligible policyholders with diagnoses on the autism spectrum disorder.

This Autism Insurance Act resulted from nearly a decade of advocacy spearheaded by Autism Speaks, the largest nationwide autism advocacy and public policy organization, and the California Association for Behavior Analysis. The Autism Insurance Act does not stipulate any age limits for clients to be covered under this law, so adults with autism will also be eligible to receive insurance coverage. Vista can work with you to help you determine if your loved one qualifies for ABA services under this mandate.



## **Next Steps**

The issues associated with your teen or adult child might seem difficult and daunting. We believe knowledge at this stage is critical to determining the appropriate path for your son or duaghter. These FAQs are just a start of your journey.

The transitional challenges you might face can be challenging and rewarding along the way. I encourage you to be patient and persistent while garnering knowledge along the way.

If you are interested in learning more about Independent Life Skills training for your teen or young adult child take I welcome you to visit our website or contact one of our staff members at 818 - 646-5560. Vista serves the Greater Los Angeles Area.

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**Empowering Independent Lives** 

# Engaging, Enabling, and Enriching Life Skills

for Young Adults with Autism Spectrum Disorder

Will she be able to get a job?

Can he live on his own?

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