

NLM

FAMILY FOUNDATION

Living with Autism in Adulthood

July 18, 2012

The Lurie Institute for Disability Policy
The Heller School for Social Policy and Management
Brandeis University
Waltham, MA



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Opening Remarks

Susan L. Parish, Ph.D., MSW
Heller School for Social Policy and Management, Brandeis University

Building Community for Adults with Autism

Denise D. Resnik
Southwest Autism Research & Resource Center (SARRC)

Many Pathways to Employment

Bill Kiernan, Ph.D.
UMASS Boston, Institute for Community Inclusion

Aging Well with Autism Spectrum Disorder

Tamar Heller, Ph.D.
University of Illinois, Chicago

In Their Own Words: Living with Autism in Adulthood

featuring the perspectives of Larry Bissonnette, Jamie Burke, Sue Rubin, and Tracy Thresher

Parent-Led Initiatives: Autism Housing Pathways

Catherine Boyle
Autism Housing Pathways

Parent-Led Initiatives: A Parent's Guide to Autism Services

Anne Larkin, Ph.D.
Lesley University

Parent-Led Initiatives: Living, Learning and Linking Adults with Autism and Other Developmental Disabilities

Maureen Manning
3LPlace

Research on Young Adulthood: New Findings, New Directions

Paul T. Shattuck, Ph.D.
Washington University in St. Louis

Break Out Sessions: Policy Recommendations

Living with Autism in Adulthood

Adult individuals with autism and their families face many challenges, not the least of which is the transition to adulthood and the urgent need to find suitable homes, employment, and social opportunities. Recently, the NLM Family Foundation sponsored a special one-day workshop, "Living with Autism in Adulthood," at the Heller School for Social Policy and Management at Brandeis University in Waltham, MA. The purpose of the meeting was to explore approaches for advancing progressive public policy initiatives pertinent to solving the problems faced by adults with autism. Participants included family members, advocates, professional caregivers, and academic researchers at the forefront of providing the studies that policy makers need.

Dr. Susan Parish, the Nancy Lurie Marks Professor of Disability Policy at the Heller School, set the stage for the day's activities by reviewing the latest data on the incidence of autism and the growing numbers of adults requiring new programs. The rest of the day was organized around lectures by nationally recognized experts, a special video presentation of adults with autism telling of their experiences, hopes and dreams, and several personal accounts of parent-led initiatives aimed at filling gaps between publicly provided services and the needs of their children. At the end of the day, the 75 audience participants broke into five focus groups, led by the expert presenters, to come up with a list of policy recommendations.

The first speaker, Denise D. Resnik, is an internationally recognized pioneer in imagining better lives for persons with autism. She spear-headed the development of the Southwest Autism Research & Resource Center (SARRC), one of the first comprehensive community-based programs serving the complex needs of individuals with autism. SARRC has grown from its original focus on early intervention, educator outreach, and parent empowerment to include job and life skills training programs, and, recently, a city-wide plan for residential living and work in Phoenix, Arizona. After a quarter of a century of leadership, SARRC is sharing the lessons it has learned with centers forming across the nation, by offering workshops and publishing valuable studies and educational materials.

Self-definition, feelings of worth, and a sense of belonging often hinge on having a meaningful engagement with voluntary or paid work outside of the home, having a place to go to on regular basis where one can contribute to society. Dr. William Kiernan, Director of the University of Massachusetts Boston Institute for Community Inclusion, presented a comprehensive analysis of the employment status of persons with disabilities and the obstacles they face in gaining employment. He gave several examples of progressive programs by the Federal Government and large national employers that are opening up opportunities for persons with disabilities to demonstrate their capacity for hard work and creatively contributing to the life of the workplace. Dr. Kiernan discussed the importance of programs to match individuals with jobs and internships.

Topics rarely discussed are: 'what happens to older adults with autism?', 'where do they live?', 'what kinds of services do they have?', 'how do they spend their time?' Dr. Tamar Heller, Director of the Institute on Disability and Human Development at the University of Illinois at Chicago, took on these questions. She described the various strategies that families have employed to provide care for their family members with autism, especially focusing on those 60 years of age and older. Dr. Heller reviewed the health problems faced by persons with autism, such as obesity, side effects of long-term medications, and nutritional issues, and described the program she has developed to address them. She called for more research to understand how aging families, especially adult siblings and their family member with autism, are together addressing the additional responsibilities associated with life planning when their aging parents can no longer do so or are deceased.

National policy-makers need data to make laws. While U.S. law guarantees access to free public education for

persons with disabilities, there are no corresponding entitlements (speech therapy, mental health counseling, social work case management) for adults. Dr. Paul Shattuck, Washington University, St. Louis, presented the first results to emerge from a ten-year nationwide longitudinal study of students with disabilities leaving high school. The major conclusion of this study was that the rates of service provision dropped dramatically once school district support dropped out. Dr. Shattuck also looked at employment statistics and measures of social isolation between persons with autism compared with those having other disabilities, finding far greater obstacles to participating in work-related or social activities.

An up-note was sounded at the meeting via a video presentation, "In Their Own Words: Living with Autism in Adulthood", that featured the perspectives of Larry Bissonnette, Jamie Burke, Sue Rubin, and Tracy Thresher, who, each in their own way, despite daunting obstacles, learned how to express themselves. These video narratives present a powerful counter-example to many commonly-held views on the kind of limited employment and life opportunities autistic individuals hope to find in adulthood.

Parents have always been at the forefront of creating programs for their disabled children. Three speakers, Maureen Manning (3LPlace), Anne Larkin, Ph.D. (Professor Emerita, Lesley University) and Catherine Boyle (Autism Housing Pathways) talked about locally-developed models for preparing for adulthood and their personal experiences at networking and advocating for their children.

As the day drew to a conclusion, the presenters chaired break-out sessions that offered audience members the chance to have their questions aired and to contribute their ideas and insights for group consideration. The breakout groups (Health Care, Family Support, Housing, End-of-Caregiving Planning for Families, Employment) each framed a set of key policy recommendations which they brought back to the full session.

Opening Remarks
Susan L. Parish, Ph.D., MSW
Heller School for Management and Social Policy, Brandeis University



Dr. Parish spoke about the demographic changes that we're facing on a national level in the US in terms of the aging of the population with autism. After researching this issue, she found that we still really don't know much about the population of adults with autism who are aging. There are no national data out there that can give us a credible picture of the strengths and needs of the adult population with autism.

We have had a significant increase in the general, non-disabled population that is elderly as the leading edge of the baby boom has reached age 65. People ages 65 years and older represented 9% of the population in 1960 and represented 12% of the total population in 2000. This age group is projected to be about 20% of the general population in 2030. Unfortunately, we don't know the contours of the aging disabled population on a national level which indicates a clear need for more research in this area.

According to Dr. Parish, Tamar Heller's group has projected that between 2010 and 2030 there will be a 65% increase in the population of adults with developmental disabilities who are living at home with family caregivers. This is staggering because of the crisis that is going on in all of the states in terms of their Medicaid budgets. The primary source of funding that we have to provide residential and other ongoing supports to people with autism and their families is evaporating as states make challenging and difficult decisions to make their Medicaid cuts. There is an imminent need for thoughtful policy solutions and advocacy to support the families who are caring for adults with autism as this population ages.

Susan L. Parish, PhD, MSW is the Nancy Lurie Marks Professor of Disability Policy and Director of the Lurie Institute for Disability Policy at The Heller School for Social Policy and Management, Brandeis University. Her research examines the health and financial well-being of children and adults with disabilities, as well as their caregiving families. She is particularly interested in family support, the health of women with intellectual disabilities, and the impact of health and poverty policies on people with disabilities and their families.

She is currently principal investigator on a study funded by the US Department of Education (NIDRR) that is testing an intervention to increase cervical and breast cancer screening of women with intellectual disabilities. She is co-principal investigator on a HRSA-funded study of the health care access of children with autism. At the Heller School, she directs the doctoral program in social policy. Parish teaches classes in disability policy and both quantitative and qualitative research methods.

She has won numerous awards for her teaching and her research, including the Padgett Early Career Achievement Award from the Society for Social Work and Research and the Research Matters! award from the Arc of the United States. She is a Fellow of the American Association of Intellectual & Developmental Disabilities.

Building Community for Adults with Autism
Denise D. Resnik, Co-Founder
Southwest Autism Research & Resource Center (SARRC)



The Southwest Autism Research & Resource Center (SARRC) is dedicated to advancing discoveries and supporting individuals with autism spectrum disorders (ASDs) throughout their lifetimes. The internationally recognized community-based nonprofit has been empowering individuals and families with early intervention, educator outreach, and parent empowerment initiatives since 1997. In 2011 alone, SARRC served 1,200 children, youth, and adults; 5,000 parents and family members; and 3,700 education and medical professionals.

SARRC's early intervention programs and nationally recognized model programs are housed at its Phoenix, AZ-based, 18,000-square-foot Harrington Campus for Exceptional Children, which serves communities throughout Arizona and across the U.S. through training, direct service, and tele-therapeutic programs.

SARRC has also been maturing with the ASD population through the development of a robust Vocational & Life Skills Academy. More than 85% of SARRC's program participants (clients) are gainfully employed in full-time and part-time positions. Programs for teens and adults are represented throughout Greater Phoenix at dozens of employment and volunteer sites and within SARRC's 10,000-square-foot Sanders Center for Autism Studies.

The co-location of SARRC's Vocational & Life Skills Academy with its Center for Autism Studies demonstrates SARRC's commitment to advancing research for adults living with autism. The Sanders Center is involved with molecular and genetic studies, clinical research, and pharmaceutical trials. SARRC is one of the most robust sites in the U.S. for the recruitment and enrollment of subjects in national pharmaceutical trials and one of the largest contributors to the Autism Genetic Resource Exchange (AGRE).

SARRC's research and school- and community-based programs have set the stage for the introduction of a replicable, adult residential model made possible through private/public/nonprofit collaboration.

SARRC co-founder, Denise D. Resnik, is a pioneer in innovative approaches to adult residential concerns. She has served as an active leader and volunteer for SARRC and national autism interests for nearly two decades. The mother of a 21-year-old son with autism, she is also president of her own marketing agency, DRA Strategic Communications, founded in 1986 and focused on the real estate industry. In addition, her firm provides significant in-kind support to SARRC and many other nonprofits. Denise is a member the Autism Speaks Housing Committee, Advancing Futures for Adults with Autism (AFAA) Leadership Council and the National Association of Residential Providers for Adults with Autism (NARPAA). She has served as a member of the Interagency Autism Coordinating Committee (IACC) of the National Institutes of Health, a member of the IACC Services Subcommittee and the NIH Autism Strategic Plan Workgroup.

Denise is the editor of *Opening Doors: A Discussion of Residential Options for Adults Living with Autism and Related Disorders*, a collaborative study published in 2010 by SARRC, the Urban Land Institute (ULI) Arizona, the Arizona State University (ASU) Stardust Center for Affordable Homes and the Family and the ASU Herberger Institute School of Architecture and Landscape Architecture. The report may be found at:
<http://www.autismcenter.org/openingdoors.aspx>.

Opening Doors responds to the pressing question looming today for millions of parents of children with autism: *Who*

will care for my child when I'm no longer able to do so? The report was produced to respond to the ever-increasing demand for more quality housing options and need for the following:

- Evaluation of existing residential programs and properties; identification of promising practices
- Development of goals and guidelines for sustainable residential community design
- Identification and analysis of available financing options that support scalability
- Increased public awareness of the growth trends in the population

The challenges associated with adult residential options are enormous—just consider: lack of consistency in the definition of residential options; lack of market data; lack of documented design guidelines; shortage of turn-key support service models; limited and cumbersome access to capital; and critical short-term needs.

Opening Doors identifies 10 design goals and numerous guidelines created to support all sectors in developing more options for individuals and their families. In addition, the report recommends the following actions, which are now being addressed by SARRC, Autism Speaks, AFAA and other local and national interests:

- National and market specific surveys
- An interactive database of housing options
- Development and testing of soft infrastructure support models
- Prototypes that research promising practices
- Responses to current and short-term demand
- Increased and systematized capital resources from public agencies
- Pursuit and testing of innovative options

Denise is committed to developing new home prototypes for individuals with autism and related disorders by increasing housing choices as the necessary underpinnings – financial, educational, public policy and supportive services – are put into place in Arizona and throughout the U.S.

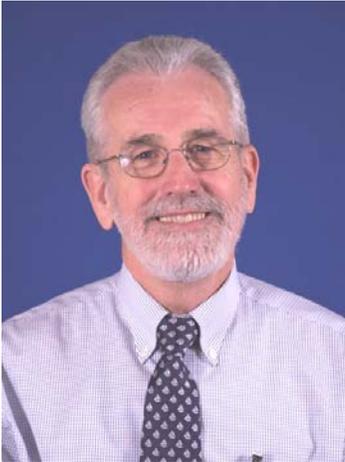
Partnering with national autism organizations across the country and SARRC, she is also committed to increasing awareness and appreciation for today's challenges, transforming promising practices into best practices and addressing critical public policy concerns.

She's currently working on a model plan in the heart of the city of Phoenix that responds to safety and security; public transit with access to jobs, recreation, health care, education and daily conveniences; and places where neighbors accept those with special needs and talents. Most of all, she hopes to advance the development of homes and supportive communities where adults with autism can live, work, learn and recreate with friends and with respect, dignity and the greatest degree of independence possible.

Denise is the co-founder of the Southwest Autism Research & Resource Center (SARRC) and an active volunteer for the organization and national concerns. She is the mother of a 21-year-old son with autism and served as SARRC's board chair from 1997-2007. Today, SARRC is an internationally recognized nonprofit organization dedicated to autism research, education and community outreach and the support of individuals with autism and their families throughout their lifetimes. The 18,000-square-foot Campus for Exceptional Children and 10,000-square-foot Sander's Center for Autism Studies, which is co-located with SARRC's Vocational & Life Skills Academy, are state-of-the-art clinical centers that serve as models for similar research and resource facilities. Her marketing firm, DRA Strategic Communications, founded in 1986, provides significant in-kind support to SARRC and many other nonprofits. Denise is also a member the Autism Speaks Housing Committee, Advancing Futures for Adults with Autism (AFAA) Leadership Council and the National Association of Residential Providers for Adults with Autism (NARPA). She has served as a member of the Interagency Autism Coordinating Committee (IACC) of the National Institutes of Health, a member of the IACC Services Subcommittee and the NIH Autism Strategic Plan Workgroup. Denise is the editor of *Opening Doors: A Discussion of Residential Options for Adults Living with Autism and Related Disorders*, a collaborative study by SARRC, the Urban Land Institute (ULI) Arizona, the Arizona State University (ASU) Stardust Center for Affordable Homes and the Family and the ASU Herberger Institute School of Architecture and Landscape Architecture.

Many Pathways to Employment

Bill Kiernan, Ph.D., UMASS Boston, Institute for Community Inclusion



The defining activity in our adult years is having a job. Dr. Kiernan's presentation explored some of the strategies that show promise for persons with autism in obtaining and maintaining employment and it centered around the following themes: trends and data, current options, and new approaches.

He began by presenting data published by the New England Federal Reserve. In 2010, the number of people entering the workforce was 10% greater than those leaving. In 2020, the number of people entering the workforce will be 15% less than those leaving. In 2015, the workforce will be more diverse and will have more older workers and 37.4% of total employment will be workers in low-skilled (entry-level) positions. From 2009 through 2018, the New England Federal Reserve anticipates a growth rate of 11.9% in low-skilled jobs (health, food, personal care, construction, and production).

Dr. Kiernan also discussed population trends and data. On January 1, 2012, 10,000 persons (Baby Boomers) turned 65. This will continue for the next 19 years, indicating that there will be some dramatic changes in the labor market that will affect people with disabilities. In 2030, 18% of the nation will be over 65 (up 13% from 2012) although this doesn't necessarily mean that they will be exiting the workforce. The point is that the workforce is aging and this is important to people with disabilities because employers are now beginning to think about the technological accommodations necessary to maintain their workforce.

Employment services trends and data were discussed. There was a 12% increase in the number of persons with autism entering the Vocational Rehabilitation (VR) System in FY 2009-10. This is only 3% of the population served by public Vocational Rehabilitation. Employment placement through VR is generally quite low. Of those people who enter the VR system looking for jobs, only about 27.2% get jobs.

Dr. Kiernan's group recently did a study on the Community Rehabilitation Provider System. Of the 11,712 programs in the US, they estimate that job placement by Community Rehabilitation Provider System (CRPs) has remained flat since 1999 (20.1% into employment). This means that only 1 in 5 people who go through these programs are getting jobs and this is clearly not ideal.

Current employment options for individuals with autism are limited. Individuals can remain in school until age 18 or 22. They can enter the Community Rehabilitation Provider System, the Vocational Rehabilitation System, or enter a waiting list for services. Clearly, we need different options.

The bulk of Dr. Kiernan's talk focused on developing new pathways to employment through revising the transition process, increasing postsecondary education, apprenticeship, internship, and national service opportunities, and utilizing technology in the job search.

He suggested reshaping the educational "Final Four+" (ages 18-22). By assigning jobs and duties to students with autism during their middle school years, schools are introducing the concept of work earlier. Kiernan recommends that parents ask for a vocational goal at every IEP meeting. The message is that the school staff should expect the student to develop the soft skills essential to success in the labor force so that they might eventually make a contribution to the community as an adult. During high school, students with autism should be exposed to work experiences in school. Later, students should have the opportunity to take classes in an institution of higher education

through a concurrent enrollment program, to participate in national service program, apprenticeship or internship, and finally, to be placed in a job when ready.

The value of postsecondary education was discussed. Individuals with autism who take courses in two and four year institutions of higher education are able to pursue study in areas of interest to them and interact socially with peers in age appropriate settings. Programs can be fully inclusive, combined, or segregated.

Dr. Kiernan suggested that we open up options for persons with disabilities to participate in national service at all levels because these experiences could be a stepping stone to jobs for persons with disabilities. For example, AmeriCorps offers a volunteer stipend of \$5,800 and an educational stipend of about \$5,800. It provides the opportunity for a person with a disability to work on a team of 10 individuals over the period of one year. In addition to providing opportunities for social inclusion, by the end of the experience, the nine people in the group without disabilities will have developed a new perspective of what it is like to work with a person with a disability. The hope is that these nine individuals will then enter the workforce with an open mind about hiring people with disabilities.

There appears to be a disconnect between employers and agencies trying to place individuals with disabilities into jobs. Dr. Kiernan discussed current job search technology that is able to filter through all of the web pages in the US and provide data about available jobs. Using this technology, it was estimated that there are roughly 3.8 million jobs advertised online every day in the US. This technology can sort jobs by zip code, and knowledge, skills and abilities (KSA) required. It enables job seekers to identify all of the employers in a local area and the types of jobs these employers fill. Dr. Kiernan believes that we need to make better use of social media websites, such as Facebook, when we think about how we can connect people with disabilities to jobs.

We have seen evidence that some changes are happening. Large employers (for example, Walgreens) are stepping up and developing employment programs for individuals with disabilities. Federal initiatives in hiring are in place. There is a proposal that companies with federal contracts will need to hire 7% of their workforce as persons with disabilities. The leader of the National Governor's Association will advocate this year for employment of persons with disabilities. Often the solutions for supporting aging workers, immigrant workers, and disabled workers in the workplace are more similar than different. Employers are embracing universal design solutions that will accommodate the current workforce, changing workforce, and the workforce of the future.

What can we do now? Dr. Kiernan closed by suggesting that we have expectations about work for people with autism; ask for different approaches to transition; talk to families about the future for their child with autism; find out about national service internships, postsecondary options; and ask for and expect a future life in the community.

William E. Kiernan is the Director of the Institute for Community Inclusion (University Center on Excellence in Developmental Disabilities) and Research Professor in the Graduate College of Education and the McCormack School of Policy Studies at the University of Massachusetts at Boston. The Institute is a joint program of the University of Massachusetts at Boston and the Children's Hospital in Boston. For the past 39 years, Dr. Kiernan has served in a variety of capacities in the Institute for Community Inclusion, has been a senior staff member of the Children's Hospital, and has been a member of the faculty of the University of Massachusetts at Boston for more than 20 years.

Dr. Kiernan has served as an international consultant in seven countries in the development of adult service systems for persons with disabilities and has provided training and technical assistance in more than 45 states. He is the author of more than 125 articles and reports in the field of disabilities with a specific emphasis on transition, employment, public policy development, workforce development and systemic change. Dr. Kiernan has been a member of several national boards, has served as the President of the American Association on Intellectual and Developmental Disabilities (AAIDD) (formerly the American Association on Mental Retardation) and as President of the Association of University Centers on Disabilities (AUCD).

In addition to holding a Ph.D. in Rehabilitation and Special Education from Boston College and a Masters in Rehabilitation Counseling from Boston University, he holds a second Masters in Business Administration with a concentration in Health Care Management from Boston University.

Aging Well with Autism Spectrum Disorders Tamar Heller, Ph.D., University of Illinois, Chicago



Dr. Tamar Heller, Director of the Institute on Disability and Human Development and the Rehabilitation Research and Training Center on Aging with Developmental Disabilities at the University of Illinois at Chicago spoke on the topic of aging well with autism spectrum disorders. She focused on key factors in aging well and the challenges for adults with autism and their families. More specifically, her presentation focused on issues to consider in promoting the health and community participation of older adults with autism spectrum disorders (ASD) and their families including the following: 1) demographic trends, 2) health disparities and health promotion, and 3) long-term support.

This topic is one that has rarely been addressed as autism was only first diagnosed in the 1940s. Many people who might have been diagnosed with autism if the condition were known ended up diagnosed with psychiatric conditions or not diagnosed at all.

Currently, there are very few older adults with autism in the Developmental Disability system. In California, only 3% of individuals in the Developmental Disability system were adults with autism over 45 years of age (Cavagnaro, 2007). 13% of adults in large state residences have autism (Larson et al., 2011). Dr. Heller presented National Core Indicators Data collected from people with developmental disabilities in 25 states from 2006-2008 (Hewitt et al., 2011). They found that 8% of the adults in the Developmental Disabilities network have autism, 4.5% of adults with ASD were 50-59 years old, and 2% of adults with ASD were 60 and older.

There is not a lot of data about the trajectory of symptoms across the lifespan. Some of the best work on possible outcomes has been published by Esbensen et al. (2009), Seltzer et al. (2004), and Shattuck et al. (2007). Some adults with autism improve with symptoms becoming less severe and frequent (up to 10-20% outgrow diagnosis), some plateau, and some lose skills. With age, there is some evidence of abatement of symptoms with fewer behavioral symptoms possibly due to the aging of the sensory system and to reduction in mental health conditions.

As Dr. Heller noted, as they age, adults with autism often have a higher rate of secondary conditions, conditions that are potentially preventable but are influenced by environmental and behavioral factors. For example, adults with autism have higher rates of obesity. This is due in part by inactive lifestyles, long-term use of certain medications, or dietary habits. Dr. Heller discussed the need to research the potential long-term effects of diets and feeding problems, including food aversions, restricted food repertoire, risk for nutritional deficiencies, and diet therapies. It is also important to look at the implications of long-term use of medications including osteoporosis and neuroleptic medication, medication for sleep disorders, psychotropic medicine for behavioral disorders, and nutritional supplements. Dr. Heller went on to discuss several health promotion initiatives for individuals with disabilities, including Health Matters, a program that Dr. Heller's group developed at the University of Illinois at Chicago, Research and Training Center on Aging with Developmental Disabilities.

In general adults with autism have low rates of achieving typical adult roles. Most adults with autism live at home with their parents and few live independently. It is estimated from a study involving a voluntary sample in two states that 25 to 30% adults with ASD live with their parents (Seltzer, Krauss, Orsmond & Vestal, 2000). As parents age siblings often play a larger role in providing care and support. Somewhere between 5 to 55% of adults with autism are employed and many are under-employed (Barnhill, 2007). Amongst individuals with ASD, there are lower rates of post-secondary education (Barnhill, 2007) and low rates of marriage and parenthood (Howlin, Goode, Hutton, & Rutter, 2004).

Dr. Heller has been involved in the Illinois Adult Home Based Waiver Study which is examining the hiring practices of people with disabilities. The Home Based Waiver program offers funding of up to three times Social Security per month and can be used in almost any way that the families deem necessary. Although the program is meant to be self-directed,

usually it is the parents who are making decisions on behalf of their disabled child. In Illinois, people with disabilities can hire their parents, siblings, family members, neighbors, agency staff, etc. to be their personal support workers and Dr. Heller's group has been studying the implications of this practice on people's lives. In their sample of 369, 77 individuals have autism (21%). As compared to individuals with other developmental disabilities, individuals with ASDs in this sample were found to have lower social and community participation, fewer opportunities for daily choice-making, and were more likely to have turnover in personal support workers. Along with the University of Minnesota, Dr. Heller's group developed family and individual versions of the curriculum toolkit, *Find, Choose, and Keep Great DSPs*, which provides strategies to help people find, choose, and keep high quality Direct Support Professionals.

With regard to long-term caregiving, over 25% family caregivers of adults with developmental disabilities are age 60 years and older (Braddock et al, 2012), which highlights the need to address the aging of the caregiver as well as the adult child with autism. Research on the impact of developmental disabilities on mothers and siblings was briefly discussed.

Dr. Heller emphasized the importance of addressing transitions after parents die. Many families do not make adequate future plans and are unaware of their legal and financial options. There appears to be a lack of collaboration between aging and disability service system, and many families have avoided contact with formal disability services.

Dr. Heller's group has developed a future planning curriculum for families and adults with developmental disabilities titled, *The Future is Now Curriculum*. The goal is for the person with disabilities to develop a letter of intent detailing their specific wants and needs for the future. Dr. Heller summarized the key outcomes of her program. 24% of those who did not have a special needs trust developed one. 64% of those who had not taken residential planning action later did so. 78% of participants developed a letter of intent. The program resulted in a decrease in caregiving burden because there was now a future plan in place. Daily choice making of individuals with developmental disabilities increased. Individuals with developmental disabilities reported doing more leisure activities and having fewer unmet leisure needs.

Dr. Heller concluded with recommendations regarding not only future research but also needed policies and practices to better support adults aging with autism and their families. These included more research on the demography of aging and autism, model demonstrations on ways to help adults with autism direct their supports, increased supports to family caregivers including siblings, and more attention to the role of adults with autism in their contributions to their families and their communities.

Tamar Heller, Ph.D., Professor, is Head of the Department of Disability and Human Development, University of Illinois at Chicago (UIC) and director of its University Center of Excellence in Developmental Disabilities for the State of Illinois. She also directs the Rehabilitation Research and Training Center on Aging with Developmental Disabilities: Lifespan Health and Function and the Institute's Family Clinics, and the TAP autism training program.

She has active projects on family support and health promotion interventions for individuals with disabilities. One of these projects is the Special Olympics Research Collaborating Center. Dr. Heller has written over 175 publications and presented numerous papers at major conferences on family support interventions and policies, self-determination, health promotion, and aging of people with disabilities. She has written or co-edited 5 books and has edited special issues of *Technology and Disability*, *American Journal on Intellectual and Developmental Disabilities*, *Journal of Policy and Practice in Intellectual Disabilities*, and *Family Relations*. She is past President of the board of the Association of University Centers on Disabilities. In 2005, she was Senator Obama's delegate to the White House Conference on Aging. As a co-founder of the national Sibling Leadership Network, she is a member of its executive board. Her awards include the 2009 Autism Ally for Public Policy Award of The Arc/The Autism Program of Illinois; the 2008 Lifetime Research Achievement Award, International Association for the Scientific Study of Intellectual Disabilities, Special Interest Group on Aging and Intellectual Disabilities; the 2009 Community Partner Award of Community Support Services, and the 2010 Outstanding Researcher Award in the UIC College of Applied Health Sciences.

In Their Own Words: Living with Autism in Adulthood
featuring the perspectives of
Larry Bissonnette, Jamie Burke, Sue Rubin, and Tracy Thresher

“In Their Own Words: Living with Autism in Adulthood” is a video montage created by the NLM Family Foundation with the gracious participation of Larry Bissonnette, Jamie Burke, Sue Rubin, and Tracy Thresher. These four pioneering adults with autism were asked to share some information about their current lives (age, current life activities, employment status, etc.), their thoughts on adult life planning, and their hopes for the future. Each submitted filmed responses to the following interview questions, communicating via typing devices, some with voice output capacity, some speaking their words, with physical independence or minimal support:

- What are your hopes and aspirations for creating the adult life you desire?
- What are the specific challenges that you believe you face or will face in your adult life (housing, companions who assist you, living in communities, relationships, employment, education, etc.)?
- What types of programs or services would enable you to achieve the adult life that you envision and/or desire?

Also included in the video were brief excerpts from the documentary films, *Wretches & Jabberers*, *Autism Is A World*, and *My Classic Life as an Artist*, featuring Mr. Thresher, Ms. Rubin, and Mr. Bissonnette.

Tracy Thresher, Age 45
Self-Advocate, Activist, and Documentary Film Star
Barre, VT



I am Tracy Thresher from Barre, Vermont. I am about to celebrate my 45th birthday. I work the presentation circuit to educate others about movement differences. Take a walk with me on my journey.

What are your hopes and aspirations for creating the adult life you desire?

My hopes are like a beautiful tapestry which I need to find the perfect combination of support to make into my own magic carpet. My wish is to create the life I see in my head on the mountaintop of my Green Mountains. To be true to the Tracy on the inside I need to have people in the mindset of peaceful open-mindedness like my dynamo who keeps her peace through rough patches. It is my desire to be independent to the best of my ability.

I communicate more slowly than I wish to in this high paced world but my thoughts are very quick. The touch of my facilitator must be one of peaceful calm. To build my dream of becoming an educator I pushed through many barriers of built up walls of enclosing people in institutions or encasing them in the trap of no outlet for their inner thoughts. It is more harmful to my soul to be in this stubborn body than I can type.

To hope is to have faith in a future that includes professional growth and not the antiquated roles of paper shredding or stocking shelves but being respected for the knowledge this life has taught me. My priority is to own or rent my own home or place with a good supportive room mate who is willing to be open to going through intensive training to get to see how my spirit relaxes with communication. I am not the person I appear to be upon a passing glance. To get to be the man I aspire to be is a lifelong journey. It is my vision quest to find more peace in my life. I think having my own home is the next step on my ladder of communication, as it is what I must have to be free of the encumbrances of others.

What are the specific challenges that you believe you face or will face in your adult life (housing, companions who assist you, living in communities, relationships, employment, education, etc.)?

As I mentioned my priority is housing or more difficult to find is a companion to be my assistant in the life of becoming more independent. The hardest part is envisioning what I need but being unable to find the perfect combination of nice and firm communication partner. The world moves quickly and I need open-minded people who slow down to listen to my typing. To live in the friendly Central Vermont community is a blessing.

We have educated many people in our community by joining forces in schools. We have also spoken to legislators to let them see our intelligence. Our social fabric is beautifully sprinkled with an eclectic mix of abilities. There is more to be done and my fellow self-advocates and our supporters are tirelessly trudging up the trail to higher thinking. Through my work I have met many wonderful people who enrich my life and feed my soul to the point I dreamt of as a lonely boy.

My family loved me to the max. However, life in school absolutely traumatized me. It became unbearable to be thought of as a child who could not be educated. Now I mentor students. It is my mission to inspire children and show neurotypical kids how to slow down to listen to typing. More importantly, how to be a friend is what kids need to learn.

I am thinking friendship is the way to open pathways to learning. On the mountaintop of success people need to have a hand to pull each other up. On the top of my bucket list is to continue to learn and teach. I graduated from the school of hard knocks; now I try to prevent other children from living through the pain of a life of misunderstanding. I have friends who have made me proud by pursuing higher formal education to earn master degrees.

I would say my education continues through my work on the circuit of presenting to schools and communities. My employment is one of typing to educate. Working on presentations is on my mind constantly. I write it on my brain then I need my facilitator to be at my side to push the words out. To come from a menial job to a professional career is my proudest moment.

What types of programs or services would enable you to achieve the adult life that you envision and/or desire?

It is my desire to, of course, be as independent as my abilities allow. I want the same for all people. The Vermont legislature is better at listening to my typing than most other states. However, I understand politics and the need to divide services as fairly as possible. Ideally, I would like my services to include funding that is more reflective of the housing costs necessary to put me on the path to independence. The primary obstacle in my experience though is training of facilitators. Harvey Lavoy, Pascal Cheng, Larry Bissonnette and I work hard to cover the state of Vermont on our shoestring budget but it is tough to get to everyone we would like to. For Harvey, it is a juggling of priorities that need to be addressed. My mission in life is to have the home of peaceful independence to communicate in daily life across environments. More than anything, I want to create a world of communication for all, to have our voices heard loudly from the hills.

The video includes an excerpt from "Wretches and Jabberers" in which Mr. Thresher, along with his companion, Harvey Lavoy, visits the office of Vermont State Senator, Phil Scott, and shares his concerns about budget cuts and how it will impact DS recipients. He expresses his intense anxieties over losing his support system because of these cuts.

In another excerpt from the film, Mr. Thresher talks about his current living situation. He types, "I have no permanent place to live. It really sucks and I have no hope of finding a place to hang my hat." Because he is unable to live on his own, he lives "out of a backpack" and sleeps at two or three different places each week. He depends on people who are paid to take care of him and stays overnight in their homes. Some nights he ends up in a county facility for people in crisis.

Jamie Burke, Age 25
University Student
Syracuse, NY

I'm Jamie Burke and I'm 25 years old and I am a senior at Syracuse University in the College of Arts and Sciences. I live in Syracuse, New York.

What are your hopes and aspirations for creating the adult life you desire?

As an adult, I want to be a successful person that is certainly enjoying the life of confidence in how I connect with my communication. Communication is very important as an adult.

I'd like to be able to work in a job like a librarian or help to talk about advocacy for people with autism. I'd like to be a writer of children's books.

What are the specific challenges that you believe you face or will face in your adult life (housing, companions who assist you, living in communities, relationships, employment, education, etc.)?

It is important to me to have that learning and to mostly know that I am subjective in my own life... (Sheree Burke, Mr. Burke's mother asks him: Could you say a little bit more about what you mean by "subjective in your own life?" What does that mean?) I really understand the ways of knowing the life of opportunity... (Sheree Burke: So, if I'm interpreting that, you're telling me that you are knowledgeable that you need opportunities offered to you in life. Is that correct?) I really am interpreting that.

What types of programs or services would enable you to achieve the adult life that you envision and/or desire?

I am really concerned about this life of living independently. I think it's hard to be with different support persons and that idea of living in a house and needing more understanding and supports for sensory integration therapies which help me to move in my brain and body. (Sheree Burke: So what you're telling us is that you're concerned about living independently and needing the supports to help you live independently like your sensory therapies?) Sensory therapies are key to the movement.

I hope that the support of facilitated communication is simply helpful in my brain. Thank you for hearing the questions and answers.

At the end of Mr. Burke's statement, Sheree Burke explained that Mr. Burke has typed his responses without support. He has been typing since he was four years old and has made incredible gains. He has gone from supported typing to be able to generate this interview text independently.

Sue Rubin, Age 34
Advocate and University Student
Whittier, CA

My name is Sue Rubin. I am 34 years old. I am a student at Whittier College. I want to be an advocate for people with autism. I am fortunate to live the life that people with autism can only dream about.

What are your hopes and aspirations for creating the adult life you desire?

I am already living the adult life I desire. I want to be an advocate for people with autism.

What are the specific challenges that you believe you face or will face in your adult life (housing, companions who assist you, living in communities, relationships, employment, education, etc.)?

When I graduate, I will need an agency to help me set up an advocacy business.

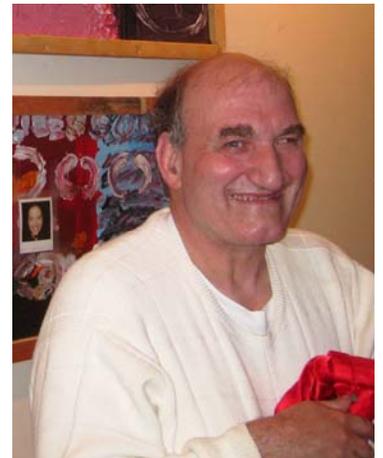
What types of programs or services would enable you to achieve the adult life that you envision and/or desire?

Supported living is very important to me.

The video includes an excerpt from "Autism Is A World" in which Ms. Rubin describes her fear and anxiety over staff changes in her supported living program and how these changes and resulting transitions might impact her life. She states that emotions are most difficult to talk about.

In another excerpt, Ms. Rubin is shown attending classes at Whittier College with a member of her support staff. She describes the challenges of being a college student with autism, expresses her love of learning, and describes the difficulty she experiences while trying to sit quietly during a two-hour lecture. Ms. Rubin states that in the times that she is not fully engaged in school, she finds that she is more susceptible to "awful autism."

**Larry Bissonnette, Age 55
Artist and Advocate
Milton, VT**



I am an artist living in Vermont and love to paint, type lots of good ideas and imbibe in lavish beer and gourmet, delicious, giving me pleasure, food. I am looking into using my movie star reviews to sell more of my art.

What are your hopes and aspirations for creating the adult life you desire?

It is another part of owning a home of my preference that I would say leading a life of meaning is looking for satisfaction by vesting yourself in activities that involve creativity and intellectual challenge like my artmaking. Passion is required for forming the basis for an ideal life.

What are the specific challenges that you believe you face or will face in your adult life (housing, companions who assist you, living in communities, relationships, employment, education, etc.)?

Tipping point for me isn't money, not mastery in life skills but lack of support people to bring me out in the real world so spotting the right partners to support my art, communication, and participation in community is critical.

What types of programs or services would enable you to achieve the adult life that you envision and/or desire?

Participation in community life is not dependent on the programs or services. Closing institutions potentially was the best populating community performance ever done by popular government so upping the pressure on programs to open up more instances of people being included in places of opportunities for big-time social connection is important.

The video includes an excerpt from "My Classic Life as an Artist" which provides some insight into Mr. Bissonnette's living situation. In the clip, his sister explains how he ended up living with her after he lost his supervised apartment due to budget cuts.

Mr. Bissonnette describes the importance of being able to express himself through his artwork. He describes his art-making process in great detail and explains, "Practically, doing art relieves overload by providing outlet for stress. Not allowing people with disabilities their patterns of inspiring art through total freedom of expression is like limiting creativity with censorship...Without art, wafting smell of earth's pleasures would kite away to land of inanimate objects so it's past point of personal hobby. Seeing work done is not totally satisfying because I'm rigged for process and not completion. Knowledge and learning of art have allowed my abilities to soar out on an airfield occupied by people who don't have disabilities. Hopeful about my knowing personal growth, it makes noteworthy my life."

Autism Is A World (2004).

Written by Sue Rubin

Directed by Gerardine Wurzburg

A Co-Production of CNN Productions and State of the Art, Inc.

2004 Academy Award Nominee, Best Documentary Short

Media Excellence Award, Autism Society of America

Henry Hampton Award, Council on Foundations

Web Site: <http://www.autismisaworld.com>

My Classic Life as an Artist: A Portrait of Larry Bissonnette. (2005).

Written by Larry Bissonnette

Produced by Zach Rossetti and Douglas Biklen, Ph.D.

A Production of Syracuse University

Winner, 2005, TASH Positive Media Award

Winner, Best Short, 16th Annual Vermont International Film Festival

Web Site: <http://myclassiclifefilm.com>

Wretches and Jabberers. (2010).

A Film by Gerardine Wurzburg

Produced by Douglas Biklen and Gerardine Wurzburg

Directed by Gerardine Wurzburg

A Production of State of the Art, Inc.

Web Site: <http://www.wretchesandjabberers.org>

Parent-Led Initiatives: Autism Housing Pathways

Catherine Boyle



Autism Housing Pathways (AHP) is a Massachusetts-based non-profit working exclusively on housing issues for individuals with developmental disabilities. Run by families, for families, it began as a group of parents interested in creating self-directed housing for their family members with autism. Organized by Catherine Boyle, this core group began meeting in June 2009, and quickly concluded that perhaps what was needed was an umbrella group, as everyone needed to do the same research regardless of what housing model they chose. In addition to doing research, such a group would envision new and different housing models, and incubate and support housing groups.

AHP's mission can be broken down into five major areas: family training and capacity building; improving professional development for direct support staff; capacity building in the public, non-profit and private housing sectors to support tenants with autism; developing a matrix of housing models; and educating policy makers.

To build capacity among families, AHP meets with parent groups around the state, giving a presentation, "Thinking About Housing", and distributing copies of its "Turning 18 Checklist". In addition, AHP reaches out via a listserv, website, Facebook, and regular meetings. Its website includes a page of housing opportunities available. Three AHP members have now been trained in the person-centered planning tools, MAPS and PATH, which are available to families on a fee-for-service basis. In the fall, AHP hopes to launch day-long housing workshops, with the curriculum targeted to meet the needs identified in a survey of Massachusetts families conducted by AHP last fall and winter. A short public service announcement regarding the need to apply for a housing voucher will be released via YouTube once a supporting website is launched.

Successful housing outcomes depend on the quality of direct support staff. Since Medicaid will not reimburse service providers for training, low cost is imperative. AHP is developing a series of four free training videos aimed at new hires or GED students considering this field. Filming has been completed on the first video, which focuses on reinforcement. The others, which cover the characteristics of autism, using pictures and technology to provide supports, and sensory regulation, will be rolled out over the next three years. AHP also has a group of volunteers able to train staff in "Quality Behavioral Competencies" for only the cost of materials. This one-day training gives staff the tools that they need to implement basic directions given by a Board Certified Behavior Analyst. AHP further plans to develop a "Seal of Approval" for vendors who adopt an AHP-approved hierarchy of trainings.

Capacity building in the housing sector to support tenants with autism is a long-term goal, and will involve developing workshops for developers and property managers, as well as rubrics for individuals with autism to help them be successful tenants.

AHP is actively engaged in developing a matrix of housing models that will meet a range of support needs and available family resources. A basic matrix has been compiled by assessing what others have already done. Next steps include brainstorming new models to fill the gaps and identifying hard-to-serve profiles. The matrix will be used to provide families with information on each model, including approximate costs, possible funding streams, boilerplate documents, process guides, and possible "bumps in the road".

In order to meet housing needs, it will be essential to educate policy makers on the scope and nature of autism housing demand as well as on the staffing levels and types of supports needed. AHP has calculated that at least 10,000 individuals with autism in Massachusetts will need affordable housing over the next 20 years. It is hoped that the results of AHP's survey will help to determine the extent of the need for supported housing.

Parent-Led Initiatives: A Parent's Guide to Autism Services

Anne Larkin, Ph.D., Lesley University



This presentation shared a mother's experience raising a child with autism and trying to provide the best services for him so that he could reach his potential. It started with a brief history of Dr. Larkin's son, John, who was born in 1965 and is now 47 years old. He was diagnosed with autism at age 3 by neurologists at Children's Hospital and the Kennedy Memorial Hospital in Massachusetts at a time when autism was not well known or researched. Doctors advised the Larkins to consider institutionalization because they did not feel that they would be able to handle the complexities of the disability, but the Larkins did not follow this advice. Dr. Larkin shared John's story, and focused on the following areas of his life: Health, Employment, Housing, Family Support and Social Networking.

Dr. Larkin began by discussing John's health over the years. Beginning at the onset of puberty, John has had four grand mal seizures, each five years apart. Fortunately, the medication has helped and he has been seizure-free for the last 15 years. Generally, he has been in good health over the last several years.

John has been "employed" on a part-time basis. Over the years, he has planted and cleaned the grounds at a nursery, cleaned areas at the airport, stacked carts at a grocery store, sorted mail (he reads and writes), and boxed candy.

The majority of his days are generally spent volunteering in the community. He visits senior centers and attends to some of their needs; he assists the residents in his day program, who are in wheelchairs, get to different off-site locations; and he completes chores at the day program.

John has been in three residences since reaching age 22. The first was a home in Bedford, MA. Generally, it was a good experience for John, and he loved being so close to his family's home. Unfortunately, the program went out of business. The second program was located in Billerica, MA. One of the parents had the home built for her son and three other residents, including John. This was another successful program, and John was very happy there. Unfortunately, due to some differences over the oversight of the home, with three parents deciding to stay with the same provider and the parent/owner wanting a change, there would be yet another move for John. He is currently in his third, and hopefully final, home. The provider owns the home, and it is lovely and spacious. John handled the move fairly well.

Dr. Larkin provided some suggestions for parents when choosing a home for their children with disabilities. She stressed the importance of considering compatibility of roommates. She commented that a variety of different disabilities in one home can be a very good thing. She suggested that parents interview several providers and be sure that they welcome family input and involvement. She stressed the importance of checking on diet and nutritional habits and encouraging academics.

In Dr. Larkin's experience, the relationships that you develop with parents of other children with disabilities become your most supportive and enduring relationships through the years. She mentioned several key organizations that provide support to families with autism, including the ARC of Massachusetts, The Federation for Children with Special Needs, and Massachusetts Advocates for Children.

Dr. Larkin was involved in the founding of an organization called Personal Advocacy and Lifetime Support (PALS), Inc. Along with other parents, she organized this program to help with networking and future planning for their children with disabilities. Together they developed a "Future Planning Book" to encourage parents to record all their wishes and plans for their children with disabilities and pass this information on to family members and future caregivers. PALS is presently a part of the ARC. Dr. Larkin briefly mentioned the Real Friends Project, a grant to assist families in developing friendships

for their children with disabilities and part of the ARC initiative.

Foundations and universities can partner with parents to develop wonderful programs for their children with disabilities. One example is the Arts Café program at Lesley University that developed through a grant from the Nancy Lurie Marks Foundation. Along with Susan Gurry and Peter Rowan, Dr. Larkin was involved in developing this three-year program for adults with autism. The young adults received classes in photography, the visual arts, movement and dance at the Lesley University campus on Saturdays. Faculty in Special Education, Expressive Therapy, Creative Arts and The Art Institute of Boston at Lesley taught the classes, and students from Lesley volunteered and formed wonderful relationships with the students with autism. It was an amazing and rewarding experience for everyone involved.

Dr. Larkin closed by urging parents to participate in programs within different organizations that influence public policy to protect funding of programs and services for their children with disabilities. She urged them to know their rights as parents particularly while their children are in school and when they transition to adulthood. Finally, she suggested that they begin the transition process at age 14, with follow-up every year, and start the future planning process as soon as possible.

Dr. Anne Larkin has been at Lesley University since 1967, starting in the Lesley College Laboratory Schools for children and, since 1973, as a Professor in the School of Education. In addition to teaching courses in special education, she has served as the Director of the Cambridge Chapter of Say Yes To Education, a scholarship program established in 1991 in collaboration with the Weiss Foundation, Lesley University, and the Cambridge Public Schools.

She earned her Bachelor of Science and Master of Education degrees from Boston State College, specializing in language arts and special education. In 1990, she completed her Ph.D. in Arts and Sciences/Reading at Boston College in Chestnut Hill, Massachusetts. Her on-going research efforts focus on the areas of literacy, inclusion, school restructuring, and autism.

Dr. Larkin has served on several boards including Cambridge Family and Children Services and the New England Resource Center for Higher Education. She founded and served as the first president of PALS, Inc., a Personal Advocacy and Lifetime Support organization that helps families plan for the future of their children with disabilities. The governor of the state of Massachusetts appointed her to serve on the Massachusetts State Board of Education, and she was elected to represent Massachusetts on the National State Boards of Education where she served on major committees responsible for publishing some of the leading studies on the current state and future of education in this country.

She has presented at local, regional, national and international conferences on education and special education issues. She has written and received many grants and has written numerous published articles focusing on autism, the role of the arts in special education, school restructuring and early literacy. She has co-authored several studies on the Cambridge Chapter of Say Yes to Education.

Dr. Larkin is the recipient of several honors including Lesley University's Annual Impact Award, the Central Middlesex Association for Retarded Citizens' Distinguished Service Award, the National State Boards of Education's Distinguished Service Award, and the Ladders, Inc. of Massachusetts' Margaret L. Bauman, M.D. Award for Excellence in Serving the Autism Community.

Parent-Led Initiatives: Living, Learning and Linking Adults with Autism and Other Developmental Disabilities Maureen Manning, 3LPlace



Maureen Manning presented the current status of 3LPlace, a non-profit organization that she co-founded with a small group of Boston area parents, including Deborah Flaschen. 3LPlace will provide a dynamic community in the greater Boston area for adults with autism and other developmental disabilities that will enable them to lead healthy and connected lives while relieving families and caregivers of isolation and worry.

As their children approach adulthood, many parents focus their planning on where and how their child will live as they themselves grow older and less capable. There are many organizations working to develop creative solutions to housing our growing numbers of adults with disabilities, including, in the Boston area, Autism Housing Pathways. 3LPlace will instead address the question, "How will our children with autism and other developmental disabilities live a meaningful life?" It will do this by partnering with families to meet individual needs; hiring, developing, and retaining a high quality staff; and utilizing its comprehensive new curriculum and training materials for educating and supporting adults with disabilities.

3LPlace will educate and support adults with disabilities in leading full lives through three strategic initiatives:

Learning. In September 2013, 3LPlace will open its Transition Program, an intensive instructional, residential program for young adults, ages 22+, with autism and other developmental disabilities. This program is designed for students who need further training or practice in independent living skills beyond that offered in their previous school programs or who may not be academically inclined to a traditional college experience. 3LPlace will offer its students an on-campus living experience similar to what typical students enjoy and intensive, hands on instruction in independent life and vocational skills using a comprehensive new curriculum being developed by 3LPlace.

The Transition Program will be based on a small campus near the Tufts University/Davis Square area of Somerville. It will open in September 2013 with up to 6 students. Students' families will pay annual tuition, room and board, and fees based on the program providing services and supports for its students 7 days per week for 11 months each year.

Living. 3LPlace will provide a lifelong community and ongoing supports for adults with disabilities. 3LPlace will focus its Community Members' program on enabling members to lead a full life in a community of peers and supportive families.

Services offered will include independent living supports/personal care assistance, employment/vocational or day program coaching, social and leisure time programs, and access to a community center hub for socializing and for fitness and recreational activities. Community members will be able to access any and all of the services at 3LPlace by subscribing to services on a cafeteria-style selection basis.

3LPlace's Community Members' program is expected to open in September 2015.

Linking. 3LPlace is collaborating with a team of advisers and consultants with expertise in autism, education, and occupational therapy to develop a comprehensive, systematic curriculum that it hopes will define best practices for teaching independent "full life" skills to young adults with autism and similar challenges.

3LPlace is committed to sharing its Transition Curriculum content free of charge so that other schools, human service organizations, and families can benefit from its development. 3LPlace plans to publish it on the Internet and create a "wiki" space for others to add to and refine the curriculum, and share lesson plans and methods for its implementation. 3LPlace also plans to offer training for educators and other providers and to create applications and tools for using its

curriculum.

3LPlace has raised over \$400,000 to date from grants and individuals, \$300,000 of which is reserved for the Transition Curriculum Project. 3LPlace will utilize this curriculum, as will other human service organizations, and school districts in Greater Boston. 3LPlace is in negotiations to lease space for its campus. It is also accepting applications for its first class of students to start in September of 2013.

Deborah Flaschen, founder and President of 3LPlace, is a parent of a 21-year-old son with developmental disabilities. In recent years she helped found and served as president of the Floortime Foundation. Deborah is also a member of the Leadership Council at Lesley University. Her business background includes over a decade of experience as an investment banker for Lehman Brothers in New York and San Francisco and Morgan Stanley International in London. Deborah earned a BA in Political Science at Tufts University and an MBA in Finance at the Wharton School, University of Pennsylvania. She resides in Brookline, Massachusetts with her husband and son.

Maureen Manning, co-founder of 3LPlace, is an attorney and graduate of Harvard Law School. She has a 16-year-old daughter with developmental challenges. For 17 years, Maureen practiced corporate law at the Boston law firm formerly known as Palmer & Dodge, where she was a partner for 10 years. Since retiring from corporate law to care for her two children, Maureen has immersed herself in learning developmental approaches to educating children with disabilities and in special education law. She is a past co-chair of the Haggerty School Advisory Council and of the Cambridge Parent Advisory Council on Special Education and has chaired or served as a director on the boards of two non-profit entities formed to benefit Cambridge Public Schools.

Research on Young Adulthood: New Findings, New Directions

Paul T. Shattuck, Ph.D., Washington University in St. Louis



A growing number of children are being identified as having autism. Children grow up to be adults. The majority of a typical lifespan is spent in adulthood; however, adulthood is the phase of life that we know the least about when it comes to autism spectrum disorders. In a recent review of literature about services for adults with autism published from 2000 to 2010 Dr. Shattuck's group found only 23 articles. Of these, only 5 included more than 20 participants. Our evidence base about the service needs and outcomes for this population is woefully thin. Autism is impacting an increasingly large proportion of the adult population, yet most studies are based on very small samples.

The period of transition from adolescence to young adulthood is especially critical to understand. Developmental theories point out that this is a pivotal period. A positive transition into young adulthood can set the stage for a cycle of accumulating advantage and positive outcomes. A negative transition can trigger a cycle of accumulating disadvantage and poor outcomes. This is also a period when there is a major shift in the architecture of service provision as youth exit special education and enter the world of adult service systems. Youth with autism are especially vulnerable during this transitional period because of their difficulties with communication and social interaction, a greater reliance on others for aid, and a high prevalence of comorbid mental and physical health problems.

National problems require national-level data to inform solutions. Dr. Shattuck's research program has focused on filling this gap for the past several years. His work makes use of data from a large, nationally representative survey of youth with disabilities who were followed for about a decade: the National Longitudinal Transition Study 2. He described some of his recent findings and mapped out areas of work that are in the pipeline.

U.S. law guarantees access to a Free Appropriate Public Education for all children with disabilities. A broad federal entitlement to supports and services goes away once students leave high school. There is no corresponding universal entitlement to help in adulthood. Many families describe this abrupt loss of services like being "pushed off a cliff." Once out of high school, the availability of services becomes uncertain and highly dependent on the severity of a person's needs, the family's own financial resources and where they happen to live. Despite this commonly understood phenomenon, we know virtually nothing in specific terms about what happens to youth with autism after they exit high school in the United States.

Dr. Shattuck reported on rates of service use by young adults with autism during the first few years after leaving high school. Forty-two percent were getting case management, 35% received mental health counseling, 24% saw a medical professional for assessment related to their disability, and 9% got speech therapy. These rates were much lower compared to the rates for these same youth a few years earlier when they were still in high school and eligible for help through special education. Most notably, 75% of high school students had been receiving speech therapy. The dramatic drop off in access to speech therapy highlights an area for policy reform, as the need for help with communication does not end with exit from high school. Yet many adult service system programs do not reimburse for this all-important type of service.

Dr. Shattuck also described data about what life looks like during the first few years after high school with respect to employment and further education. About one-third of young adults with autism had no connection to any postsecondary work or school opportunities whatsoever. This rate was higher than for youth with other types of disabilities including intellectual and learning disabilities. Family income and the severity of functional impairments are strongly associated with the likelihood of engagement. The rate of postsecondary disconnection from opportunities was 79% among youth from poor families and with low functional skills. Those with comparably low functional skills but from more affluent families had

a much lower rate of disconnection from school and work – 45%.

In summary, Dr. Shattuck noted that compared to young adults with other kinds of disabilities, those with autism have the highest rates of social isolation, residential dependence on parents, and disconnection from postsecondary work and school options. Families with lower incomes are worse off on almost every indicator.

Future work by Dr. Shattuck's group will look at the impacts of transition planning and related services provided during high school. Dr. Shattuck also noted that there is a tremendous amount of innovative experimentation happening in grassroots organizations aimed at helping young adults with autism. New program and service delivery models are rapidly emerging. He hopes to begin cataloging these and conducting case studies to identify promising practices.

Dr. Shattuck conducts innovative research that informs advocacy, policy making, and service design for people with developmental disabilities and special health care needs. Most of his current work is aimed at understanding patterns of service use and the factors that influence outcomes among youth with autism as they leave high school and transition to young adulthood.

Shattuck's work has been funded by the National Institute of Mental Health, the National Science Foundation, the Institute of Education Sciences, Autism Speaks, the Emch Family Foundation, and the Organization for Autism Research. His research has appeared in high-impact scientific journals including *Pediatrics*, *Psychiatric Services*, the *Archives of Pediatrics and Adolescent Medicine*, the *American Journal of Public Health*, the *Journal of the American Academy of Child and Adolescent Psychiatry*, the *Canadian Journal of Psychiatry*, and the *Journal of Autism and Developmental Disorders*. He has also written op-ed pieces that have appeared in leading newspapers including the *New York Times*.

Shattuck's 2009 study on the age of diagnosis among children with autism was recognized as one of the most important autism studies of the year by both Autism Speaks and the Federal Interagency Autism Coordinating Committee. Shattuck's 2011 study on services for adults with autism was recognized as one of the most impactful studies of that year by the Federal Interagency Autism Coordinating Committee.

Dr. Shattuck frequently speaks about autism at scientific meetings and to groups of advocates, family members, service providers, and policy makers. He has also consulted with public and nonprofit agencies on the design and evaluation of services for people with disabilities.

Shattuck's professional background includes work in the nonprofit sector doing fundraising and developing programs. His training includes degrees in social work, sociology, and postdoctoral training in epidemiology.

Shattuck's recent publications about autism:
<http://scholar.google.com/citations?user=RkxM8zIAAAAJ>

Shattuck's faculty web page:
<http://qwbweb.wustl.edu/Faculty/FullTime/Pages/PaulTShattuck.aspx>

Break Out Sessions: Policy Recommendations

At the end of the day, workshop attendees participated in breakout sessions moderated by the presenters and later reconvened to share the following policy recommendations.

Health Care (Moderator: Susan Parish)

- ◆ Adults with autism need access to insurance coverage that provides comprehensive general medical care, specialty care, and dental care.
- ◆ There is a need for more education and training of front line providers (and anyone else in the service system who has contact with adults with autism and their families, including receptionists, therapists, and nurses) in how to provide services in a kind, supportive, and understanding manner.
- ◆ There needs to be accountability that ensures that the provision of health care services is thoughtful and supportive of the needs of adults with autism and takes into account communication, sensory, and safety issues.
- ◆ We need incentives to promote the quality of health care that adults with autism receive and to structure the support system around people with autism and their families.
- ◆ We need systems and professionals (in-hospital autism coordinators, case managers, etc.) that coordinate the multiple medical challenges that many people with autism face.
- ◆ We need comprehensive training in medical schools, nursing schools, and schools of social work (and schools for other professions involved in the delivery of care) in how to care for adults with autism.
- ◆ We need full insurance coverage for augmentative and alternative communication which should include not just the device itself but also training and facilitation. Coverage needs to evolve as the communication technologies evolve.
- ◆ We need to create cultures in hospitals and medical practices that promote satisfaction with care and full engagement of people with autism and their caregivers.

Family Support (Moderator: Paul Shattuck)

- ◆ It is imperative that we develop ways to help families cope with issues of health and human service system navigation, system fragmentation, and lack of coordination between service providers. There are some promising innovations that are happening in other areas in the health care sector (for example, cancer navigator model, United Way 2-1-1 network, and health coaching) that can be duplicated and brought into the autism community to help families cope with these issues.
- ◆ Shattuck estimates that somewhere between one-quarter to one-third of families with autism have both severely-affected autistic children and significant resource challenges. There has not been much work devoted to assisting these resource-challenged families, particularly in the area of adult issues. More resources should be targeted at assisting vulnerable demographic segments including low-income families, immigrant/ESL families, and single-parent/single-income families.

Housing (Moderator: Denise Resnik)

- ◆ Raising capital for housing solutions for adults with autism can be cumbersome and challenging. There is a need for public policy that would incent private sector parties to get involved in the development of residential real estate for adults with autism.
- ◆ In the support service area, appropriate services need to be available for those who need assistance with instrumental activities of daily living (IADLs), activities of daily living (ADLs), and behavioral needs, and services need to be payable through Medicaid. Making appropriate services available will allow some to develop the work force, others to access appropriate services while reducing their use of inappropriate services, while freeing resources to serve those who need more intensive services.

Planning for the end-of-caregiving transition (Moderator: Tamar Heller)

- ◆ There is a need to bridge the Aging and Developmental Disabilities Service Networks that serve adults and families with autism and encourage greater communication and coordination between the two systems.
- ◆ There is a need to be supportive of reciprocal caregiving arrangements when the autistic individual is physically able to participate in such arrangements. There is also a need to support changing environments for the adults with autism through health promotion, education, and mentoring programs.
- ◆ There is a need for more funding and research in the area of educating people with autism about issues related to death/dying and grieving.

Employment (Moderator: Bill Kiernan)

- ◆ There is a need for more consistent transition supports in schools for youth ages 14-22. These should include paid employment opportunities. To facilitate that, we need greater training in transition planning and services at the certification level for pre-service and in-service teachers. Schools should be expected to have transition specialists on staff serving in a similar capacity as guidance counselors.
- ◆ There is inconsistency and disparity in how agencies address issues of employment for people with autism. There is a need for a unified policy amongst state agencies regarding how employment services should be delivered to people with autism that includes a range of delivery options and broadens the scope of what is considered as "support". How can we think about employment supports broadly enough to include things (such as communication and other behavioral supports) that would enable people to be meaningfully engaged in employment?
- ◆ We need to provide incentives for institutions of higher education, K-12 schools, and state agencies to work collaboratively so that inclusive higher education options are more broadly available to adults with autism and include not only classroom access but also supports such as residential life, social programs, recreational activities, etc.