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# Autism Agenda



Linn Benton Lincoln ESD-Cascade Regional Autism Program

# 4Ways to Help Your Young Adult with Autism Transition to Independence

The Autism Blog Guest Writer: Ben Wahl, MSW

The importance of the young adult transition is becoming more recognized within the community of providers who work with young people on the Autism Spectrum. Now if we could just increase that awareness among providers who work with young people who are *not* on the spectrum.

All joking aside, young people with Autism Spectrum Disorders (ASD) are a bellwether. They struggle with the transition from high school precisely because it is a difficult process. Having worked with young adults both neuro-typical and neuro-atypical, I have observed similar challenges for both.



Society tends to cast a view that the young adult transition is a 'launch', a sudden shift from dependence to Independence. If a young adult is not able to immediately find their path, others are often quick to pass judgment.

We have to be aware of this pressure and bring the young adult transition back into perspective. This is especially true for families with teenagers and young adults who are on the spectrum. The young adult transition is not a 'launch'; it is a series of steps. Your child with ASD will have some unique steps in this transition process, but they also have great skills to take these steps. Think about it: your child has had a longer road through the school age years, but that also means that your child has accumulated more awareness and resiliency to navigate life after high school.

By taking a more long-term view of the young adult transition, you may find that it begins to evoke less anxiety. This is no small matter; your son or daughter will notice how you approach their transition and will view their transition accordingly.

With a new perspective on the young adult transition, we can turn our attention to the specific competencies that young people with ASD need to build as they progress towards independence and self-determination. The following concepts will be helpful as you and your child engage in the transition process.

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# TRANTION TO INDEPENDENCE CONTINUED....

# • Identify Strengths

The young adults in our Delphi young adult program at <u>Aspiring Youth</u> have helped us to improve services to every client in Aspiring Youth, even our 8 year olds. One of the most important lessons these young adults have given us is the importance of identifying personal strengths. Our Delphi young adults are gaining a greater awareness of their identity and this helps them pursue appropriate education and employment opportunities. The tricky issue for young people with ASD is that this process of self-awareness often comes later than it does for their neuro-typical peers. You can help your son or daughter better understand their strengths and that is an important contribution to their transition process. If they are honing in on a specific topic or activity, acknowledge their ability to maintain a high level of focus. Catch them doing good and remind them that they possess kindness. Point out their loyalty, integrity and consistency. Then, let them know how those traits will be valued in the adult world.

# Practice Flexibility

One of the greatest differences between individuals with ASD and their peers is their challenge in being flexible and adapting to new situations. In both groups the transition to adulthood contains many uncertainties. However, the young adult with ASD will have a more difficult time adjusting to the new environment. The antidote is to try new things. While it can certainly take a lot of pre-planning for the middle school or high school student with ASD, any new setting or experience can increase the student's ability to handle change during their post-high school experience. Taking an audited community college course on 'Paranormal Activity'. Trying an instrument. Volunteering or interning in a business. All of these pursuits will help the student with ASD build comfort with new settings and experiences and will help prepare them for their adult life.

## Build Self-Accountability

Young people with ASD often find it difficult to identify their internal motivation. Yet in the context of preparing for the adult world, the intrinsic pride of achieving a good academic grade is more important than any concrete reward (ie, screen time) a student might earn. As providers and parents we have to take more steps to help students with ASD build internal motivation and pursue self-directed goals. The approach inherent in ABA therapy may be valid for younger clients and those more significantly impacted by ASD, but for older clients with High-Functioning Autism and Asperger's Syndrome, the ABA emphasis on external rewards and goals developed by the provider (and not the young person) does not build self-accountability and may actually inhibit it. Instead, we can empower ASD teenager and young adults by helping them become better connected to their own personal motivations and goals.

# • Communicate and Self-Advocate

We often think of 'social skills' as the ability to interact with friends, but in the context of the young adult transition it takes on broader meaning. As young people with ASD approach their transition, they need to implement some of their new social skills to increase communication with professors, employers and others in the adult world. Self advocating and communicating to solve conflicts is something that we take for granted. If a teenager with ASD can practice self-advocacy with a teacher, they are building skills that will serve them well in the young adult transition. Similarly, if the teenager can identify and pursue independent social opportunities, they will be building important communication skills for the less structured social world that exists after high school.

While your child's transition to independence may take longer than some of their peers, it is important to remember that it is not a race. The values and skills that you have helped your child build are what matter the most.

Guest Writer: Ben Wahl, MSW, is the founder and director of <u>Aspiring Youth</u>, which provides social skills groups, summer programs and young adult transition services.

http://theautismblog.seattlechildrens.org/4-ways-to-help-your-young-adult-with-autism-transition-to-independence/



# 4 POINTS TO HELPING FIND INDEPENDENCE

# Four Key Points to Helping a Young Adult with Autism Find Independence

This is a blog by Marianne Sullivan, Managing Director, Regional Programs and Services in the West at Autism Speaks. Marianne is the mother of a 21-year-old adult with autism. She spoke on a panel at the 2nd Annual National Conference this past weekend in Columbus.

It has always been important for people to share stories with one another to help the people around us grow wiser and stronger. I want to share with you some of my personal experiences with my son, Hunter, who is now a 21-year-old adult with autism. If you are in the process of "trying to figure things out" with your son or daughter, my heart is with you. I hope sharing my story will open up some new ways of thinking about your circumstances and possibly lead to a more positive outcome. In any case, we do know that the more we share with one another, the more we will benefit.

Let me begin by saying that while my story has had many successes, we have also had our challenges and I will share both with you. Hunter was first diagnosed with autism when he was only two years old. During those early years, his language development was extremely limited and unfortunately, this has continued throughout his life. He was unable to express his needs and feelings so frequently that he felt deeply frustrated. The frustration, in turn, was expressed by aggressive behaviors.

We decided to face our challenges with Hunter by becoming part of a team and founded a school in our area dedicated to serving kids with autism. Hunter adapted quickly at the school but even with high quality interventions, he struggled to overcome his behavioral challenges during these school years with limited successes.

Recently, I came across a school report from four years ago. I would like to share an excerpt from it:

"His parents reported they have a difficult time de-escalating situations at home when they set limits on Hunter's access to food or when he is denied his specific requests. Hunter's continued escalation of challenging behaviors resulted in his termination of services at school and district is recommending residential services."

This was our turning point (or breaking point); we decided we had to focus on a few very important goals and develop key supports for Hunter. Reassessing our priorities and getting organized seemed to be just what we needed to get on the path to success. Everything we did came back to four key areas and eventually, we started to see progress. Focusing on these key areas may also help you:

### Have a safe and supportive place to live.

When Hunter turned 19, with the help of Supportive Living Services provided by the California Regional Center, he was able to move to a new home in our community. The agency assisted us in locating and moving into his new home. He was now moving toward independence.

#### Maintain access to needed services.

We were fortunate to participate in the creation of an education center for young adults affected by autism. Hunter quickly adjusted to this new level of involvement. His support team created an educational program that focused on improving his ability to participate in various aspects of community life, while at the same time setting goals to improve the quality of his daily living activities like meal planning and household chores.

# Participate in meaningful activities.

His team continued to work on skills that would allow him to be more independent, such as money management, grocery shopping and home maintenance. It became very clear to us that his new **independence** was very meaningful and important to him. It motivated him to understand new levels of what it meant to be reasonable and accepting of a variety of circumstances. He wanted to be able to make his own decisions and have some control over his life and we supported each and every step in that direction. Engaging in leisure activities helped him in community life; he was able to walk downtown to movies and is now bowling in a bowling league with other adults.

Continued on page 4.

# 4 POINTS TO HELPING FIND INDEPENDENCE CONTINUED..

Develop friendships and relationships in a community that involves and values the input of the individual with complex communication needs.

We contacted local businesses in the community and asked them to partner with us on jobs for young people like Hunter. We were delighted a local brewery offered him an internship. With staff support, Hunter found a job. The Santa Cruz Brewery treated him like one of their own, giving him real work and real compensation from the beginning. He quickly adjusted and showed that he could be responsible and productive labeling bottles and boxes for the brewery's manufacturing department. He also prepares pallets that are now sold at Costco. Imagine how proud he is when he sees his product in Costco! Like anyone with a job, Hunter has the occasional bad day at work, which means that his coworkers have seen him at his most difficult. With support from Hunter's job staff, the company has learned ways to be supportive and as a result, they have been able to maintain their commitment to him as an employee. Hunter's self-esteem has grown as a result of his job.



If you asked me just a few years if I thought Hunter would have a part-time job, live on his own with support and enjoy his community, I would have replied, "NO WAY." While Hunter has made a number of big gains, we know there are challenges ahead. As most families know, a child's movement toward independence is not done in a day, a month or sometimes even in a year or more. Accepting this, while also keeping a focus on your day-to-day goals, is vital to your success.

I hope you remember that being a loving, supportive parent of a child with challenging behaviors, as well as his or her advocate, is a lifelong pursuit. We all go through periods of feeling overwhelmed. Trust me, you are not alone. Connect with others who share your situation and it will help! Also, remind yourself that pacing is important, so don't hesitate to take breaks when you need them. Your health and well-being are necessities! Rest brings us the relief we need and when you fill restored, and you will, you will be able to do what's needed. Stay strong!!

For more information about the transition process with your child or young adult with autism, check out the Autism Speaks <u>Transition Tool Kit.</u> Visit the <u>Adult Services</u> page of our website for more resources for adults on the spectrum. https://www.autismspeaks.org/blog/2013/07/29/four-key-points-helping-young-adult-autism-find-independence

# **COMPANIES HIRING**

# Why Some Companies Are Trying to Hire More People on the Autism Spectrum

The majority of those with autism are unemployed, but new pilot programs at big companies, such as EY and Microsoft, are discovering unexpected benefits from having "neurodiverse" colleagues.

By Bourree Lam

Interest in what's called neurodiversity is growing at American companies. This year, the accounting firm EY (formerly known as Ernst & Young) has been piloting a program to employ people with autism in order to explore the benefits of having workers of different cognitive abilities, such as greater productivity and building a more talented workforce.

According to a recent study by Drexel University, 58 percent of young adults with autism are unemployed. And yet, many of them have skills that businesses are looking for. "This program leverages the skills that people with high functioning autism often have: looking at data, dealing with mathematical concepts, attention to detail, the ability to focus over long periods of time, and looking at large bodies of information and spotting anomalies," explains Lori Golden, EY Abilities Strategy Leader who led the pilot program. Right now, EY's program has four employees who work as accounting-support associates.

EY recruited the candidates, and adjusted its training and onboarding processes to become more comfortable for individuals on the autism spectrum. In addition to regular training, Golden says that EY provided hands-on training during which employees in its neurodiversity program could watch work happen in real-time as part of job training. In turn, the program has also resulted in some thoughtful reflection from the company's managers. "One thing that happened that I thought was really interesting was that, as our supervisors went through training these individuals everyday, they stopped and asked 'Can this be improved? Are we communicating the right way?" says Golden. What EY found was that having colleagues with autism challenged the office's status quo, and made it easier to broach questions about whether or not communication and management strategies were effective and logical.

"It's a relatively new thing ... but I would say it's gaining momentum," says Rob Austin, a business school professor at Ivey Business School at the University of Western Ontario, of the growing interest in recruiting neurodiverse employees. "One of the things that companies are discovering is that there are benefits that they did not anticipate."

Austin explained that the push for neurodiversity in the workplace has Danish origins. Thorkil Sonne, a Danish telecom worker, was the instigator for bringing people with autism into the professional space. Sonne's own son has autism and he founded the company Specialisterne in 2004 with the specific aim of employing people with autism and preparing them for the workforce. Employees at Specialisterne were high-functioning autistic people who were offered jobs in the IT and technology space.

"At some point, Thorkil wasn't making enough impact. He had 75 or so people employed, but he wanted to employ a million people with autism. So he changed his model, and started trying to convince big companies to do it," says Austin. One of these companies was SAP, a huge software company, which hired people with autism to do software testing and analytics. The company now employs over 100 people on the autism spectrum, and that program served as a case study by Austin and his colleague Gary Pisano of Harvard Business School.

# COMPANIES HIRING CONTINUED .....

Two other companies that have been taking the lead on this are HP Enterprises (via an initiative called the <u>Dandelion program</u> in Australia) and <u>Microsoft</u>. In the SAP case study, the company found employees who had advanced degrees and patents in their names, but still weren't able to land corporate jobs. Austin says that the talent is there, but often missed because of the over-reliance on the interview process or the lack of flexibility on the part of companies. And now, the interest in these workers, which <u>began in the tech industry</u>, seems to be <u>spreading to other industries and job functions</u> as well.

For example, Sam Briefer, an employee in EY's neurodiversity program, was diagnosed with Asperger's Syndrome and ADHD at the age of six. After graduating from Westchester University, he was worried about finding a job. "I began sending out 30 or so applications, and I was being called in almost every day for an interview," says Briefer. "I turned down most of them because either the jobs were too stressful or not of my interest." Briefer has been at EY's Philadelphia office for over six months, and he's optimistic about his future at the company. "I'm so happy with where I am right now ... I feel like as long as I'm continuing to be a strong team player and someone who is always ready to step up and lead anything, that will be a great asset to my team." Golden says that the program has had a strong reception from EY employees, and the company is planning on expanding the program to other offices next year.

But Austin says that ultimately these programs have to make sense for the company's bottom line. The pilot programs—which companies go into with little expectation—have been producing good results in terms of finding new talent and productivity gains. "Ultimately, it's not a charity thing because it's providing far more benefit than it's costing. Every company I know that's gone into this in a serious way has gone into it with the idea that this is going to be net benefit positive," he says.

Golden says that one of the challenges EY encountered initially was finding the right people. But the company's collaboration with Microsoft, SAP, AT&T, Ford, Hewlett Packard Enterprise, and JP Morgan Chase—which includes sharing best practices and challenges, as well as creating a pool of appropriate candidates—has helped bridge that gap. "I'd like to think that this is a broader thing that's happening, and I think we have some evidence for that," says Austin. "We're simply getting better at helping people contribute more."

https://www.theatlantic.com/business/archive/2016/12/autism-workplace/510959/



# **AUTISM LIFE SKILLS**

# Autism Life Skills: 10 Essential Abilities for Children with ASD

By Chantal Sicile-Kira — Autism Society

**Teacher**: What are your greatest dreams about your future?"

Jeremy: "I want to have my own house with roommates, good friends, a fun job and be learning."

**Teacher**: "What are your greatest fears about your future?"

Jeremy: "That I will not have enough money."

**Teacher**: "What barriers might get in the way of accomplishing your goals?"

Jeremy: "You know I need good helpers. I need people that respect my intelligence."

-Interview with Jeremy Sicle-Kira Transition Year 2007-08



With two teenagers who will soon be out of school, there has been much reflection and soul searching taking place in my home lately as to whether or not we've made the right decisions as parents over the years. Rebecca, our neurotypical teenager, has just started driving and is becoming more independent. In hindsight, there is not much I would do differently if we had to start raising her all over again.

My thoughts concerning Jeremy, our 19-year-old son with autism, are somewhat different. Those who have seen him on the MTV True Life segment "I Have Autism" will remember his can-do spirit and his determination to connect with other people, but also how challenged he is by his autism. Obviously, there are many more options available to help people like Jeremy today than when he was a baby. Over the last few years, as we considered how to best prepare Jeremy for the adult life he envisioned, I wondered what we could have or should have done differently when he was younger.

This led me to think: What would today's adults on the autism spectrum point to as the most important factors in their lives while they were growing up? What has made the most impact on their lives as adults in terms of how they were treated and what they were taught as children? What advice did they have to offer on how we could help the children of today? I decided to find out. I interviewed a wide-range of people—some considered by neurotypical standards as "less able," "more able" and in-between; some who had been diagnosed as children; and some diagnosed as adults. The result of these conversations and e-mails became the basis of my latest book, Autism Life Skills: From Communication and Safety to Self-Esteem and More—10 Essential Abilities Your Child Needs and Deserves to Learn (Penguin, October 2008). Although some areas discussed seemed obvious on the surface, many conversations gave me the "why" as to the challenges they faced, which led to discussions about what was and was not helpful to them. No matter the differences in their perceived ability levels, the following 10 skill areas were important to all.

### Sensory Processing

Making sense of the world is what most adults conveyed to me as the most frustrating area they struggled with as children, and that impacted every aspect of their lives: relationships, communication, self-awareness, safety and so on. Babies and toddlers learn about the world around them through their senses. If these are not working properly and are not in synch, they acquire a distorted view of the world around them and also of themselves.

Most parents and educators are familiar with how auditory and visual processing challenges can impede learning in the classroom. Yet, for many, sensory processing difficulties are a lot more complicated and far reaching. For example, Brian King, a licensed clinical social worker who has Asperger's, explains that body and spatial awareness are difficult for him because the part of his brain that determines where his body is in space (proprioception) does not communicate with his vision. This means that when he walks he has to look at the ground because otherwise he would lose his sense of balance.

Donna Williams, Ph.D., bestselling author and self-described "Artie Autie," had extreme sensory processing challenges as a child and still has some, but to a lesser degree. Donna talks about feeling a sensation in her stomach area, but not knowing if it means her stomach hurts because she is hungry or if her bladder is full. Other adults mention that they share the same problem, especially when experiencing sensory overload in crowded, noisy areas. Setting their cell phones to ring every two hours to prompt them to use the restroom helps them to avoid embarrassing situations.

Many adults found it difficult to tolerate social situations. Some adults discussed how meeting a new person could be overwhelming—a different voice, a different smell and a different visual stimulus—meaning that difficulties with social relationships were not due simply to communication, but encompassed the total sensory processing experience. This could explain why a student can learn effectively or communicate with a familiar teacher or paraprofessional, but not a new one. Continued on page 8.

# **AUTISM LIFE SKILLS CONTINUED...**

The most helpful strategy was knowing in advance where they were going, who they were going to see and what was going to happen, so that they could anticipate and prepare themselves for the sensory aspects of their day. Other strategies included changing their diet, wearing special lenses, having a sensory diet (a personalized activity schedule that provides the sensory input a person's nervous system needs to stay focused and organized), undergoing auditory and vision therapy, as well as desensitization techniques.

### Communication

The ability to communicate was the second most important area of need cited by adults. All people need a form of communication to express their needs, in order to have them met. If a child does not have an appropriate communication system, he or she will learn to communicate through behavior (screaming or throwing a tantrum in order to express pain or frustration), which may not be appropriate, but can be effective. Sue Rubin, writer and star of the documentary "Autism is a World," is a non-verbal autistic college student and disability advocate. She often speaks about the impact of communication on behavior. She shares that as she learned to type she was able to explain to others what was causing her behaviors and to get help in those areas. In high school, typing allowed her to write her own social stories and develop her own behavior plans. As her communication skills increased, her inappropriate behaviors decreased.

Those with Asperger's and others on the more functionally able end of the spectrum may have more subtle communication challenges, but these are just as important for surviving in a neurotypical world. Many tend to have trouble reading body language and understanding implied meanings and metaphors, which can lead to frustration and misunderstanding. Michael Crouch, the college postmaster at the Crown College of the Bible in Tennessee, credits girls with helping him develop good communication skills. Some of his areas of difficulty were speaking too fast or too slow, stuttering and poor eye contact. When he was a teenager, five girls at his church encouraged him to join the choir and this experience helped him overcome some of his difficulties. Having a group of neuro-typical peers who shared his interests and provided opportunities for modeling and practicing good communication skills helped Michael become the accomplished speaker he is today.

# Safety

Many on the spectrum had strong feelings about the issue of safety. Many remember not having a notion of safety when little, and putting themselves in unsafe situations due to sensory processing challenges. These challenges prevented them from feeling when something was too hot or too cold, if an object was very sharp or from "seeing" that it was too far to jump from the top of a jungle gym to the ground below.

Many adults described feeling terrified during their student years, and shared the fervent hope that with all the resources and knowledge we now have today's students would not suffer as they had. Practically all recounted instances of being bullied. Some said they had been sexually or physically abused, though some did not even realize it at the time. Others described how their teacher's behaviors contributed directly or indirectly to being bullied. For example, Michael John Carley, Executive Director of GRASP and author of Asperger's From the Inside Out, recalls how his teachers made jokes directed at him during class, which encouraged peer disrespect and led to verbal bullying outside the classroom.

A school environment that strictly enforced a no-tolerance bullying policy would have been extremely helpful, according to these adults. Sensitizing other students as to what autism is, teaching the child on the spectrum about abusive behavior, and providing him/her with a safe place and safe person to go to at school would have helped as well. Teaching them the "hidden curriculum," so they could have understood what everyone else picked up by osmosis would have given them a greater understanding of the social world and made them less easy prey.

## **Self-Esteem**

Confidence in one's abilities is a necessary precursor to a happy adult life. It is clear that those who appear self-confident and have good self-esteem tend to have had a few things in common while growing up. The most important factor was parents or caretakers who were accepting of their child, yet expected them to reach their potential and sought out ways to help them. Kamran Nazeer, author of Send in the Idiots: Stories from the Other Side of Autism, explains that having a relationship with an adult who was more neutral and not as emotionally involved as a parent is important as well. Parents naturally display a sense of expectations, while a teacher, mentor or therapist can be supportive of a child and accepting of his/her behavioral and social challenges. Relationships with neuro-typical peers, as well as autistic peers who share the same challenges were also important to developing confidence.

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# **AUTISM LIFE SKILLS CONTINUED...**

# **Pursuing Interests**

This is an area that many people on the spectrum are passionate about. For many, activities are purpose driven or interest driven, and the notion of doing something just because it feels good, passes the time of day or makes you happy is not an obvious one. Zosia Zaks, author of Life and Love: Positive Strategies for Autistic Adults, told me that, as a child, she had no idea that she was supposed to be "having fun"—that there were activities that people participated in just for fun. It was one of those things about neurotypical living that no one ever explained to her.

As students, some of these adults were discouraged from following their obsessive (positive translation: passionate) interest. Others were encouraged by parents and teachers who understood the value of using their interest to help them learn or develop a job skill. For example, when he was little, author and advocate Stephen Shore used to take apart and put together his timepieces. Years later, this interest was translated into paid work repairing bicycles at a bike store.

# **Self-Regulation**

Respondents believed this is a necessary skill for taking part in community life. Many children on the spectrum suffer from sensory overload. It can also be difficult for them to understand what they are feeling and how to control their emotional response. Dena Gassner, MSW, who was diagnosed as an adult, believes it is necessary for children to be able to identify their "triggers" and that parents and educators should affirm to the child that whatever he or she is feeling is important. Even if it does not make sense to the adult, whatever the child is feeling is true for him or her. Various methods can be used to help them become more self-aware over time, to recognize when they are approaching sensory or emotional overload and to communicate the need for a break. As they get older, giving them more responsibility for scheduling their own breaks and choosing their own appropriate coping strategy can be very empowering.

# Independence

Independence is an important goal, but may take longer than expected. Zosia Zaks told me that parents of children with autism need to realize and accept that they will be parenting for a lot longer than parents of neurotypical children. She has a point, but I never thought I'd still be discussing certain self-care issues when my son was old enough to vote. For many that I interviewed, some skill acquisition came later in life, and many are still improving themselves and their essential skills. This is nice to know because so often, as parents and educators, we hear about the "windows of opportunity" in terms of age and can become discouraged by our own inner cynics and other well-meaning doubters ("If they haven't learned by now....").

When discussing self-sufficiency, many stated that the two greatest challenges were executive functioning (being able to get and stay organized) and sensory processing. Doing chores and establishing routines helped some as children to learn organizational skills and responsibility—two essential foundations for self-sufficiency.

# Social Relationships

Relationships are important to all human beings, but are difficult for many on the spectrum. The adults I communicated with make it clear they enjoy having relationships, including those who are mostly non-verbal, such as Sue Rubin and D.J. Savarese (who wrote the last chapter of Reasonable People). However, understanding the concept of different types of relationships and knowing the appropriate behaviors and conversations expected does not come naturally, and can be magnified for those who are non-verbal.

Many adults, such as Dena Gassner and Zosia Zaks, discussed the importance of teaching children interdependence skills—how to ask for help, how to approach a store clerk, how to network as they get older. For them, interdependence did not come as easily as it does for neurotypicals. Yet, asking people for assistance—what aisle the cookies are located in, the name of a plumber when your sink is stopped up, letting people know you are looking for a job or apartment—is how social and community life functions.

### **Self-Advocacy**

Effective self-advocacy entails a certain amount of disclosure. All of the adults I spoke with believed that children should be told about their diagnosis, and this should be done in a positive manner. Michael John Carley, who was diagnosed following the diagnosis of his son, says he always felt diff erent than others. Getting a diagnosis was liberating because then he knew why he felt different. On the topic of disclosure to others, some believe in full disclosure to all, while others choose to disclose only the area of difficulty.

Like many her age, Kassiane Alexandra Sibley, who wrote a chapter of the book Ask and Tell, was improperly diagnosed before discovering at age 18 that she had an autism spectrum disorder. She had to learn self-advocacy skills the hard way. Like many I spoke with, Kassiane believes that teaching children when they are young to speak up for themselves is the most important gift we can give them.

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# **AUTISM LIFE SKILLS CONTINUED...**

# Earning A Living

This is an issue of major concern for many on the spectrum. Some of the adults I spoke with struggled for years before finding an area in which they could work. The life skills discussed earlier in this article impact tremendously on a person's ability to find, get and keep a job. Many people on the spectrum continue to be unemployed or underemployed, which means we need to rethink our approach in how we are transitioning our youth from being students to being contributing members of society.

Temple Grandin, who co-authored the book Developing Talents, says that parents should help their children develop their natural talents and that young people need mentors to give them guidance and valuable experience. Authors John Elder Robison (Look Me in the Eye) and Daniel Tammet (Born on a Blue Day) both credit their Asperger's for giving them the talents on which they have based their successful businesses. For those whose talents are less obvious, a look at the community they live in and the service needs that exist there can be an option for creating an opportunity to earn money. My son Jeremy and his teacher created a sandwich-delivery business and a flower business on his high school campus as part of his work experience. Customized employment, including self-employment, is an option that, with careful planning and implementation, can be a solution for some.

# A Final Thought

In retrospect, there are different choices I could have made in raising and educating Jeremy these past 19 years. However, after conversations and e-mails with many different adults on the spectrum, I have concluded that there is one factor I would not have changed, the formula I used for providing a solid foundation for both of my children: Take equal parts love, acceptance and expectation, and mix well.



#### **About the Author**

Chantal Sicile-Kira is an author, autism advocate and speaker. Autism Life Skills is her third book. She is the U.S./Canada marketing director and columnist for The Autism File, a magazine debuting in major bookstores in September. For more information, visit www.chantalsicile-kira.com.

https://www.education.com/reference/article/autism-life-skill-ten-essential-abilties-ASD/

## **IPAD APPS & WEBSITES**

- LBL ESD has a Transition Network Facilitator, Vikki Mahaffy who has created a website with numerous resources. https://www.lblesd.kl2.or.us/TTAN-transition-resources/
- **HabitRPG** for android is a free app. One of several "gamification" apps out there, this one functioning as your daily checklist. As the name suggests, this app combines tracking habits and to-dos with elements from RPGs (that's role-playing games, for non-gamer folks). When you complete your tasks, you gain experience points and level up your (adorable) pixel-art avatar character. While the app has ever-increasing depth to it like joining a party, and taking on challenges, it is incredibly easy to use for the basics of getting things done.

I find it especially helpful that the app uses three categories for "doing": "Habits" (e.g. "Work Out"),

"Dailies" ("Take Medicine"), and "To-Dos" ("Call Grandma"). Nobody wants to add "Work Out" to their to-do list every day, and yet it is still important to keep tabs on the good habits you are maintaining or trying to get into. I'd recommend to put all "Dailies" as "Habits" at first, because if you don't do your "Dailies," your character takes damage.



These apps are suggested and not affiliated with LBLESD.

# **WHAT IS SPARK?**

# What is SPARK?

- SPARK is a free online study with a simple mission: to speed up research and advance the understanding of autism.
- SPARK aims to be the largest study of its kind with the goal to building a community of 50,000 individuals with autism and their families across the nation.
- The entire autism community is encouraged to participate, including adults and children diagnosed with autism, as well as their biological parents and siblings.
- By dramatically increasing the number of research participants, SPARK aims to help facilitate research that has not been possible.

An important part of SPARK is the collection of DNA so it can be analyzed to expand our understanding of the role of specific genes in the development of autism. SPARK will ask you to share basic information about your medical and family history, and if you chose, a DNA sample using a saliva collection kit.

SPARK is sponsored by the Simons Foundation Autism Research Initiative (SFARI), and scientific initiative of the Simons Foundation.

# Why Participate in SPARK?

While we are making significant progress learning about autism, we simply don't know enough. By joining SPARK, you're helping accelerate research to find causes and treatments for autism.

Additionally, you may qualify to receive:

- Updates on the latest research
- Access to experts who will arm you with information to help address daily situations
- Results from the analysis of your and your family's DNA, in the event that you opt to receive this information and a genetic cause for autism is identified
- Individuals with autism will receive gift cards valued at up to a total of \$50 for participation.

# **Register for SPARK Today**

To learn more about SPARK and register online via a secure portal, visit **www.SPARKforAutism.org/OHSU**. All data provided to SPARK will be stored without any identifying information and kept confidential.

# What to expect after registration

After you register, a saliva kit will be shipped directly to your home with clear instructions for collection and return shipping. The kit includes a tube for collection saliva, as well as an absorbent sponge that can be used for any child who is not able to spit. If you prefer, you can provide a saliva sample in-person by scheduling an appointment at your local clinical site or hospital participating in SPARK.

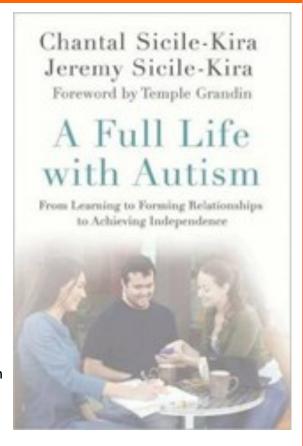


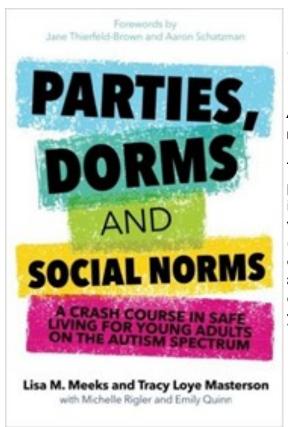
# **BOOK REVIEWS**

# A Full Life with Autism: From Learning to Forming Relationships to Achieving Independence

by Chantal Sicile-Kira and Jeremy Sicile-Kira

Autism expert Chantal Sicile-Kira and her autistic son Jeremy provide a candid, reassuring and eminently practical guide that embraces the journey from teen to adulthood. Proactive, positive and highly readable, A Full Life with Autism is an essential resource for young adults, family and professionals. It breaks daunting goals into manageable, doable tasks. Chock full of checklists and resources, it provides step-by-step ideas for transition planning, self-determination, social relationships, love and intimacy, living arrangements and support staff, post-secondary education, and employment. In this well-researched book, it is hearing Jeremy's voice that brings poignancy to the reader, opening minds to thoughts of limitless possibilities when people are supported to be their best.





# Parties, Dorms and Social Norms: A Crash Course in Safe Living for Young Adults on the Autism Spectrum

by Lisa Meeks and Tracy Loye Masterson

The late teens and twenties are exciting times, but filled with potential pitfalls as young people navigate the transition into independent adult life. This informal and frank go-to guide is filled with the information that young people with ASD say they want (and need) to know about alcohol and drugs, social media and online safety, relationship types and boundaries, safe sex, stress and emotional health, and independent living. It includes real life examples, coping strategies, practical tips and scripts to help young adults with ASD stay safe while living life to the full.



# Linn Benton Lincoln ESD Cascade Regional Autism Program

905 4th Ave SE Albany, Or. 97321

Tel: 541-812-2600 Fax: 541 926-6047

E-mail: webmaster@lblesd.k12.or.us

### **Autism Consultants:**

Skye McCloud- skye.mccloud@lblesd.k12.or.us 541-812-2663

Sue Taylor- sue.taylor@lblesd.k12.or.us 541-812-2676

 $Melissa\ Bermel-\ melissa.bermel@lblesd.k12.or.us$ 541-812-2773

Amanda Stenberg-amanda.stenberg@lblesd.kl2.or.us 541-812-2676

 $Scott\ Bradley-scott.bradley@lblesd.kl\ 2.or.us$ 541-812-2677

Michelle Neilson- michelle.neilson@lblesd.kl 2.or.us 541-812-2678

# **VISUALS**

