



AUTISM ALLIANCE OF MICHIGAN PRESENTS

MiNavigator

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Help. Hope. Answers. Today



Aging Autism Caregivers

Contributed by Sharon Milberger, ScD - Director, Michigan Developmental Disabilities Institute (MI-DDI) and MI-LEND Wayne State University

When we talk about autism spectrum disorder (ASD), much of the discussion focuses on children and adolescents with autism. There are an estimated 6.6 million individuals diagnosed with ASD worldwide, however, and 80% of these individuals are adults (Nightingale, 2012). As individuals with ASD move from childhood/adolescence to adulthood, many continue to benefit from and rely on some form of support that is typically provided by family caregivers. In the United States, of the estimated 3.6 million individuals with ASD, 71% live with family members (Braddock, 2016). In Michigan, 66% of the 157,000 adults with ASD live with their families. Of the individuals living with their families, 24% live with caregivers above the age of 60 (Braddock, 2016).





Organizations that support families and individuals with ASD believe a crisis is in the making as family caregivers age and communities lack resources and professionals to support adults with ASD (Fifield, 2016).

Over the next two decades, it is predicted that there will be a considerable increase in the number of two-generation elderly families living together where parents aged over 80 will be caregiving for an adult child with a developmental disability.

Research on family caregivers of individuals with ASD indicates that caregivers experience numerous adverse outcomes, including poorer health and decreased quality of life.

Parenting children with ASD is associated with stress, fatigue, anxiety as well as depression, particularly when compared to parenting neurotypical children (Gallagher & Whiteley 2012; Hayes and Watson 2013; Murphy et al. 2007; Smith et al. 2001).

Grandparents caring for grandchildren with behavioral problems or psychiatric conditions were eight times more likely to experience a negative impact on their own health when compared to their peers who did not report any health concerns in their grandchildren (Samuel et al., 2017).

Aging family caregivers of adults with ASD face a uniquely challenging situation as they deal with their own age-related health issues and retirement planning, while supporting their family members with ASD who are transitioning to adulthood roles (Dillenburger and McKerr 2011; Piazza et al. 2014; Seltzer et al. 2011). While research studies have documented the negative impact of caring for family members with ASD on aging caregivers, surprisingly, little research has considered how to best help these aging parents and grandparents.

In order to address this gap, the Michigan Developmental Disabilities Institute (MI-DDI) at Wayne State University was recently awarded a 2-year grant to establish the Michigan Older Caregivers of Emerging Adults with Autism and other Neurodevelopmental Disabilities Family Support Project (MI-OCEAN).

The MI-OCEAN effort aims to improve the health and well-being of this underserved population of aging caregivers by empowering them through peer-to-peer support and system change.

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This unique combination of education and peer support will bolster older adults who are trying to balance their own age-related issues while caring for adult family members with autism.

If you are a caregiver providing support to an adult family member with ASD and would like help improving your health and quality of life as well as receive resources to support you and your loved one, consider participating in this **FREE** project.



For more information,
please contact:
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This Chapter of our Lives

Contributed by David Trout Pomeroy, writer/author & father

Fraser is turning 31 this month. He has shown no interest in moving out of our house, so far. Many question why he would want to as we fend for him, offer him free rein of our living room where his computer and television are and have converted his bedroom into a setting that includes fewer trappings of his childhood and affords him the space and privacy he favors.

Early in his life I attended events in which subject experts suggested young adults with autism will be most likely inclined to actually want to move out of their family home between the age of 25 and 30, when they begin to yearn for greater independence. We assumed this would be the case with Fraser, but he has yet to express any desire to leave here. On our part, we have assured him we will never tell him he has to leave and that doing so will have to be his idea. At this point, I am questioning whether our strategy is appropriate or tenable.

In the past year we have become familiar with three different entities that assist individuals on the spectrum in making this transition. I have not sensed that any of them are particularly proactive in seeking us out, that it will continue to be up to us to take the initiative and do what we can to lay the groundwork to explore future options.

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Short of him being willing to engage in related discussions, our tendency is to keep the peace, enjoy his presence in our home and envision his needs as they currently exist.

As parents learn, all individuals on the spectrum are different. They may all have the same diagnosis but their personalities, maturity levels and aspirations are unique unto themselves. We have met young men who, according to their parents, were pleased to relocate into apartments with others and seem to benefit from the independence doing so offers.

One common pattern appears to be the individual will live with others during the week and then perhaps spend the weekends with their families. We hope eventually to create a similar scenario for Fraser and are committed to work toward that end with the assistance of the many agency personnel who are there to assist and support our efforts.

We toy with various ideas, including a plan in which he continues to live here with possibly a roommate or two with oversight, and my wife and I find a small condominium nearby where we could relocate. This plan is not quite financially compatible with our current means and is also potentially problematic according to professionals who have discussed this with us. These considerations can become overwhelming causing our heads to spin at times.

Among the various groups and individuals that have assisted us along the way, Fraser is not regarded as being a good candidate to live in a group home as he is too high functioning to fit into that model; more ideally they tend to imagine he is probably better suited to share an apartment with others on the spectrum, with adequate supervision.

As my wife has turned 60, and I am looking at 74 soon, we realize our need to remain focused on his future needs is of paramount importance. This process is not easy on anyone, but knowing we are far from unique gives us comfort as our situation is being replicated in other households with families we know and others we expect to encounter as we continue to mull all of this over. Most of our energy and efforts are expended on keeping him at an even keel in the present tense, in directing available financial assets to life insurance policies intended to provide resources for him after we are gone and trying to survive emotionally in the meantime.

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Discovering the services of the Autism Alliance of Michigan has been a major boost to our enthusiasm and confidence; and as such, we can proceed in anticipating an eventual transition for him to a new living arrangement and secure future.

Thank you for your interest in our particular story. We hope in stepping forward to reveal the nature of our experience we may become acquainted with other families that share our basic challenge and also wish to network, join forces and take on this mission with greater emphasis and focus on what lies ahead.

David is a writer/author with 50 years of experience and his wife Bonny is a therapist in Waterford, Michigan. AAoM is grateful for their willingness to share their family's story and their thoughtful consideration of the future.



Health and Aging with Autism

Contributed by Jill Matson, MSN, RN, CPNP, MiNavigator Clinical Specialist

Approximately 1 in 59 children in the US have autism according to the Center for Disease Control and Prevention. Over the next decade, it's estimated that half a million children will enter adulthood. As the number of adults living with autism grows, so do concerns for their overall health care.

In many children with autism, a host of physical and mental health problems are also present. Such problems include seizures, obesity, anxiety and depression; and more often than not, these associated problems will accompany them into adulthood.

Statistics suggest that nearly all medical and psychiatric conditions are significantly more common in adults with autism than in adults without the disorder.

In one of the first large scale studies to look at medical and psychiatric comorbidities in adults with autism, researchers at Kaiser Permanente in Oakland, California found that adults with an autism spectrum disorder had markedly higher rates of physical and mental health problems than adults without the disorder.

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Medical Problems

Diabetes (6 percent [ASD] vs. 4 percent [general population])

Gastrointestinal Disorders (47 percent vs. 38 percent)

Epilepsy (12 percent vs. 1 percent)

Sleep Disorders (19 percent vs. 10 percent)

High Cholesterol (26 percent vs. 18 percent)

High Blood Pressure (27 percent vs. 19 percent)

Obesity (27 percent vs. 16 percent)

Mental Health Problems

Depression (38 percent [ASD] vs. 17 percent [general population])

Anxiety (39 percent vs. 18 percent)

Bipolar Disorder (30 percent vs. 9 percent)

Suicide Attempts (1.6 percent vs. 0.3 percent)

Like aging adults without autism, adults with the disorder should be screened regularly by their primary care provider to identify and treat (through referral to a specialist, if needed) medical and psychiatric conditions commonly seen in adulthood.

This can be challenging, though, because many adults on the autism spectrum do not see their PCP regularly; and further, many don't have one at all.

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This may be due, in part, to the difficulty finding a PCP who is comfortable examining, communicating and providing care for adults with autism. A lack of preventative care may contribute to the number of health problems affecting more adults with autism than without.

It can be especially difficult for adults with autism to undergo more invasive health screenings like prostate and pelvic exams or colonoscopies.

Social difficulties may result in limited opportunities for regular exercise. Restricted eating, common in individuals with autism, may result in unhealthy food choices.

In addition, side effects from some of the medications commonly used to treat behavioral and mental health issues present in autism can lead to obesity, diabetes and heart disease, which are twice as likely to occur in adults with autism when compared to those without.

Notably, adults with autism are less likely to drink alcohol or smoke, possibly because smoking and drinking are more social behaviors.

Autism is more than a brain or behavioral disorder. For many individuals, it affects the whole body resulting in physical and mental health problems across the lifespan.

The average lifespan of someone with autism was found to be half that of the general population, which represents an average of 36 years versus 72 years is in one recent study (Guan 2017).

It's important to note, however, that autism itself is not a cause of premature mortality. Instead, research suggests that it relates to associated physical and mental health conditions, most of which can be treated and managed medically.

*Lisa Croen, PhD, May 15, 2014, Presentation, International Meeting for Autism Research, Atlanta. American Journal of Public Health (AJPH) May 2017. Injury Mortality in Individuals with Autism Joseph Guan BS, and Guohua Li MD, Dr. PH Author affiliations, information, and correspondence details
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AUGUST AT A GLANCE

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
				1 Employment First Conference (Novi)	2 Reading and Rhythm on the Riverfront (Detroit)	3 LEAD Kalamazoo (East Lansing) Social Saturday (Port Huron)
4 LEAD Kalamazoo (East Lansing)	5 Community Living Services training (Troy) Kids in Motion Summer Camp (Milford)	6 Teens To Work – Expanded Program for 2019 (St. Claire Shores) REST (Respite Education and Support Tools) Training (Menominee)	7 Art Workshop at Hearts for the Arts Studio (Grand Rapids)	8 TACS adaptive sailing program (Traverse City)	9 DNOM's Community Spirit Gala (Troy)	10 YOUTH Mental Health First Aid (Kalamazoo) ASD: Safety BootCamp For Parents (Canton)
11 Disability Awareness Walk (Royal Oak)	12 CranHill Friendship Camp (Rodney)	13 Camp Zip Overnight Camp (Howell) Self Determination Training (Sterling Heights)	14 St. Aidan Livonia Summer Camp (Livonia) A look into how working affects SSI/SSDI and State Benefits (Troy)	15 Summer Dance Mix (Redford)	16 Zones of Regulation Workshop (Muskegon)	17 The Miracle League of Plymouth (Plymouth)
18 Abrams Planetarium Sensory friendly show (East Lansing) My Turn: A Sensory Friendly Sunday (Dearborn)	19 Friendship Circle Overnight Camp (Kalkaska) ESDM Advanced Training (Ann Arbor)	20 4th Wall Detroit Opera House – Afternoon (Detroit) Independent Facilitation Training (Midland)	21 Summer Fun Kayaking & Paddleboarding (Midland)	22 2019 Culture of Gentleness Conference (Ann Arbor)	23 MRA 70th Anniversary Celebration (Novi)	24 FALCONERS "What's for Lunch?" (East Lansing) FREE Autism Caregiver Bootcamp Series: Lansing Area
25 LEAD Kalamazoo (East Lansing)	26 American Sign Language Class (Troy)	27 Lawn Games (Sault Ste. Marie)	28 2019 Statewide Disability Summit (East Lansing)	29 Living Well with a Disability 10-Week Workshop (Troy)	30 <i>Happy Labor Day WEEKEND</i>	31 2019 Family Days presented by Autism Alliance of Michigan (Royal Oak)

** For more information on any of these events, please contact the MiNavigator line at 877-463-2266.

2019 NAVIGATING AUTISM TODAY REGIONAL CONFERENCE

Friday, October 25th, 2019 | 10:00AM-3:00PM | The MTG Space | 4039 Legacy Pkwy, Lansing, MI, 48911



Autism Alliance of Michigan
CELEBRATING 10 YEARS

Register at
AAoMConference.org

