Tracking toward aging... medical and clinical issues affecting adults with ASD

• What do the data tell us?
• Some suppositions around aging
• Implications for aging-related services

“Aging is a lifespan process”
Data from the Longitudinal Health and Intellectual Disability Survey (LHIDS) ... lifelong physical and behavioral health trends
LHIDS – Autism: sex by age (%)
LHIDS – Autism: IQ groups

N=136
LHIDS – Autism Co-incident Diagnoses

- Other
- Williams Syndrome
- Prader-Willi
- Fragile X
- Down Syndrome
- Cerebral Palsy

N=201
Heart/circulation, hormonal, & respiratory

Adults with Autism (N=201)
Pain/discomfort disorders

Adults with autism (N=201)
Mental health/Psychiatric conditions

Adults with autism (N=201)
Other conditions

Adults with autism (N=201)
What can we glean from this?

- Adults with ASD are a heterogeneous group
  - Given what derives the syndrome, not all explicit medical general characterizations will hold
  - More is known about adults with ASD with coincident ID than about adults with normative and above normative IQs

- Some trending of characterizations may be evident
  - Reports note that 75% of adults with ASD have an ID
  - The LIDHS data show a generally normative distribution of ID

- A proportion of adults with ASD may have a coincident condition(s)

- Medical conditions show trends indicative of the need to track health and be aware of what to look for as adults age
The charrette sought to seek consensus on existing knowledge on a number of specific conditions, normally considered developmental disabilities, and that identified aging effects, condition trajectories, and long-range expectations of morbidity and mortality that differentiate people with these conditions from those in the general population.
Primary Question
What were the co-incident or secondary health and physical condition factors related to the aging of people with select neurodevelopmental conditions?

Secondary Questions
- Are there unexpected changes in physical or mental health status among people with select neurodevelopmental conditions as they age?
- How do these changes compromise life functioning either physically or cognitively with progressive age?
- How do we begin to educate family members, self advocates, direct care providers and health care providers on these issues so that they are not missed?

Focal conditions/disorders

- Genetic conditions
  - Prader-Willi syndrome
  - Fragile X syndrome
  - Down syndrome

- Non-specific conditions
  - Autism spectrum disorders
  - Cerebral palsy
  - Spina bifida
General Findings: Autism Spectrum Disorders

- Aging-associated health compromises that appear to occur in adults with ASD
  - Sleep difficulties
  - GI problems
  - Anxiety
  - Depression
  - Respiratory
  - Seizure disorders
  - Catatonia
  - Long-term adverse medication effects

- Little information is available on longevity factors, save for a muting of ‘ASD-like’ symptoms with older age.
- Little evidence of linked neuropathologies (such as Alzheimer’s disease and related dementias)

- Limitations: Sparse case identification, low Ns of older adults among established study participants, and negligible focus on aging among ASD researchers limit information about adverse health status or predictable trajectories of earlier age conditions
A study in the *British Journal of Psychiatry* reported that the risk of premature death is about 2.5 times higher for people with autism spectrum disorder (ASD) than for the rest of the population.

Findings show that there is an association between ASD and an increased risk of premature death ... At particular risk are women with ASD and intellectual disability (ID):

- On average, adults with ASD died 16 years younger than adults in the general population.... those with an ID died more than 30 years prematurely... at an average age of 39.
- Adults with ASD (without ID) died 12 years earlier... "high-functioning" individuals with good speech and language skills had double the normal risk of dying young... generally from suicide.

The study noted that some 40% of adults with ASD also had epilepsy which contributed to many early deaths (with uncertainty as to whether this was due to a predisposition or a side effect of medication).

Data from the Swedish patient registry for persons with ASD were compared with data from the general population registry; both sets were then linked to the causes of death registry:

- The study included over 27,000 individuals with ASD, of whom 6,400 also had an ID, and some 2.5 million individuals from the general population.
- The study matched general population data with the ASD group with regard to county of residence, sex, and age.
Information gleaned from miscellaneous studies
Contemporary studies

- Perkins & Berkman (2012)’s review noted:
  - ‘for both men and women with ASD at age 65, life expectancy was 3 years less than the general population’
  - ‘high rates of epilepsy in children with ASD have been consistently reported’
  - ‘most common [psychiatric comorbidities] included anxiety disorders and depression, obsessive compulsive disorders, attention deficit hyperactivity disorders, oppositional defiant disorders, and Tourette syndrome’
Contemporary studies

Kring, Greenberg & Seltzer (2010) noted that comparative studies have found that children with ASD have

- poorer health
- more compromised immunity, such as more ear infections and higher use of antibiotics than typically developing children
- approximately one out of every four individuals with autism has seizures, which is higher than rates in the general population, which often develop around the onset of puberty
- studies of gastrointestinal (GI) problems in individuals with ASD, such as diarrhea and constipation, often have their onset during

They conclude that available research indicates that adolescence is a period of increased risk for developing chronic health problems in individuals with autism.
Commentaries

• Hughes, J.R. (2009) noted ‘characteristics of autistic individuals include sleep disturbances, joint attention disorders, seizures, allergic reactions, and various behavioral changes’

• Wick & Zanni (2009), noted ‘long-term care practitioners need to prepare to see the people first diagnosed with autism in the 1980s who are now reaching old age with the need for long-term care facilities’
Commentaries

• Hughes, J.R. (2009) noted ‘characteristics of autistic individuals include sleep disturbances, joint attention disorders, seizures, allergic reactions, and various behavioral changes’

• Wick & Zanni (2009), noted ‘long-term care practitioners need to prepare to see the people first diagnosed with autism in the 1980s who are now reaching old age with the need for long-term care facilities’
Challenges for people with ASD

National Family Foundation Report ['Aging Well with Autism (55 and Older)] (2013) noted

• Current ASD screening instruments lack sound construction for assessing individuals with varying levels of cognitive impairment

• More research is needed on tracking long-term effects of medications generally prescribed to persons with ASD

• Studies should focus on the transitional elements as adults with ASD move from midlife to older age
Why we may not find who we are looking for...

- Perkins & Berkman’s (2012) review noted with respect to change over time
  - Suggest outcomes in lifespan function and symptoms can be attributed to three possibilities:
    - Improvement (that is, abatement of symptoms)
    - Plateauing (no changes in symptoms)
    - Decline (that is, worsening of symptoms)
  - When outcomes do show abatement of symptoms, there may be several explanations:
    - Changes are attributed to physiological aging processes
    - Growing self-awareness
    - Exposure to lifetime of experiences that lead to better coping strategies
Why we may not find who we are looking for...

- Perkins & Berkman’s (2012) review noted with respect to change over time
  - Suggest outcomes in lifespan function and symptoms can be attributed to three possibilities:
    - Improvement (that is, abatement of symptoms)
    - Plateauing (no changes in symptoms)
    - Decline (that is, worsening of symptoms)
  - When outcomes do show abatement of symptoms, there may be several explanations:
    - Changes are attributed to physiological aging processes
    - Growing self-awareness
    - Exposure to lifetime of experiences that lead to better coping strategies
Need for adult and later-age screening for conditions in aging adults with ASD

- **Sleep difficulties**¹
- **Gastro-Intestinal problems**
- **Anxiety**
- **Depression**
- **Respiratory problems**
- **Seizures**
- **Psychosis - Catatonia**
- **Adverse medication effects from long term usage**

• Studies of mortality indicate higher rates when severe comorbidities are present²

What does all of this mean?
What concerns are utmost

- Variability in function and social/vocational competence
- Potential for compounding conditions which may inhibit independence
- Need for screening and assessment to determine function potential and target growth areas
- Need for lifespan concern over function and health
- Aid with employment and social inclusion
- Recognition that with aging, needs and functions will change
- Planning for older age with respect to continued function
Lifelong impacts

Perkins & Berkman (2012) noted

‘the impact of aging processes and aging-related outcomes for individuals with ASD remains relatively unknown’

‘optimizing the aging process should include

- careful health surveillance and screenings for preventive health, and
- effective management of lifelong chronic comorbid physical and psychiatric issues, along with newly emerging health issues in older age’
UK report titled: “Supporting People With Autism Through Adulthood”

Main points...

- ‘... lack of diagnostic and support services also increase the burden placed on carers, particularly aging parents of adult children still living at home’
- ‘... it is possible that large numbers of adults with autism are currently being supported solely by family carers’
- ‘... such arrangements will not be sustainable indefinitely, and that specialized provision will need to be in place to prevent a crisis once circumstances change and family carers are no longer able to cope’

What can be done?

- Accurate diagnosis of all aspects of condition so lifespan problems can be anticipated
- Special services for children to ensure good health and longer lives
- Supports for carers, such as parents, grandparents, others
- Sufficient resources for specialized support services for adults
- Education, training and life style assistance
- Civic and societal participation – social engagement
- Encouraging exercise and eating healthy
Implications – aiding older people with autism

- Understanding early onset/presence of co-incident conditions so as to modify diets, health practices, and medication usage

- Planning ahead for older age with respect to financial security, preferred living setting, and support networks

- Anticipating potential age-associated problems based on disease trajectory models or studies
Collaborations

• Can the aging network offer viable assistance?
  • Generic aging network support services (senior centers, caregiver assistance, respite, congregate meals) can offer a resource to those adults and families who may wish to use them
  • Minimal specialization for people with lifelong disabilities and no specialization for people with ASD

• Other systems?
  • Elder abuse – protection from abuse, neglect and harm
  • Public safety (Police) – help with missing persons, etc.
  • Health – care for disease or condition presentations
  • Public assistance – financial supports when financially eligible