



LURIE INSTITUTE FOR DISABILITY POLICY
HELLER SCHOOL FOR SOCIAL POLICY AND MANAGEMENT • BRANDEIS UNIVERSITY

AGING WELL WITH AUTISM (55 AND OLDER)



Welcoming Remarks

Clarence Schutt, PhD
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A great deal of attention has been directed at the challenges faced by children with autism. Rarely discussed are the problems faced by the growing population of individuals with autism after age 55. These individuals have unique needs that require more research, discussion, and planning. Summarized here are the reports of experts assembled to share their knowledge about and experience with developing living arrangements, and providing health care services, for older individuals in the hopes that these examples might spark new ideas for the growing population of adults with autism and their families.

One major concern is finding ways to help older adults with autism plan for life in their senior years. As parents, friends, caregivers, and siblings pass on, those who most often have been responsible for managing lives, and providing emotional support and companionship, a natural question is who will fill this enormous gulf? What types of social structures will be in place to care for these individuals and provide opportunities for recreation, employment, and personal growth?

Persons with autism face health problems as they age like everybody else, and may have trouble explaining what ails them to physicians, who themselves are often unprepared to deal with problems unique to this population. In many cases older autistic individuals are denied access to medical screening and care. Progress is being made, as reported here through two model programs in dentistry practice and brain imaging research, which may help medical professionals in varied medical specialties adapt, understand and care for patients with autism as they age. Nationally, many programs are now being offered to the general population on wellness, nutrition, and exercise and it is important that these be adapted to help those with autism, who frequently find themselves in sedentary living conditions.

Senior life planning to meet residential, caregiving, recreational, and financial planning needs is an area where many creative ideas are surfacing as society confronts changing demographics. Can these innovative ideas from the aging and disability communities suggest models that can guarantee stabilization and structure in the lives of those aging with autism? This report identifies ways that individuals with autism can share in these developments.

In the vigorous discussion period following the presentation of experts in areas of residential and health planning, several members of the audience shared their experience in working with state and federal legislators and administrators to find ways to accelerate progress in providing housing, meaningful activities, and full access to medical care and services.

AGING WELL WITH AUTISM (55 AND OLDER)

JULY 25, 2013

Welcoming Remarks

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MORNING SESSION: Healthcare Issues and Models

Medical Care for Individuals with Autism and Developmental Disabilities Over 55

Susan L. Parish, PhD, MSW
Nancy Lurie Marks Professor of Disability Policy
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Self-Determination, Aging, and Family Supports

Tamar Heller, PhD
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Aging into the Unknown: Autism Spectrum Disorder in Adulthood

Nora Friedman, MD
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Models for Clinical Care & Research: D-Termined™ Dental Program of Repetitive Tasking and Familiarization

David Tesini, DMD, MS
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Tufts University School of Dental Medicine
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Models for Clinical Care & Research: Preparing Potential Research Participants for the MRI Environment

Trang Nguyen, BA
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Health Matters - Innovative Health Promotion Program

Beth Marks, RN, PhD
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AFTERNOON SESSION: Residential Planning Models

Mixed Income, Supportive Senior Housing as a Model

Len Fishman
Former CEO, Hebrew SeniorLife
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The Green House Project: Meaningful Transformation that Creates Lives Worth Living (sponsored by Robert Wood Johnson Foundation)

Susan Frazier, RN, MA
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Generations of Hope - Multigenerational Communities (sponsored by Kellogg Foundation)

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Discussion Summary



*Medical Care for Individuals with Autism
and Developmental Disabilities Over 55*

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We are living in a stimulating scientific environment. Scientific and behavioral discoveries are advancing knowledge about children with autism at a breathtaking pace. New genomics discoveries are being published and new behavioral interventions are being developed each day. Unfortunately, almost nothing is known about the effects of middle and late life aging in adults with autism.

It is possible that the detrimental effects that occur as a normal part of aging may have a greater impact on adults with autism. There is currently no research to help us understand this. Research must begin to focus on the mental and physical aging process in adults with autism so that we can provide the best supports for these individuals, their families, caregivers, and service providers.

Dr. Parish and colleagues developed an intervention to promote cervical and breast cancer screenings for women with intellectual disability and developmental disabilities (I/DD). They found enormous disparities in medical care access. Specifically, they found that fewer than half of the women with developmental disabilities had received mammography according to clinical guidelines and between 25-30% had received cervical cancer screening. These are the lowest rates of any group of women in the US.

They also found racial disparities. Black women with developmental disabilities were five times less likely to get a mammogram than white women with developmental disabilities. There are currently no data on women with autism specifically.

The hope is that this symposium and post-symposium discussions will launch us into a new direction of research with regard to the unique, long-term support needs of individuals with autism. The morning session of the workshop focused on healthcare and biomedical issues presented by the medical community and the afternoon session focused on innovative housing models presented by the aging community with the hope that we might bring these ideas into the disability community.

RELEVANT PUBLICATIONS

Parish, S.L., Swaine, J.G., Son, E., & Luken, K. (2013). Determinants of cervical cancer screening among women with intellectual disabilities: Longitudinal evidence from medical record data. *Public Health Reports*. (forthcoming)

Parish, S.L., Swaine, J.G., Son, E., & Luken, K. (2013). Receipt of mammography among women with intellectual disabilities: Medical record data indicate substantial disparities for African-American women. *Disability & Health Journal, 6,* 36-42.

Parish, S. L., Swaine, J.G., Luken, K., Rose, R.A., & Dababnah, S. (2012). Cervical and breast cancer screening knowledge of women with developmental disabilities. *Intellectual & Developmental Disabilities, 50(2),* 79-91.

Parish, S.L., Rose, R.A., Swaine, J.G., Luken, K., & O'Hare, L. (2012). Cancer screening knowledge changes: Results from a randomized control trial of women with developmental disabilities. *Research on Social Work Practice, 22,* 43-53.

Parish, S. L., Moss, K., & Richman, E. L. (2008). Perspectives on health care of adults with developmental disabilities. *Intellectual & Developmental Disabilities, 46,* 411-426.

Parish, S. L. (2006). Health care of women with disabilities: Population-based evidence of disparities. *Health & Social Work, 31,* 7-15.

Parish, S. L., & Saville, A. W. (2006). Women with cognitive limitations living in the community: Evidence of disability-based disparities in health care. *Mental Retardation, 44,* 249-259.

Son, E, **Parish, S. L.,** Swaine, J.G., & Luken, K. (2013). Accuracy of reporting receipt of cervical and breast cancer screening among women with intellectual and developmental disabilities. *American Journal of Intellectual and Developmental Disabilities.* (forthcoming)

Swaine, J.G., Dababnah, S., **Parish, S.L.,** & Luken, K. (2013). Family caregivers' perspectives on barriers and facilitators of cervical and breast cancer screening for women with intellectual disability. *Intellectual & Developmental Disabilities, 51(1),* 62-73.

Swaine, J.G., **Parish, S. L.,** & Luken, K. (2013). Breast and cervical cancer screening for women with intellectual disabilities. *Health & Social Work.* (forthcoming)



Self-Determination, Aging, and Family Supports

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Dr. Heller's presentation focused on research related to outcomes for older adults with autism, health considerations and disparities for this population, and health promotion and caregiving interventions.

Bridging the aging and disability fields is an important theme that we can expect to see more of due to changes at the federal level, including the merging the Administration on Aging and Administration on Developmental Disabilities under the Administration on Community Living (<http://www.acl.gov>).

From a life course perspective, "aging well" means living on your own terms, adding value to society, maintaining health and cognitive function, maximizing mobility, retaining function, and reducing the impact of chronic disease. Challenges faced by persons with autism that affect later life include unemployment, discrimination, bullying, inaccessible, non-accommodating environments, lack of opportunities, lack of lifetime social supports, and social isolation.

There is a lack of data on outcomes for older adults with autism, perhaps due to the fact that many older people were never diagnosed. Dr. Heller discussed prevalence data and statistics from Brugha et al (2011) and Mandel et al (2011).

She presented autism data from the National Core Indicators (NCI) Project, an effort by public developmental disabilities agencies to assess the outcomes of services provided to individuals and families. Currently, 12% of those served by the public developmental disabilities system in Massachusetts have autism and this number is expected to rise. 13% of adults in large state residences have autism (Larson et al., 2011). According to NCI data (Hewitt et al., 2011), 4.5% of adults with autism are 50-59 years and 2% are 60 or older.

Most adults with autism live at home and few independently. It is estimated that 25-30% of adults with ASD live with parents (Seltzer, Krauss, Orsmond, & Vestal, 2000). Few are employed and many are underemployed. There are low rates of post-secondary education (Barnhill, 2007) and low rates of marriage and parenthood (Howlin, Goode, Hutton & Rutter, 2004).

Where are persons with developmental disabilities living? 60% live with a family caregiver and only 12% are in supervised residential settings. Over 25% of family caregivers are 60 and older (Braddock et al., 2012). 45% of adults with autism are living in supported living settings with 6 or fewer individuals. 32% are

living in group homes with 6 or fewer individuals, foster and host homes, and ICFs/ID (Intermediate Care Facility for people with Intellectual Disabilities) apartments.

Dr. Heller presented data from the Illinois Adult Home-Based Waiver Study, which included those on the home-based waiver that allows them to self-direct support services. Those with ASD had lower social and community participation, fewer opportunities for daily choice-making, and were more likely to have turnover in support staff. NCI data indicated that only 2% of those with ASD in Massachusetts are using the self-directed support option.

Dr. Heller discussed risk factors for health conditions. Obesity, poor diets, long-term impact of medications/vitamins, sleep disorders, seizures, abuse and self-injury were identified as important secondary health issues for this population.

Research by Calarge et al (2009) suggests that psychotropics and other epilepsy medications can lead to osteoporosis. More research is needed on the long-term effects of medications and nutritional supplements.

In a longitudinal study, Dr. Heller examined the health of approximately 2,000 people with developmental disabilities and focused on health ratings by type of residential settings (Heller & Hsieh, 2012). Those in institutional settings were found to have the worst health ratings. Those living in the least restrictive settings, particularly women and those in middle age, had the largest problem with obesity.

Strategies to reduce health disparities that adults with autism face as they age include: greater knowledge about impairment and treatments; reduction in poverty and unhealthy environments; improved health behaviors through health literacy and promotion; improved accessibility, equity, and effectiveness of health care; and better health and fitness in later life.

Dr. Heller also discussed her own research which focused on systematic reviews across aging and developmental disabilities literature with the overarching goal of bridging these networks. Two areas examined were health promotion and family caregiving research.

Research questions included the following: What health and caregiving interventions are being examined by aging and disability researchers? What innovative approaches are being used by aging and disability researchers in interventions? What are the gaps in health promotion and caregiving research?

In the aging community, there is greater variety in health promotion initiatives (health education/psychosocial, physical activity, multicomponent, screenings, other interventions, etc.), whereas in the disability community, interventions are focused primarily on physical activity.

Generally, researchers found little with regard to caregiving interventions in the disabilities literature. The disability review places greater emphasis on positive outcomes and future planning, whereas the aging literature emphasizes caregiver stress and negative outcomes.

Summarizing findings from health promotion and caregiving reviews, Dr. Heller discussed what the disability field can learn from the aging field. The aging field used peer mentors, civic engagement programs and volunteering opportunities to improve health. The aging community also had stronger research designs and sustained use of natural settings for health promotion. Finally, the aging community has tailored evidence-based initiatives to specific groups.

With regard to family caregiving interventions, the aging community has unique care models and focus on smoother transitions in care. There is also a greater breadth of research and a wider variety of programs.

What can the aging community learn from the disability community? The disability community has developed better adaptations and curricula for people with cognitive limits. Self-determination is an important topic in the field of disability research. The disability field has had more focus on building independence and a more holistic perspective on family involvement.

In terms of next steps, Dr. Heller suggests including disability populations in aging research, implementing universal design across all research initiatives, and tailoring programs to accommodate the support needs of adults with disabilities. She recommends fostering research exchanges for cross network knowledge generation, providing a listing of evidence-based programs, exchanging theoretical models, translational approaches, and best practices for addressing the underserved. Finally, there needs to be more funding for joint projects across both aging and disability fields. Dr. Heller identified the shrinking federal and state developmental disabilities budgets and growing residential waiting lists as policy concerns.

Dr. Heller mentioned the National Sibling Leadership Network as well as toolkits developed for individuals with disabilities to direct their own supports titled, "Find, Choose, and Keep Great DSPs (Direct Support Professionals)".

She discussed her research on an evidence-based caregiving intervention called, "The Future Is Now: A Future Planning Training Curriculum for Families and Their Adult Relatives with Developmental Disabilities" (Heller & Caldwell, 2006; Factor et al., 2012). The intervention was developed to support aging caregivers and adults with disabilities in planning for the future, and to teach them about choice and self-determination. It involves the family and the individual working together to determine what their life will be like once their parents are no longer able to serve as primary caregivers.

Key outcomes of the intervention were that people developed special needs trusts, made residential plans, and developed letters of intent. Caregiving burden was decreased and for adults with intellectual disabilities there was more daily choice making and fewer unmet leisure needs. A Train-the-Trainer program to build capacity and reach community organizations has been developed.

She and her colleagues have also developed a training titled, "Taking Charge of Your Supports" designed to help the person with the disability use self-directed waivers. The goal is for the individual to become more aware of preferences, options, and making choices.

Dr. Heller identified the following opportunities for bridging the fields of disability and aging research (Factor, Heller & Janicki, 2012): Administration for Community Living, long term services and supports initiatives, consolidation of waivers, integrated/managed care and “dual eligibles”, aging and disability resource centers, Lifespan Respite Care Act, and the National Alzheimer’s Project Act.

RELEVANT PUBLICATIONS

Heller, T. & Keiling, C. (2010). Siblings of adults with developmental disabilities: Psychosocial outcomes, relationships, and future planning. *Journal of Policy and Practice in Intellectual Disabilities, 7*(1), 16-25.

Heller, T., McCubbin, J., Drum, C. & Peterson, J. (2011). Physical activity and nutrition health promotion interventions: What’s working for people with intellectual disabilities? *Intellectual and Developmental Disabilities 49*(1), 26-36.

Heller, T., Schindler, A., Palmer, S., Wehmeyer, M., Parent, W., Jenson, R., Abery, B., Geringer, W., Bacon, A. & O’Hara. (2011). Self-determination across the life span: Issues and gaps. *Exceptionality, Special Issue: Promoting Self Determination, 9*(1), 31-45.

Arnold, C.K., **Heller, T.** & Kramer, J. (2012). Support needs of siblings of people with developmental disabilities. *Intellectual and Developmental Disabilities, 50*(5), 373-382.

Heller, T. & Sorensen, S. Promoting healthy aging in adults with developmental disabilities. *Developmental Disabilities Research Reviews: Special issue on aging.* (In press).

Heller, T., Arnold, C.K., van Heumen, L., McBride, E.L., & Factor, A. (2012). Self-directed support: Impact of hiring practices on adults with intellectual and developmental disabilities and families. *American Journal on Intellectual and Developmental Disabilities, 117*(6), 464-477.

Salvador-Carulla, L., Putnam, M., Bigby, C., & **Heller, T.** (2012). Advancing a research agenda for bridging aging and disability, *International Journal of Integrated Care, 12*(16), 1-5.

Heller, T., Fisher, D., Marks, B., & Hsieh, K. Intervention to promote health: Crossing networks of developmental disabilities and aging. *Disability and Health.* (In press).

Heller, T. & Harris, S.P. (2011). Disability across the life course. Thousand Oaks, CA: Sage.

Factor, A. & **Heller, T.** (2013). Aging and Self-Determination: Research to Practice Brief. National Gateway to Self-Determination, University of Missouri and University of Illinois at Chicago.



*Aging into the Unknown:
Autism Spectrum Disorder in Adulthood*

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Dr. Friedman's presentation focused on epidemiology and prevalence rates of autism among adults, the impact of the recently revised diagnostic criteria for autism, research on outcomes for adults with ASD, gaps in research on autism in later life, and future research directions.

In May 2013, the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders was published. She discussed the recently revised diagnostic criteria, with an emphasis on changes relevant to diagnosing individuals later in life.

In previous editions, there had been five subtypes of Pervasive Developmental Disorder. DSM-5 eliminated these subtypes and combined them into a single Autism Spectrum Disorder category, with observational criteria organized along two domains: social communication/interaction and restricted/repetitive behaviors, activities, and interests.

To qualify for an ASD diagnosis, individuals need to demonstrate deficits in social-emotional reciprocity, nonverbal communicative behaviors, and in developing relationships. They also need to show two out of the four criteria in the domain of restricted/repetitive behaviors, activities, and interests. These include stereotyped or repetitive motor movements, use of objects or speech; insistence on sameness, adherence to routines, ritualized patterns of behaviors; restricted, fixated interests which are abnormal in intensity; and hyper-or hypo-reactivity to sensory input/unusual interests in sensory aspects of environment.

In previous versions of the DSM, impairments had to be present by age 3. DSM-5 relaxed this requirement stating that symptoms need to be present in the early developmental period but may not become apparent until social demands exceed capacities or may be masked later in life by compensatory strategies. This change is also relevant for diagnosing individuals later in life when access to developmental histories or the degree of impairment may have diminished over time. Symptoms need to produce clinically significant impairment in social, occupational, or other areas of functioning.

There are a number of historical considerations to keep in mind as we examine current outcomes data. Because autism emerged as a clinical entity in the 1940s, the first cohort of patients described by Kanner and Asperger are now in their 70s and 80s (see "Autism's First Child", The Atlantic Monthly, October 2010). Perhaps attention hasn't been paid to the later stages of life because this first wave of patients is just now entering late adulthood. Due to the broadening of the diagnostic concept over subsequent decades, individuals with milder impairments may have received a diagnosis later in life. Finally, it is important to

keep in mind that there is a much greater availability of resources and interventions for today's youth with ASD. How early diagnosis, early interventions, educational supports and therapies will affect outcomes later in life remains to be determined.

Based on CDC data, the estimated prevalence of autism is 1 in 88 children 8 years of age in the US. This represents a 72% increase from 2002 to 2008. A more recent US study based on parent report identified a prevalence of 1 in 50 children ages 6-17.

In the only study that has examined prevalence rates amongst adults, researchers found a prevalence rate of approximately 1% of adults living in the community in England (Brugha et al., 2011). This was comparable to prevalence rates among pediatric populations which suggests that perhaps there has not been a true increase in incidence but rather improved recognition over the decades.

Ganz (2007) calculated the lifetime per capita incremental societal cost of autism to be \$3.2 million. The largest components of this cost were adult care and lost productivity for individuals with ASD and their families. Clearly, autism carries a heavy financial burden across the lifespan.

We know that autism causes persistent impairments across the lifespan even if we have not yet fully characterized the development trajectory. These individuals will likely need ongoing supports and interventions, and researchers have estimated that there will be 700,000 adults with ASD age 65 or older by 2030 (Pivens and Rabbins, 2011). Clearly, the aging ASD population will have significant social, economic, and public health consequences that require attention.

There have been disparities in the research focus across the lifespan. Most research has focused on the early years and there is an inadequate understanding of the factors associated with adult outcomes. There have been no studies that have focused exclusively on ASD in late adulthood.

What are the research gaps that need to be addressed? We need to understand the course of ASD over the lifespan with regard to core symptom domains and associated features, neuropsychiatric symptoms, physical health/longevity, and neurobiological changes. We also need to understand what the interactions are of ASD developmental trajectories over time with typical aging processes. We also need to determine effective supports and interventions. Given that parents and siblings often serve as primary caregivers through adulthood, how will their declining health and death impact the quality of life of individuals with ASD? What are long-term financial factors impacting the family and how do other socioeconomic factors affect access to services, care and adult outcomes?

Dr. Friedman presented existing outcomes data with the caveat that most studies have sampled young adults. Paul Shattuck et al. (2007) followed a sample of adults with ASD ages 10-52 over 4.5 years to assess changes in symptoms and maladaptive behaviors. The findings regarding outcomes in adulthood were generally positive. In the aggregate, there were improvements in verbal communication and social reciprocity, reductions in repetitive behaviors/stereotyped interests, no change in nonverbal communication, and a decline in maladaptive behaviors.

Howlin et al. (2013) looked at a sample of adults with autism in England followed over an average of 37 years. They found a decrease in symptom severity which was statistically significant for restricted and repetitive behaviors and significantly improved language ratings. For those individuals who could complete repeat IQ testing, IQ scores remained relatively stable. Unfortunately, the rest of the outcomes were quite dismal. 72% had no formal education qualifications. Only 13% were living independently. The majority of the group had limited autonomy. Over one third of the group was living in specialist autism placements or in a secure hospital setting. Over half the sample had never worked or had long-term unemployment and there were high rates of social isolation. Overall, about 60% of the participants had what the researchers classified as poor or very poor outcomes.

Smith, Maenner, Seltzer (2012) evaluated a group of individuals with ASD ages 10-52 over a ten-year period. They found that daily living skills tended to increase during adolescence and the 20s, plateau in the late 20s, and decline in the 30s.

Totsika et al. (2010) looked at adults over age 50 with intellectual disability, including some with ASD. They found that the group of adults with ID+ASD had lower levels of adaptive functioning. After controlling for level of adaptive skills, there was no difference between groups with regard to behavioral problems, psychiatric disorder, or quality of life. These findings suggest that we focus interventions on improving adaptive skills to improve outcomes.

From 2000 to 2010, approximately 11,000 studies were published on ASD. During that same time period, only 23 studies focused on interventions for adults with ASD targeting employment, education, independence, and/or social participation (Shattuck et al., 2012). Clearly, interventions in adulthood have not been a research priority.

In 2010, the Center for Medicare and Medicaid Services conducted a review of evidence-based psychosocial supports and services in ASD across the lifespan. Of all the studies published between 1998 and 2008, only three out of nine of the interventions for adults were rated as evidence-based. These were behavior modification, structured teaching, and supported employment (Young et al., 2010).

In 2010, the Aging-in-Autism Work Group suggested the need to develop diagnostic criteria and instruments for assessing older adults with ASD; conduct cross-sectional descriptive studies of phenomenology in adults; conduct longitudinal studies of lifespan trajectories; conduct neurobiological studies to examine whether findings in young individuals with ASD persist in late adulthood; examine the interaction between aging, associated disease, and autistic symptoms; conduct studies of psychosocial, behavioral, educational, and pharmacological interventions in older individuals with an ASD; and develop mechanisms to support training in research on aging in ASDs (Pivens & Rabins, 2010).

To improve adult outcomes, we need to improve the evidence base for adults with ASD with respect to multiple domains, build an infrastructure of supports and services that can target the needs of this population, and be proactive in our efforts to meet the needs of individuals with ASD who are moving through adulthood.

RELEVANT PUBLICATIONS

Friedman NDB, Erickson Warfield, M., & Parish, S.L. (2013). Transition to adulthood for individuals with autism spectrum disorder: Current issues and future perspectives. *Neuropsychiatry*, 3, 181-192.

Friedman ND, Shern, K.J. (2011). Assessment and management of patients with intellectual disabilities by psychiatric consultants. *Psychosomatics*, 52(3), 210-7.



*Models for Clinical Care & Research:
D-Termined™ Dental Program of Repetitive Tasking and
Familiarization*

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The primary aim of Dr. Tesini's presentation was to highlight a model approach to dental care access for adults with autism which could be adapted for use in various medical subspecialties. Specifically, the objectives of his presentation were to address behavior issues relevant to the treatment of patients with autism and to discuss the transitioning of care from pediatric to general dentistry practices with aging. He also reviewed the D-Termined Program of Repetitive Tasking and Familiarization in Dentistry and introduced the Mutual Access Program as a model for clinical dental care.

Dental care is a main area of neglect for the developmentally disabled population and should be included on surveys aimed at understanding medical care access for individuals with developmental disabilities. It may become an even larger problem in the future because of issues related to the Affordable Care Act and dental insurance coverage for this population. Dr. Tesini emphasized the importance of early oral care as it impacts oral health and cooperation in the dental environment later in life.

Dr. Tesini discussed the fragility of the balance of dental care access for patients with developmental disabilities. Patient behavior challenges and care availability are significant barriers that need to be addressed. His presentation focused on the role of the pediatric dentist and on training received in dental schools and general practice residency programs.

When teaching at Tufts University School of Dentistry, Dr. Tesini emphasizes to students the importance of trying to understand how patients with autism experience the world and what they might be experiencing internally. Dr. Tesini encourages students not to look at autism as a disorder, but instead as a different perspective from which these individuals view the world.

He emphasizes the importance of teaching dental students the skills to recognize and guide the behavior early on to ensure the best dental outcomes for this special population. It is from this understanding that the D-Termined Program of Repetitive Tasking and Familiarization in Dentistry originated.

Because of their difficulties in communication, heightened sensitivity to, reactivity to, and fear of stimuli in the dental environment, individuals with autism are often unable to receive proper dental care without sedation. Developed by Dr. Tesini, the D-Termined Program is a behavior management approach to dentistry which relies on repetitive tasking and familiarization techniques. It has proven successful in practice as a way to provide dental care without sedation to this special population.

The program reminds us that the most important factor in being successful with patients with ASD is to be "determined". With funding from NLM, Dr. Tesini and his staff created an instructional video on the D-Termined Program that has been used in the US and Europe and distributed widely through the DVDs and on YouTube.

There are three factors which are the key to success in the D-Termined Program. First, the dentist must make repeated verbal commands ("Look at me") throughout the dental visit while maintaining eye contact with the patient. Positional modeling ("hands on stomach, feet out straight") is another crucial factor. It's important to emphasize to parents the differences between positional modeling and restraint. Finally, a verbal counting framework is crucial to success.

The D-Termined Program comprises the following key steps which take place over a series of visits: Divide the skill into small components; demonstrate the skill; drill the skill and delight the repetition. Regarding cost effectiveness and finances, it is best for dentists to delegate these repetitive tasking and familiarization steps to trained auxiliaries in the dental office.

Dr. Tesini discussed the American Academy of Pediatric Dentistry's 2011 Oral Health Policy on transitioning from a pediatric to an adult-centered dental home for individuals with special health care needs. The dental literature recommends that transition planning begin between ages 14-16, but Dr. Tesini emphasized the importance of encouraging the transition of patients much earlier than this for best outcomes.

A large problem is that there is a lack of dentists who provide care for this population of patients with special health care needs (SHCN). Only 10% of surveyed general dentists report that they often treat patients with SHCN. Greater than 70% report that they rarely or never treat patients with special health care needs.

In 2005, senior dental students reported that treating patients with SHCNs was among the top four topics that they felt they were least prepared for when they got into practice. Casamassimo et al (2004) reported that only one in four dentists received training in special care dentistry in dental school. Wolff et al (2004) reported that 75% had little or no education or clinical training in special care dentistry. Because there is such a dearth of education in the dental schools in treating patients with special health care needs, the American Dental Association has begun to focus on this area through their standards for dental education.

In reality, the pediatric dentist by default becomes the special needs dentist. Care for this special population must be coordinated if we are to achieve quality, comprehensive, and affordable care.

RELEVANT PUBLICATIONS

Froehlke, M. & Zaborek, R. (2012). *When Down Syndrome and Autism Intersect: A Guide to DS-ASD for Parents and Professionals*. Bethesda, MD: Woodbine House Publishing.

Hernandez, et al. (2011). Applied Behavior Analysis: Behavior Management of Children with Autism Spectrum Disorders in the Dental Environment. *JADA*, 142, 281-287.

Raposa, K.A. & Perlman, S.P. (2012). *Treating the Dental Patient with a Developmental Disorder*. Wiley-Blackwell.

Stein et al. (2013). Oral Care and Sensory Over-responsivity in Children with Autism Spectrum Disorders. *Pediatric Dentistry*, 25(30), 230-235.

Tesini, D.A. (2010). The D-Termined Program of Repetitive Tasking and Familiarization (DVD). Hampton, NH: Specialized Care Co. Inc.

Tesini D.A. (2010). The D-Termined (TM) Program of Familiarization and Repetitive Tasking (Audio). *Practical Reviews in Pediatric Dentistry*, 24 (4), 30.



*Models for Clinical Care & Research:
Preparing Potential Research Participants for
the MRI Environment*

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The aim of Ms. Nguyen's presentation was to highlight model approaches to medical care access for adults with autism which could be adapted for use in various medical subspecialties. Ms. Nguyen is a clinical research coordinator in Dara Manoach's laboratory at Massachusetts General Hospital. The lab uses a multimodal MRI approach to evaluate whether individuals with autism spectrum disorders (ASD) differ from typically-developing individuals in brain function and structure and whether these differences may be related to certain genes and ASD symptoms. Ms. Nguyen's presentation focused on the steps the lab takes to familiarize and desensitize research participants with autism ages 8-25 to the MRI environment.

There are a number of practical and technical challenges that researchers face when doing an MRI on this population, including participant anxiety, participant's sensory sensitivities, time constraints in the MRI scanner, scanner background noise, and scanner motion.

In preparing an autistic patient for a clinical MRI, empathy and understanding an individual's sensory sensitivities are key. Researchers must understand each participant's preferred mode of communication and level of comprehension.

Participants are prepared for the scan using the MGH Autism Care Plan. Specific pictures and a map of the research center environment are provided so that the participants know what to expect. Informing the participant of where they will be, who they will meet, and what they will do, along with specific images of these things, will improve the chances of a successful MRI scan. It's also important to have a designated waiting area prepared for participants' arrival with little or no distracting sensory or environmental stimuli.

Ms. Nguyen shared a social story (geared towards children ages 8 years and older) that the lab uses. It details every step of the MRI experience for participants with photographs. It also includes examples of typical MRI sounds so participants can practice listening to these sounds before the study.

Ms. Nguyen discussed the use of the mock scanning machine and the importance of explaining precisely how the experience in the mock scanner will differ from the real experience. To allow participants time to process the information, mock scans and real scans are not performed on the same day.

Having a family member or trusted friend accompany the participant in the mock scanner is also recommended. Use of a weighted blanket for warmth and comfort is advised. Ms. Nguyen discussed the importance of researchers being able to recognize signs of anxiety, apprehension, or pain in participants.

Motion control is a challenge with this population. Recent research has suggested that any movement greater than an average of 0.004 mm changes the apparent functional connectivity in the brain. Using both behavioral and technical methods, Dr. Manoach's lab is trying to control for this source of instrumental error in their research efforts.

Ms. Nguyen discussed some of these approaches which include things such as showing clear vs. blurry images to demonstrate movement effects, using a digital camera to explain how the MRI works, using a coin to show how much movement is needed to affect data quality, and playing a "freezing game" or "statue game" when age appropriate. They are also developing a device that uses motion sensors in ear buds to sense participant motion and change the gradient of the scanner.

RELEVANT PUBLICATIONS

Agam, Y., Joseph, R.M., Barton, J.J.S., Manoach, D.S. (2010). Reduced cognitive control of response inhibition by the anterior cingulate in autism spectrum disorders. *NeuroImage*, 52, 336-347.

Hadjikhani, N., Joseph, R.M., Manoach, D.S., Naik, P., Snyder, J., Dominick, K., Hoge, R., Van den Stock, J., Tager-Flusberg, H., de Gelder, B. (2009). Body expressions of emotion do not trigger fear contagion in autism spectrum disorder. *Social Cognitive and Affective Neuroscience*, 4 (1), 70-78.

Thakkar K.N., Polli, F.P., Joseph, R.M., Tuch, D.S., Hadjikhani, N., Barton, J.J., Manoach, D.S. (2008). Response monitoring, repetitive behavior and anterior cingulate abnormalities in ASD. *Brain*, 131(9), 2464-2478.



Health Matters - Innovative Health Promotion Program

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The primary purpose of Dr. Mark's presentation was to introduce a model program for individuals with developmental disabilities (DD) titled, "Health Matters," and discuss the process of moving it beyond university-based research settings and into the greater community, including aging seniors with autism. Of central importance is providing individuals with DD with opportunities for community engagement through accessible and acceptable health care, health promotion, and disease prevention activities as well as the importance of evidence-based health promotion research, service learning, and training.

Dr. Marks shared a timeline of the Health Matters Program from research to practice. The first five-year cycle resulted in the publication of a health education curriculum. In 1998-2003, Dr. Marks and colleagues had a university-based trial to evaluate efficacy which included aging adults with intellectual and developmental disabilities (I/DD). In 2002, the Health Matters team received funding to do a Train-the-Trainers model in the community introducing health education, fitness, and nutrition programs. In 2010, with funding from the NICHD targeting Community-Academic Partnerships (CAP), an infrastructure was set up for bi-directional research to focus on translation and outreach with the Health Matters Program.

Dr. Marks summarized the results of the Health Matters research trials from 1998-2003. In the university-based, professional-led program, results included improved exercise attitude, improved exercise self – efficacy, increased outcome expectations, decreased cognitive-emotional barriers, improved life satisfaction, and improved cardiovascular fitness, strength and endurance.

For the community-based Train-the-Trainers program, she discussed the importance of providing realistic and adaptable structure within the unique constraints of the settings and the challenge of securing staff that could run these programs effectively. In the community-based program, they found improved perceived health behaviors, improved exercise self-efficacy, improved nutrition/activity knowledge, improved cholesterol and glucose levels, improved fitness/flexibility, and improved exercise/nutrition socio-environmental supports.

Widespread translation in CBOs (Community Based Organizations) for reach, adoption, implementation, and maintenance is challenging. They found that they needed to focus on CBO capacity, building staff capacity, and long-term maintenance of health/wellness goals for individuals with I/DD.

The Health Matters CAP aims for bi-directional infrastructure for community-based, participatory research, service learning and training. A comprehensive and relevant understanding of community issues of urgent concern is a priority for Health Matters.

The Health Matters Program takes an eclectic approach to the determinants of health. In addition to biological factors and behavioral practices, they have included socio-economic and environmental issues as well as access to health care services and programs in the model. Another area of focus is determining whether the right infrastructure is set up for staff to succeed. Universal design is the crux of the Health Matters program as health education materials must be accessible to a wide variety of people. Health Matters hopes to move beyond the day residential programs to work with local health departments.

Health Matters researchers found that day/residential programs often lacked infrastructure for recognizing signs and symptoms of disease in people with disabilities. Additionally, Dr. Marks was surprised to find that adults in these programs had never been pushed to exercise early in life. Physical fitness is an area that is often overlooked and should be an important component of day/residential programs moving forward. As we move to community recreational programs, we are systematically making it more difficult for children with intellectual disability to learn basic physical health and exercise skills.

With regard to defining community programs, the Health Matters program is actively looking to create community-based health promotion programs where the people are. As they work with organizations to build capacity, it's important to define what the community's view of health is. Finally, outreach to community for collaboration is a critical piece of sustainability. Dr. Marks emphasized the need for buy-in from stakeholders within the community to keep the program going and the importance of obtaining policy support to provide financial stability.

Dr. Marks discussed her concerns that people with disabilities will be left behind within the Affordable Care Act. Health promotion is an important piece of the Affordable Care Act, but we have to think strategically about how we can scale up health promotion in a systematic way.

Dr. Marks' presentation then shifted to health status of support employees. Caregiver stress and burnout are linked to poor health, emotional problems, unhealthy lifestyles, poor quality of life, and marital and family problems.

There is no data from the Bureau of Labor Statistics about the health of people who are providing direct care support to individuals with disabilities in day/residential programs. To address this priority, we need to understand what is happening to the health of direct support staff.

Health Matters researchers examined health behaviors of support employees who took the Train-the-Trainers program and taught a 12 week program, and found that staff has significantly improved social-environmental supports for nutrition, exercise outcome expectations, nutrition outcome expectations, increased their knowledge and amount of fruit and vegetable intake, and changed nutrition stage and behavior.

Dr. Marks introduced briefly four programs that are actively in the evidence-based pipeline.

- (1) The Train-the-Trainer Workshop is a structured workshop to organize, start, and sustain a tailored physical activity, nutrition, and health education program for people with I/DD. Other focuses include building capacity within the organization and developing self-determination and self-advocacy skills.
- (2) The Health Advocacy Program for Health Professionals was developed to increase understanding of healthcare experiences and needs among adolescents and adults with I/DD, and enhance personal control over health and health practices. The program is for allied health professionals and health care providers.
- (3) The Signs and Symptoms Program is focused on early recognition of health problems. The objectives are to instruct professional caregivers to observe early signs and symptoms of new or changing health concerns among people with I/DD and increase continuity of care within CBOs. The program is for professional caregivers, allied health professionals and health care providers.
- (4) The objectives of the Peer to Peer HealthMessages Program are to teach people with I/DD and supports to become Healthy Lifestyle Coaches and Mentors to implement a 12-week HealthMessages program for peers and enhance health advocacy skills. The program is for people with I/DD and support staff.

With regard to strategic plans, Health Matters is working with Cornell University to conduct organization assessments. In evaluating organization needs and capacity, they examine culture, policies, commitment, resources, and knowledge and self-efficacy. The intent is to understand where organizations feel they are in terms of these domains and come up with a strategic action plan.

Employee wellness programs are linked to organizational outcomes and a healthier workforce linked to higher job satisfaction and performance. In the future, the hope of the Health Matters program is to link organizational culture with employee retention.

Dr. Marks shared findings from the Health Matters' organization assessments. They have found low access to internal and external resources, low levels of perceived organizational commitment and policies for health promotion, average perceptions related to policy and self-efficacy, and high levels of positive attitudes towards nutrition and exercise for people with I/DD.

A goal of the program is for the community partners to dispel myths and change attitudes. Through dissemination of their research results, Health Matters hopes to change attitudes in the community so people understand that individuals with I/DD see themselves as healthy as opposed to 'sick', chronic conditions are lifestyle-related as opposed to disability-related, and health promotion strategies can be effective in changing lifestyle habits.

RELEVANT PUBLICATIONS

Marks, B., Sisirak, J. & Heller, T. (2010). Health Matters: Exercise and Nutrition Health Education Curriculum for Adults with Developmental Disabilities. Philadelphia, PA: Brookes Publishing.

Marks, B., Sisirak, J., & Heller, T. (2010). Health Matters: Establishing Sustainable Exercise and Nutrition Health Promotion Programs for Adults with Developmental Disabilities. Philadelphia, PA: Brookes Publishing

Marks, B., Sisirak, J., & Chang, Y.C. (2013). Efficacy of a Train-The-Trainer Program to Improve Health Status for Adults with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities*, 26(4), 319-334.

Heller, T., Hsieh, K., & Rimmer, J.H. (2004) Attitudinal and psychological outcomes of a fitness and health education program on adults with Down syndrome. *American Journal on Mental Retardation*, 109, 175–185.



Mixed Income, Supportive Senior Housing as a Model

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The aim of Mr. Fishman's presentation was to spark discussion about senior community models that might be relevant to older adults with disabilities. The aging and disability fields have many similar primary goals including living on your own terms; adding value to society, family and friends; building social capital; and maintaining physical health and cognitive functioning. The convergence of these two fields has been reflected by the creation of the Administration on Community Living and the mushrooming of the managed care for dual eligibles (both those 65 and older and younger adults with disabilities).

In the US, we are spending 18% of our gross domestic product on healthcare. Unless we radically change that system, we'll be spending 25% of our GDP by the year 2030. We are already spending 1.5 times more than our closest competitor, Canada, and about twice as much of GDP as Western Europe. If we get to the point at which we are spending near one in every four dollars in the US economy on healthcare, there will be little left for everything else. To be realistic, we have to plan for a world in which there is less government funding and even more reliance on families.

Mr. Fishman's presentation highlighted the example of Hebrew Senior Life (HSL), a nine-site system of senior housing and healthcare, serving 5,000+ seniors of all religions, ethnicities, and incomes in the Greater Boston area. HSL is also home to one of the largest geriatric research centers in the US, a major academic teaching center, and is an affiliate of Harvard Medical School.

The Hebrew Rehabilitation Center offers long-term care, adult day care, and post-acute rehabilitative care and is also where academic teaching takes place. HSL trains over 900 students in the field of geriatrics annually in numerous disciplines. Training is also provided through health career internships and career ladder scholarship programs.

The Institute for Aging Research is the largest provider-based geriatric research center in the US whose essential qualities include an applied setting, interdisciplinary studies, and a Harvard Medical School affiliation. Research focuses on the four high-impact areas of mobility, cognition, palliative and end-of-life care, and quality of healthcare.

For the past decade or more, HSL has been pursuing a new model of senior care. Usually, senior organizations view the world through the lens of long-term care, with some supportive housing, and even less community-based services. In contrast, HSL downsized long-term care, changed the way they

provided it, adding rehabilitative services and increasing the amount of supportive housing, research and community-based services.

Affordable housing sites in the Boston area included the Jack Satter House in Revere, MA, the Simon C. Fireman Community in Randolph, MA, Orchard Cove in Canton, MA and NewBridge on the Charles in Dedham, MA.

Mr. Fishman described the Center Communities of Brookline comprising three buildings with a total of 517 units. Residents are charged a mix of market rate, moderate, low, and very low income rents within these communities. Although it had been anticipated that a mixed-income model would not work, it has been a successful approach.

HSL apartment-houses for seniors are enriched with substantial services, reflecting their belief that even very frail elders can be supported in the community if the housing has the right set of services. For example, 100 Center St. houses 223 residents ages 39-101, of which 42% are age 90 and older.

The enriched, supportive services that are provided include social services/care management, transportation, HSL medical group, and HSL home care. There is a team of social workers who assist residents with emotional, psychological and financial issues. There are busses that take residents to shopping and cultural events. They installed a primary care practice which provides 24-hour home care and serves residents as well as seniors in the neighborhood.

100 Center St. has a fitness center with trained staff. There is a Resident Assessment Program with a Wellness Coach that uses the evidence-based COLLAGE program (physical, cognitive, emotional assessment) and Vitality 360 Program. "Get Up & Go" is an exercise program open to seniors in the CCB neighborhood.

In terms of other CCB supportive services, there is also a full-service meals program offered to all residents. Having a dining program is crucially important to senior living. Additionally, they offer resident programming and education.

Mr. Fishman believes that the senior housing model in the US should move more towards an integrated community housing model that is more person-centered, community-integrated, and inclusive. To create opportunities for meaningful community involvement, it is important to make center activities accessible to those in the larger community.

Within Center Communities of Brookline, roughly 80 residents are younger adults with disabilities which has provided opportunity for this population to interact with a typical senior population. Only a few of those 80 have crossed the age 65 line. This may be the first cohort of aging adults with disabilities at HSL.

RELEVANT PUBLICATIONS

Fishman, L. (2004, July 6). Turning the senior care 'pyramid' upside down. *The Boston Globe*.



*The Green House Project:
Meaningful Transformation that Creates Lives Worth Living
(sponsored by Robert Wood Johnson Foundation)*

**Susan Frazier, RN, MA
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The primary aim of Ms. Frazier's presentation was to highlight an innovative model approach to long-term care which could be adapted for use with an aging autistic population. The hope is that greater awareness of the Green House Model might spark discussion and idea generation, and widen perspectives of possible long-term residential solutions for those with autism and related disabilities. Currently, there are 152 Green Houses operating in 25 states. There are 150+ homes in development in six additional states.

The Green House Model provides an optimal setting for residents of all ages to grow. It is transforming the way we think and feel about aging and potential organizational structures. In the Green House Model, they strive to create a real home, not just a "home-like" environment.

What are the characteristics of a real home? To create warmth, a smaller size is better. To utilize technology to its fullest advantage, most Green House homes use electronic medical records and wireless paging devices to keep noise to a minimum. The Green House Model encourages the mindset that growth is possible regardless of age or cognitive decline. It is based on the belief that all people are creative, resourceful, and whole, and elders can grow in an environment in which they are deeply respected and there is a fundamental level of worth given to each individual.

The homes are designed to look similar to those in the surrounding community. Privacy is key. All Green House homes have private rooms and a private bath. The Green House model is about intentional community, creating community within the house and providing opportunities for staying connected to the outside community.

One of the Green House Model's core aims is to create a meaningful life. Autonomy, control, and choice about how, where, and what to do with one's life are universally important to growing and thriving.

Green House emphasizes the importance of relationships and facilitates "deep knowing" and reciprocity between residents and support staff. It places decisions with elders or as close to them as possible. Green House homes support a life worth living through engagement, enjoyment, sense of purpose, and continued growth.

Another priority of the Green House Model is to have empowered staff. Ms. Frazier emphasized the importance of creating conditions for empowerment so that direct caregivers are able to more deeply know the elders, and be able to have access to the necessary resources to support meaningful lives for them.

In the Green House Model's reframed organizational paradigm, the elder is at the center of the organizational chart. It is about collaboration with the direct caregivers and elders and allowing them to actively participate in the decisions. This requires us to redefine the roles and responsibilities of the direct care workers, nurses and clinical support team.

The Green House Model is a research, evidence-based model. Research published in 2007 examined satisfaction and clinical outcomes. Researchers looked at Green House homes compared to the traditional nursing homes and found that on the basis of quality of care and quality of life the Green House Model provides an attractive alternative to traditional skilled nursing care.

A later study (2011) looked at staff time and clinical outcomes. In the Green House homes, the direct care worker also takes charge of cooking, housekeeping, and laundry. Does this compromise the amount of direct care time provided? In actuality, when direct care is carefully defined, it was found that there were 30 minutes more direct care time in a Green House home despite tending to ancillary functions. In fact, by these measures, there was four times more engagement between elders and direct care staff in Green House homes.

Another study examined nursing care quality and the relationship between nurses and direct care staff, reporting that the communication between the two was seamless in Green House homes. What was striking was how quickly potential medical and communication problems were detected as a result of the close relationship between elders and staff.

The compelling facet of the Green House Model was illustrated by a consumer research survey conducted by Edge Research. After caregivers saw a four-minute video about the Green House Model, 97% indicated that the Green House Model addressed their greatest concerns about nursing homes; 90% thought that it was important for providers to build more Green Houses in their community; 68% of the caregivers believed that Green Houses were better for a relative than being cared for at home; 61% of the caregivers believed that Green Houses were better than adult day care; 73% would drive 15-60+ miles to receive Green House services; and 60% would pay 5%-25%+ more to have their loved one in such a model.

RELEVANT PUBLICATIONS

Kane, R., Cutler, L., et al. (2007). Resident Outcomes in Small-House Nursing Homes: A Longitudinal Evaluation of the Initial Green House Program. *Journal of the American Geriatric Society*, 55(6), 832-839.

Kane, R., Cutler, L., et al. (2008-2009). Effects of Green House® Nursing Homes on Residents' Families. *Health Care Financing Review*, 30(2), 35-51.

Sharkey, S., Hudak, S., et al. (2011). Frontline Caregiver Daily Practices: A Comparison Study of Traditional Nursing Homes and The Green House Project Sites. *Journal of the American Geriatrics Society*, 59(1), 126-131.

Jenkins, R., Sult, T., et al. (2011). Financial Implications of THE GREEN HOUSE® Model. *Senior Housing & Care Journal*, 18 (1), 3-21.

Bowers, B., Nolet, K. (2009). Exploring the Role of the Nurse in Implementing THE GREEN HOUSE® Model. University of Wisconsin. Unpublished.



*Generations of Hope
Multigenerational Communities
(sponsored by Kellogg Foundation)*

**Brenda Eheart, PhD
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Hope Meadows is an innovative model for multigenerational housing which could serve as an example for serving the aging autistic population. Founded by Dr. Eheart more than thirty years ago with funding from the State of Illinois, Dr. Eheart envisioned a support community for adopted individuals in the foster care system.

The insecurity of not knowing with whom or where they will be living is a common theme for children in foster care. Hope Meadows provides a mechanism for resident families who could always be there to care for these children and offer a sense of security. It is a community of about twelve families who have adopted children from the foster care system and who are committed to supporting each other.

Dr. Eheart described the challenges she faced in securing surplus military housing for Hope Meadows with 80 housing units on 20 acres. Realizing that only twelve units would be needed to house the families, she made the rest of the units available to older adults for a reduced rent, provided that they could volunteer six hours per week to support the children, parents, and community. In practice, the families, each with four adopted children, live in units of 3200 sq.ft., and the elder residents, who share in the recreational and community life of the residents live in 1600 sq.ft. units.

Dr. Eheart discussed the need to adapt their housing to fit the needs of the residents over time. A challenge that they have encountered is that as elder residents become more aged and frail, the large size of these multi-story units can no longer accommodate some of them. Because it is so critical to keep these elders in the community, they are creating Hope Houses, single-story units designed for frail elders.

Based on the video shown at the meeting, this purposeful, intergenerational model is the type of community that can provide a daily environment of connection, engagement, and care.

The success of this program relies on training residents to work within this philosophy of shared responsibility and support, including a group of parents empowered with the knowledge and skills to parent children with troubled pasts.

In March 2013, Chicago Magazine ran a story titled, "When Autistic Children are Children No More". Author Cassie Walker Burke wrote that what people with developmental disabilities need most is a place where they can build relationships and friendships.

Developing these intergenerational relationships over the long-term is at the heart of Hope Meadows. Formal institutions have traditionally not been designed to provide what a caring extended family can do and perhaps that's where this model offers a glimpse of how to fill this pressing need.

Dr. Eheart discussed several other intentional multigenerational communities in development, including a community for wounded veterans and their families in New Orleans, a community for young mothers exiting foster care at age 21 in Washington, DC, a community of incarcerated young mothers re-entering society in Virginia, and a community for frail elders recently diagnosed with Alzheimer's or dementia on Bainbridge Island.

Generations of Hope Development Corporation has received numerous inquiries about building intergenerational communities for adults with disabilities. Spearheaded by David Green, a parent of an adult with autism, Osprey Village, an inclusive, intergenerational residential community to support developmentally disabled adults and their families, is expected to open in 2015 in Bluffton, South Carolina. In Spokane, Washington, there is another community for individuals with disabilities in the early stages of development being spearheaded by another parent of an adult son with autism.

Today, as we think about aging well with autism, the time is right to think about the power and the promise of community and connection. This is one of the most promising ways for beginning to address the concerns of the aging population of individuals with autism.

RELEVANT PUBLICATIONS

Power, M. B., Mitchell, E. T., **Eheart, B. K.**, & Hopping, D. (2011). The power of language: Practice in a shared site. *Journal of Intergenerational Relationships*, 9(3), 281-292.

Eheart, B.K., Hopping, D., Power, M.B., Mitchell, E.T., & Racine, D. (2009). Generations of Hope Communities: An intergenerational neighborhood model of support and service. *Children and Youth Services Review*, 31(1), 47-52.

Power, M. B., **Eheart, B. K.**, Racine, D., Karnik, N. S. (2007). Aging well in an intentional intergenerational community: Meaningful relationships and purposeful engagement. *Journal of Intergenerational Relationships: Programs, Policy and Research*, 5(2), 7-25.

Eheart, B. K., Power, M. B., & Hopping, D. E. (2003). Intergenerational programming for foster-adoptive families: Creating community at Hope Meadows. *Journal of Intergenerational Relationships: Programs, Policy and Research*, 1(1), 17-28.

Eheart, B. K., & Power, M. B. (2001). From despair to care: A journey of the old and the young at Hope Meadows. *Children and Youth Services Review*, 23 (9/10), 691-718.

Hopping, D., & **Eheart, B. K.** (Eds.). (2001). Generations of Hope: An intergenerational model for foster care and adoption. *Children and Youth Services Review*, 23 (9/10), 675-810.

DISCUSSION SUMMARY

MEDICAL CARE

DEMOGRAPHICS AND PREVALENCE

- There was some discussion regarding how the new Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V) criteria will affect prevalence rates. The members of the working group who created the new criteria published studies which showed that prevalence rates would remain comparable. In US and Canadian clinical sites that treated pediatric populations, they found that the prevalence rates were generally comparable between DSM-IV diagnoses of Pervasive Developmental Disorder (PDD) conditions and DSM-V Autism Spectrum Disorder (ASD) diagnoses.

In individuals who had been diagnosed with Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), a subset of those may be individuals who have social impairments but lack the restrictive, repetitive behaviors, activities, and interests. That cohort may be captured by a new diagnosis called social communication disorder, a new addition to DSM-V. There is some speculation that many who may lose ASD eligibility will shift over to that diagnosis.

The Arc of Massachusetts is attempting to accurately estimate the incidence of autism in Massachusetts. They believe it is about 1.1% of the general population or 75,000; however, the 1 in 50 statistic from the recent Centers for Disease Control and Prevention (CDC) parent study essentially doubles that figure.

The Arc is interested in crafting legislation to set up a confidential data collection repository within Health and Human Services in Massachusetts and is looking for guidance from other states that have maintained a similar registry. Many states are cautious of creating such databases because the waiting list data they currently keep has been used for lawsuits across the country.

HEALTHCARE AND MEDICAL ISSUES

- There is currently little data regarding the specific age-related, physical health issues aging individuals with autism will face, and this is crucially needed by service providers specifically. Moving forward, it will be important to define clearly demarcated groups and look at the trajectories of each.
- Related to secondary conditions and ASD, some expressed concern over the lack of support by the Department of Mental Health (DMH) and failure to acknowledge comorbidity of ASD with mental health. DMH will often reject an application because they ascribe difficulties to a primary diagnosis of ASD, and many patients fall through the cracks because DMH and Department of Developmental Services (DDS) won't take them.

A large problem is lack of consistent research regarding the percentage of people with ASD and mental health issues. Another issue is that many of the screening instruments are not well-constructed to assess individuals with varying levels of cognitive impairment and these instruments may not be effective in terms of determining the prevalence rates of these comorbid mental health issues. Finding psychiatric specialists who can provide care across the lifespan presents another challenge.

- The Massachusetts chapter of the National Developmental Disability Nurses Association and the Massachusetts Arc are in the process of conducting healthcare assessments of autistic individuals in the community. They are working with five other states to gather this information which will eventually be reported to the CDC.
- More research is needed to determine the cumulative effect and possible consequences of lifelong medications for managing autism spectrum disorder symptoms. Since some of the common psychiatric medications are relatively new, there hasn't been much research on the effect of their long-term use.
- Families have expressed frustration over the fact that they can't find primary care physicians for their adult family members with autism so many are still seeing pediatricians at age 30+. There needs to be a fundamental change to the medical and dental professions that will ensure increased training in basic medical/dental schools in working with a patient population with disabilities.

The Lurie Center for Autism (Massachusetts General Hospital) did an adult outreach project led by their adult internist, Dr. Susan Connors. She and a volunteer over the past two years have started doing rounds in local community-based physician offices in which they are introducing physicians to autism and providing consulting services and training in how to care for these individuals. Through this project, they have been able to place 60 individuals in primary care practices.

HEALTH PROMOTION

- Since the majority of caregivers of people with autism are family members, and this number might grow due to the switch in federal/state reimbursements, how can the health promotion interventions be made more applicable to families? In the Health Matters Train-the-Trainers program, they are hoping to adopt a parent-centered approach in which they try to understand the interests and needs of the family caregivers in their real, day-to-day life. An intervention aimed at improving the health status of the family caregivers was suggested.

POLICY ISSUES

- Do you anticipate any movement in terms of policy guidelines or requirements to start thinking about self-determination in the real sense in which the individual takes control over his/her own life as opposed to the responsibility being placed on the family? A lot of policy initiatives contain the terms “self-determination” and “person-centered planning” but whether the people are actually doing it is a different question entirely. The aging and disability communities seem to differ in their definitions of these terms.

POST-SECONDARY EDUCATION AND ADULT ACTIVITIES

- Of the 750,000 students with disabilities at colleges in the US, over half of them are at community colleges which in particular lack the resources to create programs tailored to the needs of students with autism. Another significant challenge is that employers are reluctant to hire these graduates and many people fall through the cracks.
- Recognized as a national model, DriveWise, developed by the divisions of Cognitive Neurology and Occupational Therapy at Beth Israel Deaconess Medical Center (Boston, MA), offers an objective evaluation of driving safety for people of all ages who have experienced neurological, psychological and/or physical impairments. The DriveAdvise program received funding to create a video on Asperger's and driving and found that there is a lack of research regarding the type of instruction that these individuals need.

RESEARCH GAPS

- Are there studies which might indicate whether there is a significantly higher percentage of autistic individuals among those who are in prison or homeless? In a study at North Carolina prisons, Susan Parish and colleagues found a high prevalence of people with developmental disabilities; however, they did not specifically look at autism. About 50% of prisoners in the US have developmental disabilities, but the group was not aware of studies specifically looking at autism rates in prisoners.
- Research should focus on what happens in midlife and the occurrence of midlife crises for the aging autistic population.
- Where are these people with autism over the age of 55? There are presently 8,000 people in the Massachusetts General Hospital (Boston, MA) system who have some kind of autism diagnosis. This presents an interesting opportunity to understand using bioinformatics the heterogeneity of this population.

HOUSING AND LONG-TERM CARE

HOUSING MODELS

- When trying to replicate the Hope Meadows community model elsewhere, what evidence is there that the general senior population will want to participate in this kind of community? Osprey Village (the non-profit organization which is developing an intergenerational community to support developmentally disabled adults) conducted market research which showed that there are large numbers of people in the greater community who would be interested in participating in an intentional multigenerational community. Dr. Eheart is convinced that aging boomers want meaning and purpose in their lives and that there will be enough interest.
- What will it take for aging seniors with autism to be included in an integrated, enriched senior community? The aging field seems to be moving towards creating diverse communities. For example, Hebrew SeniorLife (HSL, Roslindale, MA) successfully integrated people of low- and market-rate income into a single community, and there are seniors with autism living in HSL's Center Communities of Brookline. The challenge is that we are just beginning to understand aging in ASD and our knowledge base is small.

RELATED PROGRAMS IN DEVELOPMENT

- Cardinal Cushing Centers (Hanover, MA) has embarked on a project to transform their campus into an intergenerational village where people of all ages and abilities can engage with one another and neighboring communities in a safe, supportive setting. They hope to create an engaging community that offers state-of-the-art services to those with developmental challenges, while providing a sustainable, enriching environment where people of all ages will experience enhanced positive interactions. They have received funding from the Federal Home Loan Bank and the campus will include 37 affordable housing units. Adjacent to the campus, there are 150 units of elderly, low-income housing and 200 acres of land that have yet to be developed.
- The Madison House Autism Foundation (Rockville, MD) has created The Autism Housing Network, an interactive, virtual platform (in the beta stage) for those interested in creating and sharing housing options and resources for autistic adults and others with intellectual disability and developmental disabilities (I/DD). A challenge they have faced is that Centers for Medicare & Medicaid Services (CMS) and Housing and Urban Development (HUD) consider many communities of people living together in a congregate setting as an "institution" and use that as justification to cut off funding. This is a problem because many of those with ASD must live in a congregate setting due to the high cost of services. CMS will be coming out with a ruling in Fall 2013 and it is a priority of the Madison House Foundation to make sure that "community" will be defined as broadly as possible.

AFFORDABILITY OF HOUSING

- Affordability of housing continues to be a primary concern for the aging autistic population. The most important thing that the autism community can hope for is funding for Section 8 vouchers because that helps to ensure financial independence for the ASD population. There are many on the spectrum who use Section 8 vouchers to own their own homes, rent from parents or elsewhere, etc.

CONCLUDING REMARKS

Aging well with autism into the retirement years indeed poses many questions for individuals and their families, as we heard from our presenters and from audience members during the discussion period. These are not one-dimensional issues because health care, recreation, and companionship are inextricably linked to residential setting, planning for which is fraught with worry on many fronts. Co-housing is proving to be a workable model, not just for the post-retirement population in general, but for others, such as foster care families and those with diverse disabilities. At the center of each of the flourishing programs presented there is often an individual, driven by personal need to care for a family member, or just someone who cares enough to do something in the face of seemingly depressive facts, who gathers the resources and sets the agenda for change. Often overlooked in providing for health care is the lack of experience of medical practitioners, but there are successful examples in the practice of dentistry, and in preparing subjects for neuro-imaging research, where prior conditioning of expectations on the part of patient and doctor alike can have good outcomes. In the search for a biomedical explanation for autism new directions often open up when bridges are made to other fields, such as cancer research, where progress has been rapid. This meeting provided an encouraging glimpse of how life planning for aging adults with autism can benefit from the robust interchange of ideas between progressive senior and autism communities.

ADDITIONAL RESOURCES

Collins-Bride, G. (2011). Health Care Maintenance Guidelines for Adults with Developmental Disabilities. Retrieved from: http://developmentalmedicine.ucsf.edu/odpc/docs/pdf/practice_pearls/health-care-maintenance-guidelines-adults-with-dd.pdf

Ellison, N, Rosielle, D. (2007). Palliative Care for Adults with Developmental Disabilities. Fast Facts and Concepts. Retrieved from: http://www.eperc.mcw.edu/EPECRC/FastFactsIndex/ff_192.htm

Griswold, K.S., Goldstein, M.Z. (1999). Issues Affecting the Lives of Older Persons with Developmental Disabilities. *Psychiatric Services, 50*(3), 315-317.

Kingsbury, L.A. (2008). People Planning Ahead: A Guide to Communicating Healthcare and End-Of-Life Wishes. American Association on Intellectual and Developmental Disabilities.

Krogman, L. (2005). The Nurse Practitioner's Role in Caring for Adults with Developmental Disabilities. Community Health Care for Adults and Elders with Developmental Disabilities Research and Training. Retrieved from: https://depts.washington.edu/aedd/nurse_pract_text.htm

Massachusetts Department of Developmental Services. (2012). Massachusetts Department of Developmental Services Adult Screening Recommendations 2012. Boston (MA): Massachusetts Department of Developmental Services.

Messinger-Rapport, B.J., Rapport, D.J. (1997). Primary Care for the Developmentally Disabled Adult. *Journal of General Internal Medicine, 12*(10), 629-636.

Moriston, S.G. (2007). Forgotten Citizens Disparity in Health Care: Inadequate Formal Nursing Preparation on Issues of Routine Cancer Screening for Women with Developmental Disabilities. *International Journal of Nursing in Intellectual & Developmental Disabilities, 4* (1).

Rimmer, J. (2005). Introduction to Achieving A Beneficial Fitness for Persons with Developmental Disabilities. Retrieved from: <http://www.ncpad.org/104/795/Developmental-Disability-and-Fitness>

Salvatori, P., Tremblay, M., Tryssenaar, J. (2003). Living and Aging with a Developmental Disability: Perspectives of Individuals, Family Members, and Service Providers. *Journal on Developmental Disabilities, 10*(1): 1-19.

Shireman, TI, A. Reichard., Backes, JM, & Greiner, KA. (2010). Quality of Diabetes Care for Adults with Developmental Disabilities. *Disabil Health J, 3*(3), 179-85.

Tyler, CV, Zyzanski, SJ, Panaite, V., Council, L. (2010). Nursing Perspectives on Cancer Screening in Adults With Intellectual and Other Developmental Disabilities. *Intellectual and Developmental Disabilities, 48* (4), 271-277.

Wilkinson, JE, Culpepper, L., Cerreto, M. (2007). Screening Tests for Adults with Intellectual Disabilities J. *Am. Board Fam. Med., 20*(4), 399-407.