I am truly excited to bring you this edition of Golden Years! If I was to ask you the questions of who is one of the most famous older adults with autism, and who is one of the most internationally renowned researchers in the field of aging and intellectual disabilities, I am sure that the vast majority of you would answer Dr. Temple Grandin, and Dr. Tamar Heller! Well, surprise, surprise, Golden Years is proud to feature interviews with both of them!

Also in this issue is a conference report of this years' AAIDD aging-related presentations. I am also thrilled to announce that the Gerontology Division has two new officers. Dr. Julie Moran is our new Vice President, and Dr. Lynne Tomasa is our new Secretary. A warm welcome to them both. I will be glad of their enthusiasm and expertise, and will be shamelessly capitalizing on their abilities to help strengthen and grow our Division! We all share a common passion of wanting to make a difference to improve the quality of life of older adults with IDD, and of their family caregivers too. Let me introduce them to you.....

Dr. Moran is a board certified Geriatrician, and she joined the faculty of Beth Israel Deaconess Medical Center (BIDMC) in the Division of Gerontology, and holds an appointment as an Instructor of Medicine at Harvard Medical School.

In 2006, she founded the Aging and Developmental Disabilities Clinic at BIDMC Senior Health, a busy consultative practice that serves the needs of older adults with intellectual and developmental disabilities. Dr. Moran was awarded a Geriatric Academic Career Award in 2007 to support her work in education and curriculum development in the field of aging and intellectual and developmental disabilities.

Dr. Lynne Tomasa leads the Aging and Transitions project at the University of Arizona Sonoran UCEDD. She received her BA and MSW from the University of Hawaii and her Ph.D in Higher Education with a minor in Gerontology from the University of Arizona. She has worked with older adults in a variety of capacities since 1983. As part of her role at the Sonoran UCEDD, she has interviewed older caregivers of adult relatives with intellectual and developmental disabilities; developed a caregiver roadmap; led caregiver support groups; taught service providers about aging issues; coordinated additional training programs, and assisted with program evaluation for a person -centered planning project. Her research interests include caregiving and end of life care. Dr. Tomasa has also taught a graduate course in Aging and is involved in developing curriculum for medical students and family practice residents in aging and interprofessional education. I hope you share my excitement regarding the future of our division with their involvement!
She is arguably the most famous person with autism in the world today. A compelling speaker, advocate, and an educator on the subject of autism. She is the writer of numerous bestselling books including *Thinking in Pictures*, *The Way I See It*, and *Emergence: Labeled Autistic*. She is also a renowned animal scientist. She was recently named as one of the 25 “Heroes” in this year’s Time 100 annual list of the world’s most influential people. She is the subject of a recent HBO film “Temple Grandin” which has garnered 15 Emmy Nominations including the best actress nod for Clare Danes. She is the remarkable, “different but not less”, Dr. Temple Grandin.

My gleeful excitement when Dr. Grandin’s personal assistant Cheryl, cheerfully and promptly responded to my request for an interview for our humble Gerontology Division Newsletter, further increased when I later listened to my phone messages and heard Dr. Grandin’s distinctively clear and authoritative voice. Dr. Grandin was en route back to her home in Fort Collins, Colorado, and happily offered me the chance to chat with her while waiting to board her flight. Seizing the opportunity for this brief encounter, the following is the content of our conversation.

EP: Dr. Grandin, I would like to say how thrilled I am to be able to talk to you today. I would like to start by asking you about the recent HBO movie, starring Clare Danes. What did you think of it?

TG: Oh I thought it was wonderful, and accurate, very accurate. It did a great job of describing the sensory overload and anxiety. I met with Clare Danes for half a day. I also gave her 5-6 hours of old video tapes of me from years ago. She would study them for hours on her iPod.

EP: I thought it was fascinating how the movie was able to capture how you visualized your thoughts.

TG: Yes, that’s exactly how I see things.

EP: I want to ask you about the “hugging machine”...the machine that was based on what you had observed being used to steady cattle for inoculations. How often had you actually seen the “hugging machine” in action before you decided to design and construct one for yourself?

TG: I just saw it once before I made it.

EP: Oh really! Just once. You have an innate understanding of animals and their behavior. Could it be that because you saw the cattle being calmed that it might have worked for you because of a placebo effect?

TG: No, it is the deep pressure that really does works. It is very, very calming. Many therapists use heavy blankets to wrap kids in, it helps to calm them down.

EP: Do you still use your hugging machine?

TG: It broke a couple of years ago and I haven’t got around to replacing it yet. I haven’t felt the need to.

EP: So you really did those experiments with your hugging machine using other college students as participants?

TG: Yes I did and I published a paper based on the results – you can get it from the pubmed database.

EP: In the film, you had a roommate during college who was blind. Did you keep in touch?
TG: That roommate was actually my roommate during grad school at Arizona State University, not when I was in college. They condensed that bit for the movie. She heard about the movie. She has recently got in touch with me through my website.

EP: Switching topics now, currently there is little research that addresses the aging process of older adults with autism. I'd like to ask about your experience of growing older. As we get older, generally our senses are not as sharp as when we were younger. Have you found that as you have aged, that you are not as sensitive to overstimulation?

TG: No, but I've learned over time to cope with it better…that helps…you know some older folks have problems hearing in noisy crowded environments…they can't filter out other noises like they used to. (An airport announcement interrupts us, as if to demonstrate the point).

EP: Have you had any significant issues or problems with your health over the years.

TG: Well, my hormones…first they were up, then after menopause they went down! I've also had G.I. problems, as do many with autism, but I follow a low carb diet, and that helps. I exercise more now.

EP: As you have got older, have you noticed any changes in your behavior or mental health?

TG: I'm much less anxious. In the movie it ends before I reached my 30's. I used to suffer more with anxiety back then. Then I started taking antidepressants... it helped my anxiety tremendously. They worked for me. In my book, Thinking In Pictures there is a chapter Believer In Biochemistry. I'm a great believer in biochemistry. I'm still taking antidepressants. They still work for me.

EP: How about your career over the years? In the movie it follows you through college for both your Bachelor’s and Master’s degree. When did you complete your PhD?

TG: In 1989. Since my PhD I have been working in both the meat industry and Colorado State University. (Professor of Animal Sciences). It was different going back to school. I had to study longer, twice as long. I've talked to other non-traditional students and they say the same. It took me longer to learn.

EP: Having just completed my PhD at the age of 40, I can wholeheartedly agree with you. In your earlier career you designed special corrals for cattle and humane slaughter methods. Could you tell me about your more recent projects?

TG: I've been designing auditing programs, audit programs that monitor animal welfare. I design and check compliance to process controls for meat handling for many companies including McDonald’s. I have also developed a scale that determines animal welfare during these processes. It's very important that animals are monitored correctly. The whole oil spill and BP, that mess is a result of not following processes and procedures correctly.

EP: So Dr. Grandin, you are currently 62 years old, are there any plans for retirement in the future?

TG: (An emphatic) NO... oh no...I wouldn't
know what to do with myself! I have to keep my mind busy. When I do retire, I’d do things like give talks at my local science museum. If I became physically disabled, I would have an active presence on the internet. I’d have to figure out what to do—I couldn’t be bored out of my mind. My mother, she is 83 now and still going strong.

EP: Your mother is a very tenacious lady.

TG: Yes, my mother encouraged my strengths and interests...you need to do that...develop a kid’s strengths. I was interested in art, and my mother developed that.

EP: When did your interest in science begin? Often people who enjoy science are not so interested in art and vice versa. Perhaps because you are a visual thinker is why you appreciate both?

TG: I was always interested in science too. My grandfather was an inventor. He was an MIT trained engineer. He co-invented the automatic pilot. When I was a kid I would ask him questions all the time, questions about the sky, things around us...he would explain everything to me.

EP: It seems that your mother was always encouraging you to be independent too.

TG: Yes, she was always pushing my independence and that I should socialize with others. That is very important. She would insist that I ride my bike into town, that I should get summer jobs, that I should go to my Aunt’s Ranch for a summer (as shown in the movie). I didn’t want to always do these things, but she insisted. I didn’t want to go to the ranch but she insisted.

She was always concerned that I acted appropriately and used proper table manners and was polite. I had to behave in restaurants – there was no excuse for not using cutlery correctly. I remember when I was in school I started lapping from a dessert top like I was a dog. That was not okay so it was taken away from me. I was bought up in the 50’s and manners were very important. Being punctual was also important. I had an alarm clock from the age of 7.

I am worried about a lot of bad behavior I see today that is not being corrected. I recently saw an autistic boy throwing things in a convenience store. That is not acceptable. Kids need to be socialized more, things like getting them involved in shoveling snow, newspaper rounds, chores for neighbors, that’s how they learn to socialize, by being around others. They learn manners, taking turns, and how to interact with others.

I would also like to mention my concern about “reasonable accommodations” – that it is creating a disability culture when it goes too far. It needs to be balanced...there are certain things that should be done. For example, ramps, lighter course loads, quiet environments, non-fluorescent lighting, extra study time, those sort of things. But sometimes there are accommodations requested that are too much to the point of being ridiculous. I have had some very successful students who needed accommodations.
I opened the back door for some students because I had the back door held open for me. Overall, the main issue with student success is their own motivation. We should also figure out how we can do things more cheaply. Lower income folks need help getting resources that could help their kids. Old laptops are cheap, and lying around everywhere. These would make the world of difference to kids who are non-verbal. We waste the resources that are already available. (Another airport announcement is made). that's my flight!

EP: Dr. Grandin, it has been a real pleasure talking to you. I want to thank you again for taking the time out of your day to speak with me. You are an inspiration and hero to so many of us. Any quick last comment?

TG: I just feel that it is my duty to give information that everyone can use – useful, practical, and sensible advice.

As we said goodbye to each other, I have to admit how star-struck I felt to have had the opportunity of a one-to-one conversation with the great Temple Grandin. The debt we owe her for casting light into the way a person with autism experiences the world, how they think, how they perceive their surrounding environment, as well as the challenges and triumphs she has personally experienced, is truly immeasurable. I then reflected on the fact of how a word can so misrepresent the reality of what a person actually is. The word autism literally translates to mean “self”, so how ironic it is that Dr. Grandin continually shares her experiences and unique insights for the benefit of millions of people. Dr. Grandin is, in fact, one of the most self-less individuals I have ever met, or indeed, ever likely to encounter. Quite simply, she is a true national hero!

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Temple Grandin photographs on pages 2, 3, and 4, by Angus Bremner. www.angusbremner.com

Information regarding Dr. Grandin’s books and future speaking engagements can be found at www.templegrandin.com
To continue our series to highlight the most prominent researchers in the field of aging and I/DD, "Golden Years" is extremely proud to feature Dr. Tamar Heller. Dr. Heller is Professor and Head of the Department of Disability and Human Development, University of Illinois at Chicago 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 and projects on family support and health promotion interventions for individuals with disabilities.

Dr. Heller has had the type of distinguished academic career that is a true inspiration to all of us. She has authored over 140 articles, book chapters, and technical reports. She has co-edited and co-written four books and 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 has presented at over 200 conferences, including 58 internationally. She has been the Principal Investigator on countless grants totaling in excess of $20 million. She is a Fellow of the International Association for the Scientific Study of Intellectual Disabilities, and the 2009 Community Partner Award of Community Support Services.

Finally, still by way of introduction, in 2005, Dr. Heller was one of the then Senator Obama’s delegation to the White House Conference on Aging. More recently she has served as the Director of the Research Committee of the Disability Policy Committee for President Obama’s White House Campaign.

An incredibly busy person, I considered myself very fortunate to talk with Dr. Heller recently, to ask about her career and research.

EP: I just want to start by thanking you for your willingness to do this interview. My first question is—When did you first become involved in aging issues?

TH: Actually when I was finishing my dissertation, I was involved in work regarding deinstitutionalization and residential transitions in general. I was asked to work on an aging project that was looking to moving people into assisted living-type settings. It was research that was funded by the Retirement Research Foundation. Through this, I was introduced to the Gerontologist Powell Lawton. I was a fan of his theories of the interaction of a person and their environment, and how to improve their fit. Also in the early 1980’s I was sat next to Matthew Janicki at some banquet. We had never met, and I didn’t know who he was. We started chatting and he asked me if I would write a book chapter on aging with DD and residential options. It was one of the first ever books on aging with DD.

I then had a grant from the DD Council to study family caregivers. It was part of the RRTC Aging and DD out of the University of Cincinnati. I was also looking at the outcomes of transitions out of Nursing Homes, that was a 10 year study. The next RRTC was transferred to UIC, we are now in the 2 year of our 4th 5 year funding cycle (1993-88).

EP: What aging-related research project have you found most interesting?

TH: Aging family caregivers is my prime area. I have been able to go beyond descriptive research to approach the question of how can we help people. There have been two ways, I have been involved with consumer-directed research and policy, and how that impacted outcomes over the period of 10 years. The other is family future planning, which involved implementing an intervention and testing its effectiveness. How you can do things that help people the most? That is the most exciting to me. I also think the research we have done in the area of health promotion has been important.

EP: What are your current projects?

TH: We are continuing our work on consumer directed services. We are looking at the impact on outcomes when consumers use the money for family and friends to provide their supports, and how it is different from using professionals. We are looking at outcomes like their community participation, and self-determination. We are also looking at the perspectives of the family and how it affects them. There are several types of consumer-directed Medicaid waiver services available, but there isn’t a lot of research that looks at their effectiveness.

I’m also involved with a project with Special Olympics. We are looking at the outcomes of their Health Athlete Health Promotion Program. We have participation from pilot sites in three countries, Kenya, Mauritius, Belgium, and two US States, Arizona, and Indiana.

In Illinois we are continuing our work regarding residential transitions. I’m still very interested in environmental factors that predict success.

EP: What do you see as being the major challenge in research for aging and I/DD?

TH: I think the major challenge is how do we bring the two systems together (aging and disability) so that we can benefit from both sides. Gerontologists do not generally know our work. I’ve been to many conferences regarding caregiving, and they do not usually consider caregiving in a lifelong context, such as caregiving for a person with ID. Although I am pleased that Rosalynn Carter’s Institute on Caregiving does include details regarding our Futures Planning Curriculum on their evidence-based caregiver intervention database.

EP: What do you see as being priority areas of research in aging and I/DD?

TH: I think health issues are still major. There are two main issues - dealing with health issues and how to bring nursing supports to folks so they can stay in place. The other issue is what happens after there is no longer a family caregiver? How we prepare for residential supports when there is no family caregiver any more. I think we are seeing less and less residential supports, and group homes, and the funding that supports them, so we need more creative ideas.

I’m also involved with the Consortium on the “National Gateway to Self-Determination for Persons with Developmental Disabilities” along with University of Missouri and University of Kansas.

I was also the co-founder of the National Siblings Leadership network, and I am currently serving as their Treasurer. We produced a White Paper from the first conference in 2007. I am really excited that we have an International Conference for the National Siblings Leadership Network coming up on August 7-8. Sibling issues are often a part of aging issues, as siblings are often involved in supporting the primary caregiver, and in many cases take over the role of primary caregiver.

More details are available at http://www.idhd.org/Events.html

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We need new models, how can we develop the substantial supports needed. They need to be more active, to ensure a meaningful life with meaningful activities. They need to go further than they do.

EP: Every researcher has a favorite article that they have written. What is yours, and why?

TH: I liked my article regarding reciprocity not because it was the best research, but because I liked the idea. I also liked my earlier article on caregiving. I also really liked the article regarding the impact of consumer director supports.


EP: What has been the proudest moment in your career?

TH: There have been two.

When I was invited to be the keynote speaker at two international conferences within the same week. One was in Israel, the other in the Netherlands. I felt very honored.

The second was when I was asked to be a White House delegate.

EP: Over the course of your career there have been momentous changes in the field of I/DD. What are your predictions for the future with specific regard to aging and I/DD?

TH: I see that the way the field is moving - there is more and more reliance on the family. So I think there will be more emphasis on informal supports, and helping families with the training and resources they need to provide these more informal supports. I think that is the general direction, unless there is a backlash to that, but I don’t think so right now.

In the field of aging we have evolved from providing programs in existing settings (e.g. an aging program in a workshop), then integrating into already existing resources within the aging population, to person-centered choices, which we have been working with for a while. We are at a point where we need new models. With decreasing budgets, and resources, it is going to be very interesting to see what ways we come up with to support families and aging persons with DD.

I also think there will be more in the trends for self-determination. It is much more nuanced than some in the field would suggest. We need to ensure that we meet the goals and do the things that the person with DD really wants to do. We have to keep working towards that goal.

On that note I will close by thanking Dr. Heller for sharing her insight, experience and vast expertise in the field of aging and intellectual disabilities with the readers of Golden Years. Having such a truly illustrious career, there is no doubt that the impact of Dr. Heller’s work had a far-reaching significance on the quality of life of innumerable older adults with intellectual disabilities.

For further details regarding Dr. Heller’s work, as well as a super website for resources, visit the University of Illinois—Chicago’s Institute on Human Developments main website www.idhd.org/
Dear Gerontology Members!

The dog days of summer are upon us, and though the annual conference was just a few weeks ago, it already seems like a lifetime has passed! The theme of the conference was *Imagining the Future, Celebrating the Past*. It was a very apt title, as there was a definite nostalgic tone to this year’s conference, but it was balanced with optimism for the future. Even with the fast-paced nature of modern life, it is still very easy to recall many aspects of why this conference was a memorable one: great attendance, thought provoking keynote speeches, the choice and diversity of the breakout presentations, the hall-busting poster sessions, and not forgetting that great location too! AAIDD transitioned from its major change of leadership for over two decades, by bidding a final farewell to Doreen Croser, and warmly welcoming to the new Executive Director, Dr. Maggie Nygren.

Though Doreen leaves behind a great legacy, and particularly for our Division with her staunch support of aging issues, we are extremely fortunate to welcome Maggie, who has a wealth of experience in aging programs—a win-win situation for all of us Gerontologists!

There were two panel presentations on Aging at this year’s conference—and both were very well attended. It is great to see the building momentum and interest in the passion we all share! Even though Leigh Ann Kingsbury and Catherine Rush had to withdraw due to unfortunate family circumstances, we were able to cover their absences, and we hope that they will be able to present next year. The Gerontology Division’s Aging Panel session featured Management of Epilepsy in Elderly People with Developmental Disabilities presented by Dr. Baldev Kaur Singh, MD, from Westchester Institute for Human Development. I presented my dissertation research, The Effect of Compound Caregiving in Older Parental Caregivers. At very short notice Dr. Julie Moran kindly discussed her experiences at the specialist Aging and IDD clinic that she founded and directs at Beth Israel Deaconess Medical Center, a teaching hospital of Harvard Medical School.

The 2nd aging panel session featured “As People Age”...An Overview of a Dementia Training and Questionnaire for People with I/DD presented by Melissa A. DiSipio, Philadelphia Coordinated Health Care (PCHC), followed by Aging and Disability Resource Centers: Connecting the Dots in Long-Term Support Service Networks presented by Dr. Barbara J. Ettner, PhD, of The Lewin Group. In the email in which this newsletter was distributed, the handouts from all 5 of these presentations were attached.

I am also pleased to report that Dr. Wayne Silverman, was presented with AAIDD’s Research Award this year. Our congratulations to Wayne for a very richly deserved award. Wayne presented for the Gerontology Division’s panel last year, and also presented for our very successful Aging and End of Life Webinar Series, on Dementia and Down Syndrome.

This year also saw the passing of the gavel of AAIDD President from Dr. Joanna Pierson to Dr. Mike Wehmeyer. I personally want to thank Joanna for her unwavering support and helpfulness both before and during her tenure as President, and her oversight of the Task Forces. I am also looking forward to Mike’s tenure as President. I’ll end by appealing to all of you out there to become as involved with the AAIDD as your schedule will allow. Please consider becoming an active member of the Gerontology Division, by submitting information regarding upcoming workshops/conferences, consider presenting at AAIDD’s national conference, write about your experiences, professional or personal, anything that we can share with others...we can always learn something new from each other!

As for next year, I hope to be able to say a big “Howdy” to many more new faces at AAIDD’s annual conference in Texas! Come join the fun!
Upcoming Conferences on Aging 2010-2011

2010 RCI National Summit & Training Institute
October 20-22, 2010
Georgia Southwestern State University
Americus, GA
http://www.rosalynncarter.org/news/summit_keynote/

2010 GSA’s 63rd Annual Scientific Meeting
TRANSITIONS OF CARE ACROSS THE AGING CONTINUUM
November 19-23, 2010
Hilton, New Orleans Riverside
New Orleans, LA
http://www.geron.org/Annual%20Meeting

American Academy of Hospice and Palliative Medicine & Hospice and Palliative Nurses Association
2011 Annual Assembly
February 16-19, 2011
Vancouver, British Columbia
http://www.aahpm.org/education/cc/call2.html

Association for Gerontology in Higher Education (AGHE)
37th Annual Meeting and Educational Leadership Conference
Living the Old Age We Imagine: Higher Education in an Aging Society
March 17-20, 2011
Hilton Cincinnati Netherland Plaza
Cincinnati, Ohio

American Society on Aging
2011 Aging in America Conference
April 26-30, 2011
Hilton San Francisco Union Square
Parc 55 Wyndham Hotel
San Francisco, CA
http://www.agingconference.org/AiA11/index.cfm

The American Geriatrics Society
2011 Annual Scientific Meeting
May 11-14, 2011
Gaylord National Resort and Convention Center
National Harbor, MD
http://www.americanageriatrics.org/annual_meeting/

Compiled by Lynne Tomasa, PhD, MSW
Where Are Our Older Adults?

We all know that the aging population of adults with IDD are living longer than ever. However, rarely do we get to hear about this special group of older people.

Help me to redress this! As gerontologists we use the terms young-old (65-74 years), old-old (75-84 years), and oldest-old (85 years +). It is a fact that in terms of the percentage of the population - the oldest-old have seen the largest increases in the general population for a number of years - furthermore, they are also projected to have to largest increase in the foreseeable future.

Given the dramatic gains in life expectancy in the last 30-40 years in the population with IDD, it is reasonable to expect that there are now a substantial number of older adults with IDD who are reaching all three of these aging categories!

Let’s keep highlighting older adults in future newsletters. Please contact me if you know an older adult that we should feature, or you would like to share a story about someone you know or serve.

Have Something to Say? Don’t Be Shy!

Are you interested in submitting a feature piece for a future edition of Golden Years? Do you have an important announcement? Would you like to highlight an upcoming conference or workshop? Any topic related to aging of potential interest to Gerontology Division members would be welcomed.

Deadline to be considered for next newsletter is December 1, 2010.

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Words of Wisdom

A pessimist sees the difficulty in every opportunity;
an optimist sees the opportunity in every difficulty.

Sir Winston Churchill