Improving Health and Wellness for Individuals with ASD

Healthy Weight Management for Youth with ASD: What We Know and How to Help

By Danielle Zito, PsyD and Shana Nichols, PhD, ASPIRE Center for Learning and Development

With obesity a growing epidemic in the United States, much attention has been placed on weight loss and healthy weight management. Unfortunately, research has shown that individuals with Autism Spectrum Disorder (ASD) are at an increased risk of struggling to maintain a healthy weight (Tyler, McDonald & Menezes, 2013). As a result, such individuals are at an increased risk of developing serious health problems including diabetes, sleep apnea, asthma, and heart disease, in addition to social difficulties such as isolation, discrimination, and low self-esteem.

Get Moving and Eat Right: Risk Factors for Weight Issues

One major cause of weight-related issues in ASD is limited physical activity, compared to both suggested guidelines and that typical of their peers (Sorensen & Zarrett, 2014). Why do youth with ASD move less?

- Motor skill difficulties are common for youth on the spectrum (McCody, Jakicic & Gibbs, 2016).
- Youth with ASD are more likely than typically-developing peers to engage in sedentary activities, such as watching television and playing video games.
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- Youth with ASD are more likely than typically-developing peers to engage in sedentary activities, such as watching television and playing video games.
- Weight gain side effects such as aversions or preferences for particular food textures, smells, colors, temperatures, or presentations (McCoy, Jakicic & Gibbs, 2016).

Medical issues which are associated with weight gain such as genetic conditions, metabolic disorder, and gastrointestinal problems (de Vinck-Baroody et al., 2015).

Weight gain side effects of psychotropic medications usually prescribed to individuals with ASD, such as atypical antipsychotics (Broder-Fingert et al., 2014).

Healthy Weight on page 23

Leaders Honored at MHNE Annual Awards Reception

By Ira Minot
Executive Director
Mental Health News Education

On June 29th, Mental Health News Education, Inc., (MHNE) publishers of Autism Spectrum News and Behavioral Health News held its first combined Leadership Awards Reception at the NYU Kimmel Center overlooking Washington Square Park.

Receiving honors at the sold-out event were four outstanding leaders from the autism and behavioral health communities, including: Donna Colonna, Chief Executive Officer of Services for the UnderServed (S:US), Gary Lind, Executive Director of AHRC New York City, Arlene González-Sánchez, Commissioner of the New York State Office of Alcoholism and Substance Abuse Services (NYS OASAS), and Dr. Fred Volkmar, Professor of the Yale University Child Study Center.

The event was attended by many executives, program directors, consumers, corporate partners, and state and local state agencies from both communities, who enjoyed a lively networking opportunity before the summer vacation season. MHNE Board Chair Constance Brown-Bellamy moderated the program which included a Media Award presented to MHNE Associate Director, Debra Pantin and board member Mr. Robert Ring.

Dr. Alan Siskind, Founding Chairman of MHNE stated, “This combined behavioral health and autism leadership awards annual event marks a new future for MHNE, one of unity, education and friendship.”

Our Honored Sponsors are listed on page 15, and to view our event photos, go to: www.bit.ly/MHNE2017Photos.

Left to Right: David Minot, Debra Pantin, Arlene González-Sánchez, Dr. Fred Volkmar, Gary Lind, Donna Colonna, Constance Brown-Bellamy and Ira Minot
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**Editorial Calendar**

**Fall 2017 Issue:**

“The Latest Advances in Autism Science”

Deadline: September 7, 2017

**Winter 2018 Issue:**

“Assessment, Diagnosis and Science-Based Interventions”

Deadline: December 6, 2017

**Spring 2018 Issue:**

“Understanding and Treating Psychiatric and Medical Conditions Associated with Autism”

Deadline: March 1, 2018

**Summer 2018 Issue:**

“Supporting Children with ASD at School”

Deadline: June 1, 2018
For families with a loved one diagnosed with an Autism Spectrum Disorder (ASD), navigating the health care system and accessing services can be a significant challenge. In fact, a 2009-2010 National Survey of Children with Special Health Care Needs examining the relationship between a child’s special health needs and (1) access to services, (2) quality of care, and (3) family impact found caregivers of children with autism experience more difficulty accessing services, a lack of shared decision-making and care coordination, and adverse family impact as compared with caregivers of children with other developmental disabilities or mental health issues (Vohra, R., Madhavan, S, Sambamoorthi, U. & St. Peter, C., 2014).

A model of care that addresses these barriers is the patient-centered medical home (PCMH), which is a team-based approach to providing proactive, comprehensive, and well-coordinated care, which includes facilitating access to non-medical social and community-based support services (Strange, K.C, et al., 2010). In the medical home model, primary care providers need to either expand services or enhance capacity to coordinate care with other providers and services in order to manage all aspects of patient care (Ginsburg, S., 2008). One approach to implementing the medical home model is locating multiple providers and services in the same integrated setting. Research shows that providers working together to collectively take responsibility for addressing all aspects of a person’s health and wellness results in increased access to care, enhanced patient experience, improved coordination of services, and more successful health outcomes (Nielson, M., Langner, B., Zema, C., Hacker, T. & Grundy, P., 2012).

An integrated approach can work especially well for individuals with ASD who often require more specialized care from multiple providers and often require additional therapeutic and related services. Autism is associated with increased prevalence of certain medical and behavioral health conditions such as seizure disorder, gastrointestinal disorders, depression, anxiety, attention deficit disorder, and obsessive compulsive disorder (Belardinelli C, Raza M, Taneli T., 2016). In addition, characteristics associated with autism can make it difficult for families to maintain good oral health care (Nelson, T. & De Bord, J., 2015). Optimal medical, specialty and dental care for individuals with ASD requires a team approach with specialized knowledge, active communication, effective partnerships, and in many cases behavioral intervention strategies. Implementing the medical home model in an integrated setting promotes increased (1) awareness, (2) access and (3) coordination among providers.

see Integrated on page 24
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Tools for Successful Healthcare Transition

By Adrienne P. Robertiello, BS
Autism Educator
Children’s Specialized Hospital

Transition from adolescence to adulthood affects many areas of life including health, education and training, employment, living situation, and possibly guardianship. Autism spectrum disorder (ASD) presents unique diagnostic and medical management challenges throughout a person’s lifespan. As many youth with ASD have complex healthcare needs and face the cessation of many of the entitlements within the children’s system of services, the separation from a pediatric healthcare provider can often be challenging. Studies reveal 60% of transition-age youth with ASD have at least two health or mental health conditions in addition to ASD and 75% take at least one medication for medical or mental health issues. According to the 2009-10 National Survey of Children with Special Health Care Needs, the majority of youth with ASD have a primary care physician who treats only children. Despite recommendations that transition preparation and discussion begin in early adolescence, the survey found this had not occurred for most youth with special health care needs.

Medical practices with formal policies on transition ensure all youth have access to the same transition services, the transition process is accomplished in a systematic way, and all members of the transition team (youth, family, and healthcare providers) have defined roles in the transition process. A primary care medical home equipped to care for adolescents with ASD through their transition into adulthood can positively impact the transition experience and improve the lives of those involved.

This article describes a model program with tools to ensure seamless transition to adult healthcare for youth with ASD. Children’s Specialized Hospital’s pediatric Special Needs Primary Care (SNPC) has received National Committee for Quality Assurance (NCQA) recognition as a Patient-Centered Medical Home. In this setting, children with ASD and other complex conditions receive coordinated care. Aligning with medical home standards and guidelines, the SNPC team provides primary care as well as coordinates care with both external and internal sub-specialists. In 2015, Children’s Specialized received a grant from the New Jersey Governor’s Council for Medical Research and Treatment of Autism to create a medical home program for children and youth with ASD. The focus of this grant was creation of optimal care coordination practices. In 2016, a second grant was awarded by the Governor’s Council to specifically develop a structure to promote seamless transition into adult healthcare for youth with ASD within the medical home model. This Autism Medical Home Transition Collaborative joins the hospital’s pediatric SNPC team, autism team, family faculty, and neurodevelopmental specialists with two Rutgers University affiliates: RWJ Family Medicine adult providers and The Boggs Center on Developmental Disabilities. Focusing on improving the evolution of care for individuals with ASD, this collaboration promotes improved care delivery to adolescents and young adults with ASD.

The Autism Medical Home Transition Collaborative has created an evidence-based, practical, and replicable healthcare Autism Transition Tool encompassing many of the complexities of the ASD healthcare transition process. It provides templated reference sheets which identify topics for discussion, necessary skills, and supportive resources. Topic areas include primary care and wellness, dental care, specialty care, personal hygiene, nutrition, and fitness, behavioral health, sexuality and relationships, safety, education, healthcare provider choices, guardianship, adult service systems, and financial considerations. Additionally, the Autism Transition Tool will be used to support education delivery to the hospital community.

Within the Autism Transition Tool are a “Practice Level Checklist” and a “Patient Checklist.” The Practice Level Checklist prepares the pediatric practice for implementing a formal transition policy and process. This involves educating staff on the transition needs of youth with ASD, and specifically how these needs are addressed within the practice. It also includes the creation of an internal transition registry to ensure all adolescent patients within the practice receive appropriate transition care as outlined in the practice’s transition policy. This registry allows the practice to follow up with youth who have transitioned to adult services at a post-transition check-in.

The Patient Checklist is age specific and prompts the adolescent, family, and provider to complete items on their respective checklist in three age groupings: Stage One (12-13 years of age); Stage Two (14-16 years of age); and Stage Three (17-21 years of age). Included throughout the three stages of the Patient Checklist are psychosocial assessments inclusive of safety concerns, social skills, and activities for daily living; transition readiness activity; development of an autism medical passport summarizing the care plan and goals; assessment of health insurance status for adulthood; determination of need for guardianship; and addressing patient and family benefits (e.g. Supplemental Security Income, Social Security Disability Insurance, state disability services, special needs trust). Among the many resources within the Autism Transition Tool are tips for locating adult providers and questions to ask when interviewing a prospective adult provider.

One of the final activities of the Patient Checklist is a warm-handoff between the pediatric healthcare provider and the adult care provider prior to the patient’s first appointment with the adult care provider. Essentially, this discussion includes a review of the patient’s medical history, current plan of care, active issues, chronic conditions, likes and dislikes, goals, and typical length of appointment. While many elements of this discussion may be included in the autism medical passport, a simple conversation may facilitate a shared mental model and help provide seamless transition by ensuring both the pediatric and adult primary care providers have a shared understanding of the patient, his or her healthcare needs, and care preferences.

Lastly, the Patient Checklist includes a follow-up check-in with the patient and family post-transition as a close to the transition process. The dual benefits of this brief check-in are to ensure the adolescent has effectively transitioned and to provide an opportunity to evaluate any gaps in the practice’s transition process.

In the next phase of this grant, the hospital will implement the Autism Transition Tool into the SNPC and include within their Care Navigator™ software program. Care Navigator is used as a primary communication and education tool facilitating shared care across departments and systems of care throughout a patient’s medical journey. The Care Navigator is designed to turn clinical and lifestyle quality data into actionable care planning and health promotion information in order to promote better health. The technology provides for continuous feedback, monitoring, and interaction among patients, family members, physicians, and clinical support staff.

To build the capacity of the health care system to serve adults with ASD and related intellectual and developmental disabilities, the Autism Transition Tool will be made available for use by other healthcare providers who care for adolescents with ASD.

The hospital provides other tools and resources for youth with ASD and their families to support health, safety, and other areas of life. One tool is a mobile app “Healthier Me.” Created through Children’s Specialized Hospital’s Kohl’s Autism Awareness program, the app educates and reinforces activities which support good hygiene habits, healthy eating, watching out for food allergies, keeping active, and staying safe.

The hospital also provides The Community Hub (www.childrens-specialized.org/kohlsautismawareness) as a centralized online source of resources aimed at enhancing function and quality of life, increasing safety, and improving the effectiveness of community services.

For additional information about autism healthcare transition tools and other Children’s Specialized Hospital resources, please contact Aditi Doshi, project manager at ADoshi@childrens-specialized.org or visit www.childrens-specialized.org.

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Visit the www.childrens-specialized.org/KohlsAutismAwareness to start your journey!

Learn more or support us at ChildrensSpecializedHospital.org 1-888-CHILDREN
Three Expert Tips for Realizing Your Wellness Goals

By Mallory Hubi, MS, MA
Health and Wellness Coordinator
College Internship Program

W hen we don’t feel well, it seeps into every aspect of our lives. Lethargy, a poor attitude, inertia, and even maladaptive coping mechanisms can be common signs that we aren’t operating optimally. Although social skills and career skills hog much of the limelight as important areas of function for people on the autism spectrum, I like to understand wellness as the glue that holds our lives together.

As I work with young adults with autism and other learning differences, I have the opportunity to support their health and wellness goals as part of a holistic transition to independence. Some of the students I work with are working through sensory issues with things like the texture of food, the feeling of sweat on their body, even the great outdoors. Others have trouble with coordination, and others yet are genuinely disinterested in cooking or physical activity.

Whatever the reason may be, we can find comfort in knowing that the path to health and healing has always been individualized - and finding what works for people with autism is no different. Below you will find some tricks I use to help students realize success.

1. Individualize for Independence

If we can understand health as unique to each individual, then surely it should be up to each person to design their own fitness, diet, and stress management protocols. My students create their own individualized fitness protocols, meal plans, and stress resilience routines.

Given the space to create something for themselves, students choose exercises that they feel confident they can perform, meals that they will realistically eat, and they take advantage of the tools they have in their stress resilience repertoire.

I have recommendations, but I must always bear in mind that they are mere suggestions to remind students of the direction in which they are going. Ultimately, in the transition to successful independence, my students will be the ones to decide what goals they will actually pursue.

Evan, a student of mine, explains, “You can take it into your own hands. If you want to be awesome and fit, do all that stuff and eat a bag of spinach. You need to have a choice in what you do; that way you have the freedom to do what feels right.”

Whether we identify as runners, vegetarians, meditators, musicians or otherwise, each person has their own unique wellness profile - the work lies in discovering that profile and pursuing it.

2. Be Realistic: Start Small

Because everyone is at a different place on their wellness journey, it is essential that I meet students where they are. For those who could benefit from a new habit or lifestyle change, I must bear in mind that it likely won’t happen easily or overnight.

I follow in the footsteps of James Clear, a writer in the field of habit formation and human potential, by encouraging students to make any changes in routine so small that they can’t help but succeed.

Jacob is a student who wants to get into better shape, but has struggled with finding the motivation to exercise independently. He decided to make a small habit of 10 pushups every day for one month. It went so well that he did 20 crunches every day the next month. “When I did it, I liked having done it. I thought, ‘Yay, I did some workout today.’”

Jacob put himself on a trajectory of success. By starting small, he is planting the seeds of follow-through and of commitment to health. Reckoning that he did his daily habit about 80% of the time, a huge improvement on his previous intentions to exercise independently, Jacob is now confident that he will be able to follow-through if he sets his mind to new goals in the future.

Another student, also named Jacob, knows he would benefit from eating more fruits and vegetables. His strategy to start small, by incorporating vegetables into his nightly dinner, came with a surprising discovery: “You get used to it! Now, I like eating veggies more and more. I’ll boil broccoli, asparagus, or cauliflower to eat with every meal.” He still doesn’t eat a lot of fruit, but is easing his way in by being open to trying new recipes that involve fruit.

If I were to put a big bowl of fruit in front of Jacob and say, “Eat this every day if you want to be healthy,” it would be a total turn-off. He wouldn’t trust me, and worse yet, he would continue to avoid fruit. Since he knows he can tolerate trying a small amount of fruit, and that it’s okay to mix it into a greater recipe, he dabbles...
Desite the existence of severe and challenging behavioral presentations for many children with autism spectrum disorders living in residential and inpatient settings, children with complex ASD continue to be underrepresented in the literature (Siegel, et al. 2015) and there is a marked lack of research literature to help residential and psychiatric inpatient staff identify which behaviors may be definitively associated with a possible co-occurring psychiatric or mental health diagnosis such as ADHD, anxiety, phobia, depression, and more. Some studies suggest a high rate of co-occurring psychiatric conditions such as Anxiety Disorders, Oppositional Defiant Disorder, Attention Deficit Disorder, and Mood Disorders in children diagnosed with ASD (Orinstein et al. 2015, Joshi et al. 2010; Simonoff et al. 2008; de Bruin et al. 2007; Leyfer et al. 2006; Gadow et al. 2005). In the first study of psychopathology and ASD, Emily Simonoff and colleagues found as much as seventy percent of children diagnosed with ASD are expected to have a comorbid psychiatric disorder and 41% with two or more. Communication and cognitive impairments have been identified as barriers to assessing psychiatric comorbidity in individuals with autism (Leyfer et al., 2006) and distinguishing co-occurring diagnoses in individuals with ASD can be especially difficult in individuals with limited/minimal expressive language and communication skills (Siegel, et al. 2014; Kim, Paul, Tager-Flusberg & Lord, 2014). Additionally, children with ASD’s are more likely to experience greater psychiatric symptom severity than their typically developing peers (Gadow, et al 2005), are six times more likely to be psychiatrically hospitalized and experience 12 times more psychiatric hospitalizations than children without ASD (Croen, Najjar Ray, Lotspeich & Bernal, 2006). There is currently no data for the likelihood for children with ASD in addition to significant cognitive and language impairment entering into residential placements or long term psychiatric inpatient care. Children with severe and complex ASD at risk of or currently living in residential care will likely have complex mental health and behavioral profiles that would benefit from specialized screening, assessment and intervention. The Centers of Excellence in New York State conducted a literature review in an effort to develop a cohesive representation of the current literature regarding co-occurring psychiatric diagnoses in children whose autism requires a level of care that prevents living at home in the community and requires either residential or long term psychiatric inpatient placement. Knowing children with autism spectrum disorders are likely to have one or more co-occurring psychiatric conditions (Gadow et al 2005) and children living in residential care will have a complex constellation of challenging behaviors, delayed cognition and impaired language skills, we wanted to know; what is the likelihood of a co-occurring mental health disorder for a child with complex autism being admitted to intensive care facilities? And what is considered best practice see Comorbidities on page 16
Are You Mindful or Is Your Mind Full?

By Marty McGreevy, MEd
Westchester Coordinator
New Frontiers in Learning

In today’s ever-changing and fast-paced world, the concept of being in the present moment and practicing mindfulness has never been more important. This is especially true as it relates to young adults as they begin navigating the college environment. For those learners who have been diagnosed with autism spectrum disorders and other various learning differences, for example, being able to work on skills related to brain-body connection, staying in the present moment and sharpening executive functioning skills is paramount to overall success, confidence and development during their academic journey.

Academic status and grades frequently become the most important focus as it relates to daily performance, be it during middle school, high school or college. It is important to note that to be successful in school and carry out all necessary executive functioning tasks daily, one must be of sound mind and body to perform optimally in the classroom and at home. Basic needs, such as diet and nutrition, water intake and hydration, proper and consistent medication protocol, as well as a healthy sleep cycle all play important roles in establishing a healthy student in mind and body. When young adults are away from parents or guardians for the first time, such as in college, and they are left to manage their own personal, social and academic schedules, things can fall apart quickly. It is important to have conversations and practice such skills long before they leave the nest. Having a proper plan in place with plenty of time for students to practice, generalize and demonstrate independently that they can handle all of the responsibilities of daily living is essential.

Often times, parents ask us as professionals to identify the most important skill areas for students to work on prior to the transition to college, and, many times, the response focuses on the “basic needs” areas as mentioned above. Generally speaking, students’ academic content and executive functioning needs can be provided via good communication with faculty, on campus help centers, disability coordinators, and private coaches. Students may be reluctant, however, to seek help for general day-to-day adaptive and independent living skills, such as maintaining a healthy and balanced schedule, having a proper sleep cycle, incorporating mindfulness and exercise into weekly schedules, and maintaining a healthy and balanced diet. Further, if a student is on medication, being consistent with that protocol, as well and staying properly hydrated on a daily basis is also crucial.

It has been noted in previous research that one should be drinking water to the level of about half one’s body weight in ounces per day to be properly hydrated (Elkaim, 1). More often than not, college students do not come close to meeting that baseline level, and the same most likely can be said for the general population as well. When a student is dehydrated, their brain and body are disconnected, their nervous system is not working optimally, and their performance with basic academic tasks may be hampered (Heid, 1). When young adults experience dehydration it is proven that their brains need to work harder to function normally. Awareness about mindfulness and stress management is the first step towards creating better and more consistent healthy habits. The implementation of such habits need to start when a student is much younger, ideally during middle school, so that good habits can be practiced early in order for them to become more automatic by nature. By the time a student is ready to be on his or her own, say at college, they should be confident in their ability to take care of themselves. They should know their body, the way they perceive the world, and what type of learner they are. They also should want to continue to try to take care of themselves both physically and emotionally speaking. This is not always an easy task; however, there are many support systems out there, including health professionals, assistive technology, and resources on college campuses, as well as professional organizations, who can teach these skills to young adults.

A sense of independence is something that has a lot of power and intention. Independence does not develop overnight, and students must first want to become more self-reliant, be able to listen to support staff, family, and friends who can provide knowledge and wisdom on this process. Being truly independent takes time, see Mindful on page 26.

Marty McGreevy, MEd

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The Importance of Adult Service Providers in the Transition Process

By Laurel Ciavarri, PhD, BCBA, LABA
Supervisor, Behavioral Support Services Bridgewater

Transition is broadly considered to be a process or period of change. Transitions can vary in scope on several dimensions such as small to large, quick to prolonged, easy to difficult, and from the perspective of those impacted, minor to life changing. Transitions are an inherent part of life and are challenging to varying degrees for everyone, but can be particularly difficult for individuals with disabilities such as autism. One of the largest transitions a child with disabilities will experience is the transition from student to adult, marked by a shift in services provided by the education system to those provided by adult service providers. This transition is so notable because it consists of a change in almost every aspect of the individual’s life. The school, the bus ride, teachers, fellow students, and curriculum that have been the center of the weekday routine for years will end. For some this will also mean a change in living arrangements. The place they have called home, whether with family or in a residential school, may change to a home managed and staffed by a community-based residential provider. There are a variety of services available to students entering adult services, with models designed to address a range of needs. In terms of day services, two primary areas of focus include habilitative and employment supports, and can be provided independently or in combination. Day habilitation programs provide support and training focused on skills necessary for adult daily living and target skill deficits that create barriers for more independent completion of tasks or participation in activities. Day habilitation services are provided using a team approach and includes input from disciplines such as occupational, physical, speech and language therapy, nursing and behavioral supports. Participation in goal development by family/guardians as well as the service recipient is encouraged to ensure a focus that is consistent with a personalized vision of the future.

Residential options vary greatly as well, and range from group homes equipped with 24/7 staffing to targeted supports for a minimal number of hours in an unmanaged/independent residence. A group home in and of itself has a range of possible features such as the number of residents that share the home, the staff ratio and staff expertise (i.e., training/certification in specialized areas such as medical issues, aging, behavioral interventions, etc.). Individualized home supports, in comparison, may include staff support around specific skill areas or needs at specified times during a day/week. For example, in cases where an apartment is rented independently or within a building managed by a service agency, staffing is provided to assist with a selected goal (i.e., community access) for two hours each weekday.

Given the magnitude of this transition, it is no surprise that there has been a considerable amount of focus on the process for ensuring that students are prepared effectively. A formal transition process is mandated by the Individuals with Disabilities Education Act (IDEA) with the intent of establishing a plan for the transition within the Individual Education Plan (IEP) to post-school activities/programs that target individualized needs, interests, strengths and preferences.

One step of the transition process that has received less focus is that of the logistics of the final component of the transition. That is, the process by which the student is introduced to and begins attending a new program. It is not uncommon for students to have support strategies for transitions of daily life. These strategies may include use of pictorial cues and schedules (Dettmer, Simpson, Myles & Ganz, 2000), prompting sequences, timers, transition cards and activity sequencing (Hume, 2008). Yet, for perhaps the largest transition into day habilitation or residential home services, there is little available to providers to guide the entry process, demonstrate efficacy of transition strategies or contribute to a discussion of factors that may influence the success of a transition style.

A key to remedying this centers on one of the existing recommendations of the IDEA, 2004. Specifically, the inclusion of all relevant members of a child’s treatment team in the development and ongoing evolution of the transition plan. In a review of publications pertaining to transition planning for students with autism from 1996-2008, Hendrick (2012) found that participation in IEP meetings included external support...
Exercise and Dietary Choices: Practical Advice Drawn from a Review of Current Literature

By Monica E. Carr, PhD, University of Melbourne, Australia and Stacey Raza, BSc Sports, MSCN, Private Nutrition Consultant

Obesity rates for children in the U.S. have risen significantly over the last decade. Currently, one third of all children between the ages of 2 and 19 years in the general population are described as overweight or obese (Curtin, Jojic, & Bandini, 2014). Drawing from data provided in the National Study of Children’s Health, Curtin and colleagues reported that children with ASD were 40% more likely to be obese than those in the general population.

Dietary choices and participation in physical activity are two major factors that contribute to the health and wellness of all individuals (Curtin et al., 2014). Both of these factors are something that we have some ability to control. For many members of the general population, developing better lifestyle habits including healthier eating patterns and regular exercise can contribute significantly to achieving better health and wellness. However, individuals on the autism spectrum may encounter additional challenges to their overall wellness as a result of food fussiness, difficulty participating in exercise that is caused by deficits in social communication or delays in motor development, or weight gain that may occur as a side-effect of antipsychotic medications (Dawson & Rosanoff, 2009).

Inflexibility, preoccupation with sensory stimuli, or a preoccupation with smell and/or textures that often accompanies a diagnosis of ASD can have a negative impact on nutritional intake. Often times the reason for food fussiness or problem eating is not clear, and the confusion that arises can cause parents or other caregivers tremendous anxiety. A Functional Behavior Assessment (FBA) is a multi-layered method of determining the purpose of a behavior that identifies the underlying cause-effect relationship. This step is particularly important when planning an intervention, as this information allows a treatment provider to answer the question, “What purpose does this behaviour serve?” (Hadaway & Brue, 2016). Matson & Fodstad emphasized the importance of including a FBA and direct observational methods relating to feeding when conducting comprehensive assessments and planning treatment.

A variety of food-related problems in children with ASD have been treated. While the majority of research has targeted food selectivity, studies have also examined eating compliance, rapid eating, inadequate food consumption, and food packing. Initial findings have been described as promising (Matson & Fodstad, 2009).

One fairly typical challenge is young children who consume large volumes of sugar-laden and nutritionally empty flavored drinks, which if left unaddressed this behavior can become problematic. A successful study described gradually increasing the percentage of milk in a flavoured milk drink frequently consumed by a four-year-old girl with autism. In another study a FBA demonstrated that escape from demands was the underlying cause of refusal of non-preferred foods for a five-year-old boy with ASD. The subsequent treatment consisted of the boys’ mother presenting broccoli, grapes, cheese, chicken or hot dogs, one at a time. Sessions were terminated either when the new food was accepted, or 30 minutes passed. Food acceptance was also reinforced by subsequent...

see Choices on page 22
Addressing the Needs of Under-Resourced Families of Children with Autism

By Briana Bronstein, MAEd, Diondra Straiton, BA, Heather J. Nuske, PhD, Melanie Pellecchia, PhD, BCBA, NCSP, Erica Reisinger Blanch, MSEd, and David S. Mandell, ScD
University of Pennsylvania

The Autism Intervention Network on Behavioral Health (AIR-B) is a network of researchers whose goal is to improve access to evidenced-based treatments for children with autism spectrum disorder (ASD) in under-resourced communities. The AIR-B network consists of two related studies: Mind the Gap (MTG) and Building Better Bridges (BBB). MTG is an intervention designed to engage caregivers of newly diagnosed children with ASD. Many under-resourced and ethnic minority families are lost to the service system during the time between obtaining an evaluation for an ASD diagnosis and receiving ASD-specific services. MTG aims to engage families of children with ASD earlier and improve their access to ASD-related services. BBB is designed to improve the transition process for children with ASD and their families as they transition between schools and service systems. Many families of children with ASD struggle with school transition; these struggles often are exacerbated in under-resourced communities that have limited school funding. Currently, no tested, US-based intervention programs are designed to improve the school transition process for children and adolescents with ASD; therefore, BBB is designed to facilitate a bridge between schools and families.

Many interventions developed through university-based research programs are not sustained when implemented in community settings, especially in under-resourced communities (Dingfelder & Mandell, 2011; Eiraldi, Wolk, Locke, & Beidas, 2015; Glasgow, Vogt, & Boles, 1999). The research-to-practice gaps are much too long for these interventions, averaging at 17 years (Balas & Boren, 2000; Grant, Green & Mason, 2003). In order to improve the feasibility and sustainability of the interventions developed by AIR-B projects and to hasten the community implementation of the interventions (e.g. Aarons, Hurlburt, & Horwitz, 2011; Brookman-Frazee et al., 2016; Mendel, Meredith, Schoenbaum, Sherbourne, & Wells, 2008), the network is using community-partnered participatory research (CPPR) methods. CPPR emphasizes an equal partnership between community stakeholders (e.g. family members, clinicians and teachers) and academic partners to develop and implement research-informed community programs (Jones & Wells, 2007).

Through the use of CPPR, members of the AIR-B network work with community stakeholders to develop interventions for under-resourced families of children with ASD in Pennsylvania, California and New York. The AIR-B network fosters many community partnerships with families, early intervention agencies, public school districts, support groups for families of children with ASD, and disabilities rights organizations. These partnerships provide both a platform for essential community input in intervention development, and a gateway to increase research team involvement in ASD-related community events.

Community Input on Intervention Development

Before creating the interventions, the research team used focus groups and interviews with under-resourced families of children with ASD and service providers to obtain community input. The research team met with 105 parents/caregivers and 125 providers across sites to discuss barriers and facilitators to accessing ASD-specific services.
Research shows that the roots of autism spectrum disorder (ASD) generally start early—most likely in the womb. That’s one more reason, on top of a large number of epidemiological studies, why current claims about the role of vaccines in causing autism can’t be right. But how early is ASD detectable? It’s a critical question, since early intervention has been shown to help limit the effects of autism. The problem is there’s currently no reliable way to detect ASD until around 18–24 months, when the social deficits and repetitive behaviors associated with the condition begin to appear.

Several months ago, an NIH-funded team offered promising evidence that it may be possible to detect ASD in high-risk 1-year-olds by shifting attention from how kids act to how their brains have grown [1]. Now, new evidence from that same team suggests that neurological signs of ASD might be detectable even earlier.

That evidence comes from a study of children at high risk of ASD, who as babies underwent specialized brain scans while asleep to measure connectivity between different regions of the brain [2]. Using a sophisticated computer algorithm to analyze the scans, researchers could predict accurately which infants would receive a diagnosis of ASD 18 months later—and which would not. While the results need to be confirmed in larger groups of babies, these findings suggest that neuroimaging may be a valuable tool for early detection of ASD.

In the new study, researchers enrolled 59 babies who were 6 months old and had an older sibling diagnosed with ASD. That gave each a 20 percent chance of also developing the condition. The team, including Robert Emerson and Joseph Piven at the University of North Carolina at Chapel Hill and John Pruett at Washington University School of Medicine, St. Louis, then performed brain scans of each infant while napping, using functional magnetic resonance imaging (fMRI). That’s an imaging technique specially designed to measure neural activity.

With the scans in hand, the team created maps that, like a wiring diagram, showed the interconnections between 230 defined brain regions. All told, the researchers mapped out 26,335 brain connections spanning the entire brain.

Eighteen months later, the now-2 year-olds returned for a follow-up visit, where they underwent a series of cognitive, behavioral, and diagnostic assessments. Eleven of the 59 toddlers were determined to have ASD, or just over the predicted 20 percent.

The researchers wondered whether they could find clues as to those outcomes in the children’s brain connectivity maps. In an exciting sign of research progress, they could. Of the 26,335 functional brain connections measured at age 6 months, the researchers identified 974 that were related to the later development of ASD.

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Janet Z. Segal, LCSW
Comorbidities from page 9

for screening, assessment and intervention for co-occurring psychiatric conditions within residential and hospital settings?

Methods

The purpose of this literature review was to evaluate the current literature on psychiatric comorbidities in individuals under age 21 with ASD living in full-time residential care. This systematic literature review followed the PRISMA statement (Liberati, Altman, Tetzlaff et al., 2009) in order to identify all of the current research on the prevalence, assessment and treatment of ASD individuals living in residential care with at least one comorbid psychiatric disorder.

Search Strategy - We searched PsycINFO, PubMed, and Web of Science from the beginning of time until July 2016, using three separate controlled search terms, or Boolean strings, targeting articles related to ASD, residential care, comorbidities, and the assessment, prevalence and treatment of these individuals.

Study Selection - Abstracts were to be selected from the resulting articles if they met all of the following "soft" criteria:

1. Includes severely impacted populations (low IQ, "low functioning").
2. Individuals living in residential care.
3. Ages 21 and under.
4. Includes comorbidities with ASD.
5. Has information on assessments, prevalence or treatment of these individuals.

Articles were to be excluded if they are not scholarly peer reviewed articles, they are not written in English, or are books. During the coding process, articles were also excluded if the full contents of the article resulted in:

1. Not being relevant to or about ASD
2. Were meta-analyses.
3. Included those with high-functioning ASD.
4. Full article (only abstract English) was in another language.
5. The comorbid disorder was "self-injurious behavior."
6. They were medication trials.

A team of research assistants trained to meet reliability of Cronbach’s Alpha >.70 (Cicchetti, 1994) reviewed and included appropriate articles.

Literature Search Results

- 423 citations were screened for duplicates from the three databases.
- After removing duplicates, 242 Non-Duplicate citations were screened for inclusion.
- During the abstract review process, 49 articles were retrieved.
- During the coding process, 44 more articles were excluded.
- In total, n=4 articles included in the final data set.

Discussion

Despite the possible high prevalence of comorbid mental health disorders in children with ASD living in residential settings, there are very few research studies on effective treatments for comorbid symptomatology that is distinct from the treatment of symptomatology related to a diagnosis of ASD. Our review yielded 4 articles; 3 of which were case studies (n=1). This included 2 case studies concerning the use of ECT for catatonic depression (Siegel, Milligan, Robbins, & Prentice, 2012; Wachtel, Griffin, & Reti 2010) and 1 case study using systematic desensitization for phobia of dogs (Chok, Demanche, Kennedy, & Studer, 2010). One article, published in France, provided the most pertinent information as it discussed proper recognition of co-occurring medical and psychiatric conditions as predictive of improvement in challenging behaviors such as aggression, self-injury, disruption, agitation and tantrums.

Although there are a number of studies that discuss the correlation of intellectual/developmental disabilities and mental disorders, most focus on this co-occurrence in adults specifically and intellectual/developmental disabilities generally and none were specific to children with a diagnosis of ASD who have intensive care needs, as evidenced by the necessity of a residential or long-term inpatient placement. Providers caring for these children often confront challenging behaviors that need highly targeted and specialized treatment. Many providers look to the literature for empirically supported assessments and treatments of psychiatric conditions specifically designed for children unable to live in the community and have minimal language and/or cognitive skills to describe symptoms. What they find is a tremendous gap.

In this case, it becomes important to identify what this review does not tell us – it does not give us empirically supported information regarding screening and assessments that are effective and sensitive this population. It does not tell us best-practice for differential diagnosis, or how to tease apart what behaviors or symptoms may be the result of ASD and what may be attributed to OCD, ADHD or social phobia, for examples. And with a few exceptions, it does not tell us the best treatment approaches for children with complex ASD experiencing certain psychiatric disorders.

Conclusion

We conducted a systematic review of the literature to catalogue existing information regarding the prevalence of co-occurring psychiatric disorders as well as commonly used, empirically supported assessment instruments and treatments for such disorders for children with ASD living in residential settings. See Comorbidities on page 26.
Balancing Health and Safety Issues with Individual Rights in Adults with Intellectual Disabilities

By Maggie Haag, LSW, Allan Forster, and Mary Jane Weiss, PhD, BCBA-D
Melmark

The history of treatment of individuals with developmental disabilities is fraught with violations of personal liberties. In a seminal article, Bannerman, Sherman, and Sheldon outlined the need to respect individual rights in the context of effective treatment (1988). Since that time, service providers have struggled to balance these liberties with the need to habilitate. While we have focused extensively on how to build skills and create meaningful experiences for those we serve, we continue to refine ways to uphold personal choice in the context of service provision. Humane treatment was not universally available until recently, and many safeguards now exist to ensure that the rights of individuals with developmental disabilities are respected, that they are afforded personal liberty, and that they are provided with maximal choices in their care and goals.

The rights of adults with disabilities are universally acknowledged and are considered in treatment planning more now than ever before. When making decisions on behalf of a person that is unable or unwilling to make decisions for himself, safeguards are put in place to protect that person’s rights. For example, many states have taken on a person-centered planning model in which all services and supports designed for an adult with disabilities is centered around the individual’s needs, wants, interests and preferences. For an individual who is unable to communicate these aspects of his life, this usually takes place on the context of an interdisciplinary team (IDT) which includes important people in that person’s life such as parents/guardians/family members, healthcare providers, clinicians, case managers, and direct support workers. However, even with all of these processes in place, adults with disabilities are still at risk of having their rights violated, even by the most well-intended members of their IDTs. Carefully creating supports and ensuring safeguards to assure the protection of the individual’s rights is essential to treatment planning.

Rights violations do not always come in the form of an egregious act. They can often be subtler, and they are often the unintended consequences of making choices for someone without really considering...

see Balancing on page 20
agencies in just 30 percent of IEP meetings. An inclusive meeting ensures that the perspectives of providers and caregivers that work with or see the child in varied contexts and settings can contribute to goal development. In light of this, an initial recommendation for effective transition planning is to remedy the barriers to participation in the IEP meetings by external providers and/or identify alternative methods for their contribution to the IEP process.

A second recommendation is to consider whether the requirement for an inclusive IEP can be extended to include the future provider. There are several important contributions a future provider can make to ensure an effective transition plan. A primary contribution is a familiarity with the adult service models available and the skills necessary to be successful within those settings. As described, there are several service models, and there are notable differences in their structure compared to school-based services, including lower staff-to-student ratio, staff credentialing, classroom/work-group size, instructional style and curriculum content. If, for example, postsecondary plans include placement into a habilitative or residential program with a lower staff-to-student ratio or a specific job type, incorporating strategies to establish the skills to work within the projected future ratio or the identified work skills can be incredibly helpful to the student’s success. Similarly, other goals specific to the future placement environment could be identified and incorporated into the transition plan.

Certo, et.al. (2003) presented the Transition Service Integration Model, in which the receiving nonprofit adult provider worked closely with the school, rehabilitation and developmental disability systems for the year prior to exiting the school system for students with disabilities and employment goals. The results describe a high rate of success in that 63 percent were matched to an employment position that was able to be maintained post-graduation through the provider, 88 percent of the transitions occurred with no break in services, and 71 percent were still employed after three years. While more research is necessary for those receiving employment services and research is needed for those receiving day habilitation services, these results demonstrate the benefits of a greater level of involvement from the adult provider early in the transition process.

A third recommendation centers on the logistics of the entry to the new adult program. Providers often have a default process for referral review and entry to the program. However, the default process may not be conducive for many individuals with autism with specialized or individual needs around transitions. Creating an individualized entry to a new program should include questions such as: How many visits should occur, by whom, in what locations (existing program/school/home or, in the future program/home) and for what duration? At what point should this process begin – has the student historically fared better with short/rapid implementation of new routines, or with a more gradual/slow introduction of change? Would the use of a social story to introduce the new routine, people and places be helpful? What types of activities would be most helpful during the introductory visits? If initial visits target more preferred and low-demand contexts, what process for introducing task requirements typical of the environment would be best?

Enormous strides have been made in ensuring effective and appropriate services within children’s programming. Similar advances are underway within adult services, and creating a more cohesive effort between the two during the transition process may set the stage for an enhanced transition experience for providers, family/parents, and students receiving services.

For more information about Bridgewell, please visit www.bridgewell.org.

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Did You Know?

You may not know this, but a couple of months ago I un-friended you on Facebook. I mean, we weren’t exactly friends in the regular sense. We never met for coffee or talked on the phone or texted each other. We don’t even live in the same state, and I haven’t seen you in over ten years. I did enjoy scrolling through my newsfeed and seeing your name pop up every once in a while, and looking at pictures of your family and your dog.

But then one day you posted a joke about someone riding a short bus, and my stomach kind of flipped. I was surprised, and sad. Did you know my son Jack has autism? Maybe you didn’t. You only met him once, when he was less than a year old and we hadn’t yet heard the diagnosis that would change our lives forever.

Mrs. Cariello? I believe your son has something called Autism Spectrum Disorder. I bet your children are healthy and whole and they would never flap their hands or yell out f&^% when the grocery store doesn’t have the right kind of frosting. He is healthy. He is whole. He does flap his hands and yell bad swear words in the grocery store. But he does other stuff, too.

He bakes cakes and he puts his hands over his ears when fire trucks go by and at bedtime he lines six pillows along the side of his bed. I don’t know why.

Every morning he takes a bath at exactly 6:30 am, and then he checks the battery on my laptop. If it’s low, he plugs it in for me. Then he makes himself breakfast—this week it’s two egg whites with toast because he heard on the radio that egg yolks are bad for your cholesterol.

He is funny and interesting and surprising and mysterious.

Here’s the thing, though. I’m not interested in convincing you to like him. I’m only interested in convincing you to step back, and make room for him.

Did you know we have to point things out to him all day long? I don’t mean trains and birds and little brown puppies walking down the street—although we used to have to point stuff like that out when he was little, so he would look at us and then look at the puppy and realize we were talking to him.

Jack, Jack! Look at me. Look at Mommy. Do you see the dog? Woof-woof, dog!

Now we have to actually name feelings and emotions for him; things you and I take for granted because we can figure out if someone is angry or frustrated or worried by the way they twist their mouth or move their eyebrows.

Jack, Jack! Look at me. Look at Mommy. I am angry now. I am angry you said a bad word.

And when we’re not pointing out puppies or trying to explain what it means when we frown, we have to name his own internal dialogue—his own behavior—so he may one day recognize it for himself. In a way, we are his mirror.

Jack, Jack! Look at me. Look at Mommy. You are jumping a lot. How does your body feel?

Did you know how hard it is to raise a son who has autism? Constantly, I have to watch him to make sure his new medication isn’t making him feel depressed and I worry if he’s sleeping enough and I think about how he’ll ever drive a car or manage a checking account.

Did you know how hard it is to be a child with autism?

Can you imagine what it’s like to exist in a perpetually challenging world and try to figure out all the complicated rules and understand why people say avocados cost an arm and a leg when all they really mean is that guacamole is expensive?

He is my son. What you say, and write, and think about him—and others like him—matters.

He matters.

Trying to convince people of this is like laying bricks in a long, crooked line. They are jagged, and heavy. Many are chipped at the corners, and they feel dusty and dry when I turn them over in my hands. I’m not sure what I’m building exactly, but I cannot stop.

see Did You Know on page 22
Furthermore, choice is an entitlement to all a person’s happiness and quality of life. Often, someone else comes in, perhaps a dietician, and informs the IDT of what this person can and cannot eat. The IDT then makes plans and arrangements to ensure the person is not eating anything not on the “approved foods list.” How often is the person who is being impacted by these decisions asked for his opinion? How often are IDTs really trying to determine what foods on that new approved foods list are foods that the person really likes? Do teams ensure that the individual is not routinely then given non-preferred foods? This may seem like a very simplistic example, but taking the right to decide what a person will eat away from him or her is truly a rights violation. Typically, treatment teams involved in these choices do not intend to exert undue control over all aspects of a person’s life. Such events occur because service providers are ultimately held accountable for the health and safety of the individuals they serve. A failure to respond to dietary recommendations when a person is diagnosed as pre-diabetic can be neglectful on the part of the service provider. It is service providers who must work hard to identify ways to ensure that the individual surrounding this issue?

2. Have we offered the necessary supports to assist the individual in choice making?

3. Have we identified the preferences of the individual surrounding this issue?

4. Are we continuously assessing the preferences of the individual surrounding this issue?

5. Have we built-in systems that identify and support changes in a person’s decisions/preferences?

6. Is there an absence of coercion in the decisions made?

Ensuring that all of the supports necessary have been provided to promote participation and providing opportunities for optimal choice making are crucial for person-centered planning. Additionally, keeping an open-mind from a service provider perspective and working to understand cultural and personal differences is also critical. The below case study outlines the process taken for individual in balancing the person’s rights with his health and safety needs.

Case Study

John is a 54-year-old man who has been in residential placement since the age of five. He has intellectual disabilities and is non-ambulatory, but he is able to drive his motorized wheelchair. John is verbal but can be difficult to understand with people who do not know him well. John is able to tell people what he wants and make choices, but there are many things he is not able to get for himself due to physical and cognitive limitations.

John has a very involved family who come to visit him weekly, and speak to him on the phone regularly. One of his family members is his legal guardian, and participates in all treatment team decisions made for John. This relationship is very important to John and he takes his family member’s opinions very seriously, and it will often sway his own opinion. John’s family members will often bring him his favorite foods when they come to visit, and these foods are often unhealthy and usually include a variety of junk foods.

John’s family has a history of obesity, and John is also obese. Since John is non-ambulatory, he is at a higher risk for skin breakdown and has a history of skin breakdown. John also does not like to shower or get repositioned in his wheelchair or bed, which in turn can cause skin issues to take much longer to heal. Both John’s weight and skin integrity issues pose serious health risks to John, so the IDT wanted to develop a behavior plan that could help address both of these issues.

The first component that occurred prior to any treatment plan development was education. A team meeting was held with John and his family to discuss the health issues John is facing, as well as the consequences of not addressing these issues. Ensuring John and his family members had the information necessary to understand why a change may need to occur helped the treatment team explain their ideas in a much more open-minded forum. This helped the family accept that they should consider bringing healthier food options when coming to visit John for their weekly visits. Since the whole family has issues with weight, education about healthier alternatives was also provided, as they admitted they themselves did not know how to eat healthier and expressed an openness to the information.

The next component of the planning process was ensuring that John’s preferences were all accounted for and could be incorporated into John’s plan. This also included ensuring that John still had the opportunity to make choices within his plan, even if the choices he was making were not always the ones the treatment team preferred. Since John had a heavy preference for unhealthy food items, the team had to develop strategies that would encourage him to make healthier choices without forcing them on him. Additionally, since John did not like showering, the team had to identify ways to motivate John to shower.

It had been identified early on that John was very motivated by attention and participating in activities, as well as motivated by people telling him what a great job he was doing. The team developed a healthy alternative menu for John with his input, and as part of his meal planning he gets to go to the grocery store to buy the ingredients for his lunches as well as help to prepare his lunches each night for the next day. He has a variety of meal items to choose from, and he decides which meal he will go grocery shopping for. John loves being able to participate in his meal prep, and also loves telling everyone he sees the next day about the lunch he prepared. Staff

see Balancing on page 21
Let’s Get Physical: Exercise and Health Issues in Adults with Autism

By Shannon Doty and Jason Wolf
Madison House Autism Foundation

The research is clear: autistic adults are spending too much time on the couch. While children with autism may flourish by taking advantage of numerous opportunities for group exercise and team sports, these activities become increasingly scarce after they “age out” of school at age 21. Adults with autism have been found to exercise significantly less than their neurotypical peers, and this has been linked to multiple health problems such as obesity (Hilgenkamp et al., 2014). Yet, researchers are finding that the presence of exercise, as well as the support system that comes with group activity and a team-like setting, can improve health, social challenges, and the overall wellness and lifestyle of adults with autism.

Public Health Implications

The importance of exercise among adults with autism has only recently garnered interest among researchers. According to David Geslak (2016), a leading researcher and personal trainer for people with autism, a self-monitoring chart where he marks his healthy eating, and encourage him to store more often, which is also preferred. This case illustrates some of the components of person-centered planning, and provides a real life example of how habilitation goals can be balanced with respecting individual rights. Managing these issues with adults with developmental disabilities is a complex process, and requires clinical skills, compassion, commitment to effective treatment, and respect for individual dignity and choice. Treatment teams need to become more adept at assessing the need to examine issues of choice and personal liberty. In addition, the human service fields need to share more strategies for respecting these issues and finding creative solutions that support effective treatment and preserve individual rights.

Maggie Haag, LSW is Senior Director of Residential Services, Allan Forster is Director of Adult Services, and Mary Jane Weiss, PhD, Bcba-D, is Senior Director of Rehabilitation at Melmark. The mission of Melmark is to serve children, adults and their families affected by a broad range of intellectual disabilities. With service divisions in Bervyn, Pennsylvania, and Andover, Massachusetts, Melmark provides evidence-based educational, vocational, clinical, residential, healthcare and rehabilitative services, personally designed for each individual in a safe environment of warmth, care and respect. For more information, please visit www.melmark.org and www.melmarkne.org.

Balancing from page 20

has been trained to give him a lot of attention and praise when he talks to them about his healthy eating, and encourage him to keep up the good work.

For his hygiene routine, John keeps his self-monitoring chart where he marks down each night that he showers. John loves to show off his chart and his clean appearance to the staff, and every time he shows his chart and he has showered, the staff provides a lot of attention and praise for engaging in that activity and they encourage him to keep up the good work. He is now seeking attention for his hard work, and he seems genuinely pleased by his ability to report on his success.

Since the implementation of this plan, John has been more involved in making choices about his meals, more involved in his hygiene routine, and more cooperative with both. Another important component of this plan is that even though John has access to the healthier foods and choices, he is still allowed to make a different choice if he wants to. The whole idea of the plan is that John will be more motivated to make the better choices because he will get more access to other things he enjoys as a natural consequence, such as more praise and attention, as well as getting to go out to the store more often, which is also preferred. By incorporating choices and preferences into the plan, as well as by having provided education, John has been the driving force behind the plan components and success. John has shown true progress in some ancillary and important ways, including reduced skin issues and reduced weight. While changes may need to be made in the future if he does not make progress with his health, these changes will be made with his input.

This case illustrates some of the components of person-centered planning, and provides a real life example of how habilitation goals can be balanced with respecting individual rights. Managing these issues with adults with developmental disabilities is a complex process, and requires clinical skills, compassion, commitment to effective treatment, and respect for individual dignity and choice. Treatment teams need to become more adept at assessing the need to examine issues of choice and personal liberty. In addition, the human service fields need to share more strategies for respecting these issues and finding creative solutions that support effective treatment and preserve individual rights.

References


www.mhnews-autism.org
in the experience and is becoming used to fruit without being overwhelmed by the call to change.

3. Where Intentions Go, Actions Follow

When we are clear about what we want and why and why we want it, living in alignment with our goals is relatively simple.

Anastasia is a student who knew that it would be better for her wallet and her health if she dined out less frequently. Because she enjoys journaling, tracking her meals to see the trajectory of her progress was a natural fit. She says that reducing the number of meals she ate out-on-the-town was “hard at first, but first, it helped me set the intention, making the promise to myself, and sticking to my goals.”

Anastasia also recalled how helpful it was to have someone checking-in to hold her accountable. Consistent reminders help us reaffirm our intentions, that way we continually make decisions that are aligned with those intentions.

Such reminders can come in many forms, from a person who wants to hold us accountable, to a recurring event on our calendar, or even an object in our home that we load with meaning, such as a painting of a waterfall in the home that we use as a reminder to stay hydrated.

Conclusion

The reality is that we will forget, we will get too busy, and we will probably even avoid following-through on our commitments at some point. That is why having reminders and trusted allies to hold us accountable to our intentions are so helpful. We will probably find ourselves wanting to show up for our goals and have a total life makeover, when we know just one small change that we can actually sustain will plant a hearty seed for future success. The bottom line is that health and well-being are unique to each individual. Each one must find it it right for him/herself and pursue it, even if it doesn’t seem like “all that and a bag of spinach.”

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References


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What Can We Do?
Tips for Parents and Professionals

Although many people are thankfully focusing on effective interventions for weight management, not much has been done regarding ASD-specific programs. The US Center for Disease Control and Prevention (2015) recommends at least 60 minutes of aerobic activity and muscle and bone strengthening activities per day for children and adolescents. Physical activity should be moderate to vigorous; it should increase heart rate and rate of breathing. It is recommended that the chosen activities appeal to and accommodate a child’s interests. This is particularly important for youth with ASD. For example, for a child fascinated with insects, a nature hike might be appropriate and engaging.

In addition to increasing physical activity levels, it is recommended that youth engage in no more than 2 hours of sedentary “screen time” per day (McCoy, Jakicic & Gibbs, 2016). However, because video gaming is a major hobby among ASD youth, one particularly creative intervention that has recently gained attention is to substitute typical video games for active video games in which the player must physically move around in order to control the game (Strahan & Elder, 2013). Not only does exercise lead to effective weight management, it also has been shown to enhance self-regulation and motor skills (Sorensen & Zarrett, 2014), strengthen executive functioning skills (Tan, Pooley & Speelman, 2016), and improve mood. Exercise is also cost-effective, because it can be performed in one’s home or community with minimal equipment (Bremer, Crozier & Lloyd, 2016).

Another avenue of intervention is improved nutrition (Strahan & Elder, 2013). Weight gain prevention programs would be wise to include basic education about healthy food choices and awareness of hunger and fullness cues. It is also a good idea for parents to consult with a qualified health professional, such as a nutritionist or dietician with specific experience in working with youth with ASD, should food selectivity be a particular issue. Furthermore, primary care physicians should be actively involved in addressing any weight-related difficulties and coordinating treatment among providers. Parents and medical professionals would benefit from discussing the early risk of unhealthy weight in children with ASD with each other so that supports and strategies can be put into place as early as possible (Hill, Zuckerman & Fombonne, 2015). Finally, it can be very helpful to work with a psychologist, since his/her background in behavior change and teaching skills can help support the child or adolescent and caregivers in making and maintaining healthy lifestyle changes.

Furthermore, research with adults has shown that those who track their exercise and diet are more likely to lose and maintain weight than those who do not (Kruger, Michels Blanck & Gillespie, 2006). Such programs use engaging visual supports that are appealing to youth with ASD. Given that many youth have access to cell phones and because several of the activity trackers come in fun shapes and colors, older youth and teens are likely to enjoy the experience and be motivated to interact with the technology. Recommended apps and fitness trackers include: MyFitnessPal, Lose It!, Fitbit®, and Misfit.

Danielle Zito, PsyD

In all, weight management is an important topic that will likely gather greater attention in the ASD community as rates of obesity continue to rise. Although this can be a difficult issue, parents and caregivers can work with professionals to implement meaningful strategies such as early prevention, proper education, and opportunities for fun exercise.

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Increased Awareness

Primary care physicians play an important role in the early recognition of autism. Research shows that early treatment of autism results in better long-term outcomes. Implementing developmental screenings, partnering with parents to discuss behavioral or developmental concerns, and observing for signs of autism during visits all increase the chance of early diagnosis (Rice, C.E. et al., 2010). Increasing primary care provider awareness and expertise in accomplishing these goals is easier and more efficient in an integrated setting with access to support from on-site behavioral health providers. It allows for more efficient consultation as well as opportunities for education and training support (Ginsburg, S., 2008).

An integrated setting can also enhance each team member’s awareness of how each role comes together to treat the whole-patient, which is a cornerstone of the PCMH model. Providers (primary care, specialists, behavioral health and dental) treating a patient with ASD often have specific limited interactions that result in a particular view of that patient’s treatment progress. However, studies show that when multi-discipline providers are onsite to support with regular interactions improving the individual practitioner’s awareness and understanding of how their specialty fits in with the whole-person perspective is greatly enhanced (Ginsburg, S., 2008).

Lastly, an integrated setting can also enhance awareness of ASD-related family and community supports. A diagnosis of autism can be initially overwhelming for families. On-site access to behavioral health support for family counseling can be an important support to help families navigate treatment options and learn more about the diagnosis.

Increased Access

Studies have found that integrated settings increase access to services and enhances patient/family satisfaction (Ginsburg, S., 2008). Bundling services together at one location can more easily accommodate multiple visits on one day, and offers a structured and familiar environment that can be comforting for many individuals with ASD. An integrated setting increases access to dental services, behavioral health, medical specialties such as neurology and gastroenterology, and therapeutic services such as speech and occupational therapy. During primary care visits providers can use the shared electronic health record to see when patients are due for other services and more easily facilitate scheduling of those appointments.

Integrated settings with multiple providers also allows for warm handoffs, where the primary care doctor can introduce the patient to other providers in real-time. Warm handoffs help increase patient engagement and enhance continuity of care. In fact, warm handoffs result in an 80% return rate for behavioral health visits as opposed to 40% from traditional referrals (Van Houten, P. & Johnson, M., n.d.).

On-site behavioral health services can also increase patient compliance with needed health services, which enhances access to care. Routine medical and dental visits can be extremely stressful for patients with ASD. Deficits in communication skills and behavioral patterns characteristic of people with ASD can significantly complicate routine medical and dental procedures (Limeres-Posse, Castano-Novoa, P., Abeleira-Pazos, M. & Ramos-Barbosoa, L., 2014; Nicolaidis, C., Kripke, C.C. & Raymaker, D., n.d.). The sights, sounds, and odors typically present in healthcare environments can be distracting and intolerable, especially for patients with sensory processing issues.

Desensitization is a type of behavioral therapy used by trained professionals to help people overcome fears, phobias, and other anxiety disorders. It teaches relaxation and stress management techniques, while gradually exposing people to distressing situations, so that the person can eventually face the feared situation without fear or anxiety. Research shows that desensitization techniques can successfully reduce anxiety related to medical procedures and increase compliance with treatment (H Owenstine, R., 2006). Integrated settings with primary behavioral health specialists allows for effective implementation of these techniques and monitoring of patient progress (observation during actual medical and dental visits).

Increased Coordination

In addition to playing a critical role in the early diagnosis of autism, primary care physicians also support the long-term management of autism, which includes treating associated medical conditions and coordinating care with other specialists involved in the patient’s care (Carbone, P.S., Farley, M. & Davis, T., 2010). Waiting for specialists and delayed communication between providers can negatively affect treatment. In an integrated setting providers share the patient’s electronic health record and have immediate access to accurate and up-to-date information; treatment notes, test results, and prescribed medications. Communication and care coordination is also greatly enhanced through the use of internal messaging capabilities (Burton, L.C., Anderson, G., Kues, I.W., 2004).

While a shared electronic health record makes developing and tracking multi-disciplinary treatment plans easier to accomplish, an integrated setting allows for the added bonus of in-person case conferencing to supplement written notes (Ginsburg, S., 2008). Multi-discipline care coordination helps improve health outcomes and increases patient safety. For example, certain dental treatments may require sedation for patients with ASD or other special preparations to ensure the safe delivery of dental procedures. Consultations with primary care and access to a patient’s full medication history is critical to ensure patient safety.

In conclusion, integrated settings can further advance the medical home model by increasing (1) awareness, (2) access and (3) coordination of care for patients and families with ASD. Studies have shown that multi-discipline sites enhance interprofessional collaboration and increase

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services and improving school transitions for children with ASD. The result extracted from these interactions informed the development of useful, feasible and sustainable interventions.

The research team also established advisory boards composed of community stakeholders at each site to provide continuous feedback regarding the fit and feasibility of the two interventions. These relationships resulted in important changes to the interventions. For example, parent education module topics for MTG were suggested by partners from a local early intervention agency. Similarly, for the BBB intervention, public school district administration teams were actively involved in providing knowledge of transition-related tasks and important transition dates for a checklist to be used in the intervention. The community advisory boards continue to meet monthly and are vital to the development of interventions that will sustain beyond the research timeline.

Academic Involvement in the Community Research team members and community partners host an annual community conference for caregivers of children with autism. The conference is designed by location, content and advertising to engage urban families who may otherwise be unable to attend such events. The conference is free, includes free child-care, travel reimbursement and access to community resources. Local vendors and volunteers attend, and caregivers are invited to other families and participate in workshops. This conference is one example of the research network’s attempts to engage community stakeholders in activities aimed at improving access to high quality services for individuals with ASD. Research team members also attend many local community support groups and trainings related to developmental disabilities in order to bridge the gap between academic researchers and community members and increase community involvement with the research network.

Implications and Recommendations

The use of CPPR and community-academic partnerships has facilitated the development of community-informed interventions with improved fit with the communities in which they will be implemented. The research team will maintain current partnerships and form new ones. Soon, pilot studies of the MTG and BBB interventions will begin to gather preliminary information regarding the feasibility of the interventions before implementing them on a larger scale.

Throughout the pilot studies, community stakeholders will play a key role in developing and refining the interventions.

Researchers interested in utilizing CPPR methods in their work should consider using the following strategies: participating in local events and support networks; soliciting continuous feedback from community partners about intervention development and organizational fit; recruiting in frequently visited and accessible neighborhood locations (e.g. corner stores, schools, laundromats); providing compensation and travel reimbursement for community partners and researchers; and sharing resources about local supports with community partners and families.

CPPR offers a useful and under-used approach to bridging the research-to-practice gap in order to address the needs of vulnerable populations in educational and behavioral health systems. Researchers interested in implementing sustainable interventions within under-resourced settings should consider adopting CPPR methods to improve the effectiveness of those interventions and broaden the research knowledge regarding this methodology.

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and for all of us is something that we truly never master, but try to improve. When it comes to students with learning differences, being able to be independent is something that may come with more obstacles; however, it is certainly not an impossibility to achieve. By starting out discussing personal, independent living and academic goals with your student at an early age and role-playing and generalizing different goals in many different facets of life, the student can see the benefits of working hard to achieve independence.

Mindfulness is the basic human ability to be fully present, aware of where we are and what we are doing, and not overly reactivity or get overwhelmed by what surrounds us. The question is, how does one become so enlightened? How does a student practice this skill, harness and embed it into their daily lives? There are many ways to practice mindfulness, such as deep breathing exercises, basic yoga stretches, different creative writing and journaling techniques, as well as several different forms and modalities of meditation. Finding and using sources of inspiration, such as art and music for example, can help students reduce stress and quiet their minds.

Other examples that are gaining popularity include incorporating essential oils and aromatherapy, yoga or exercise classes, and massage therapy. Integrating these into your health protocols can help with stress reduction and one’s general feeling of well-being. There is great power in setting daily intentions and goals as it relates to mindfulness. Reminding yourself of your sense of purpose and your commitment to yourself and your goals is the root of achieving success.

In the end, there is no one specific way to work on mindfulness and one’s general wellness. Good, healthy habits become part of one’s routine and need to fit into a daily schedule; one’s belief systems, philosophies. Having and maintaining a healthy school and life balance is essential for overall health and wellbeing. Trying different exercises, reading and researching the topic of health and wellness further, and consult with professionals in the field are some good first steps. The world certainly is not going to slow down anytime soon; however, we can make the conscious choice to slow our minds down, invest in ourselves and strive to be the best and most authentic version of ourselves we can be.

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care settings. The results of the search revealed significant limitations of the literature and a clear need for increased research into this understudied group with significant treatment needs. We hope future research will more accurately measure the prevalence of comorbid psychiatric disorders in this population, and also develop sensitivity assessments and treatments that meet the needs of children with ASD in residential care who may be experiencing a co-occurring psychiatric disorder(s).

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This article was prepared by Rebecca Girard in her capacity as an employee of DDI. The opinions expressed in this article are the author’s own and do not necessarily represent the opinions, interpretations or policy of New York State or the Federal Government of the United States.

References


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While team sports may benefit autis tic adults in many areas, some individu als may prefer to work with a one-on-one trainer. We know that social challenges can negatively affect one’s relationship with exercise, and it is important that autistic adult and their trainers build a foundation of trust (Gelsak, 2016). According to Gels ak (2016), command-based communica tion is often ineffective in engaging the cli ent in physical activity, and a more creative communication strategy may be necessary. Additionally, some adults with autism may not communicate through speech, which may require a trainer to be in-tune with behavioral cues in order to respond appro priately. To create a positive experience, trainers may need to adopt unconventional approaches and make a concerted effort to understand the likes, dislikes, and needs of an autistic client. Simple adaptations that incorporate the interests of an autistic client can be effective in building a positive rapport. For example, if a client is fasci nated with bright colors, chasing colorful balloons around the gym may be a more motivating form of exercise than simply walking on the treadmill.

Providing Better Solutions

Exercise is necessary to help alleviate health problems that may be brought on by medication or a sedentary lifestyle, as well as helping to improve the social skills adults with autism need for independence. While other forms of treatment have been prioritized over exercise, it has continued to increase in popularity as its effectiveness in combating obesity and aiding social interaction becomes more evident. It is important to continue to provide more opportunities for adults with autism to engage in exercise in order to improve their quality of life as well as their overall wellness.

References


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