

## Aging Well with Intellectual/Developmental Disabilities Living on the Edge June 25, 2013

### New Population of Older Persons

**Dianne:** Paralleling the general population explosion of people over 60, a new population of older persons is growing in our communities. For the first time in history, people with intellectual or developmental disabilities (I/DD), such as Down syndrome, autism, or cerebral palsy, are living longer and facing the challenges that come with age. For years people with I/DD did not have many options for integration into mainstream society. However since the 1970s, community living and better healthcare have been two of the biggest reasons for this important societal change. But many are still living on the edge of society.

In Jefferson County we have a double silver tsunami. You are probably aware that about 13% of Jeffco's population is now over the age of 60, and in 25 years that will almost double to 23% or almost 1 in 4. On a nationwide basis the University of Chicago does a lot of research on intellectual or developmental disabilities and they estimate that the population of people with I/DD will double between 2000 and 2030. **However in Jefferson County, the number of people with I/DD doubled in seven years and tripled in 15 years.**

**People Served by DDRC Ages 40+**

Year	40-49	50-59	60-69	70-79	80-89	90-99	Total 60+
1998			24	6	1	0	31
2002		73	39	13	2	0	54
2005		94 (11)	42 (3)	15 (1)	4	0	61
2010	244 (24)	170 (14)	42 (4)	22 (3)	3	0	67
2013	207 (20)	192 (19)	67 (8)	25 (2)	2	1	95

(number on waiting list by age)

People are living much longer thanks to many factors but primarily to changes in society's attitudes such as living in the community—not isolated in institutions or at home—and they receive better health care, nutrition and exercise. The life expectancy of a person with I/DD was 9 in the 1929, 12 in 1947, 50 in 1970, and now about 70.

Now those numbers are impressive but the issues get even more complicated. Most people with I/DD age in ways that are like the general population such as declines in vision, hearing and dental health as well as heart and breathing problems. HOWEVER this aging happens somewhat faster. Instead of considering a person with I/DD "older" at 60 as the federal government does, many are exhibiting aging issues as early as 50 and in some cases even earlier. For example, people with cerebral palsy find that their already-compromised muscular strength further deteriorates with age, limiting what they can do for themselves. Their fatigue and pain increases while their endurance decreases so they experience more stress and depression.

A century ago people with Down syndrome lived to an average age of only nine. Their average lifespan has increased steadily to about 55 now, BUT most people develop the plaques and tangles of Alzheimer's and associated issues in their 40s and 50s—about 10-15 years before the general population. Researchers are actively looking into this and right now believe the reasons are tied to their extra copy of the 21<sup>th</sup> chromosome and the interplay of proteins and genotypes. Understanding Alzheimer's in people with DS may help understand development of Alzheimer's in all people.

**Jo Lynn:** 2013 Definition of I/DD: Two components considered when determining whether an Individual has an Intellectual and /or Developmental Disability are an I.Q. below 70 or a condition such as Down syndrome, cerebral palsy, epilepsy, autism or other neurological conditions resulting in either an impairment of general intellectual function or adaptive behavior similar to that of a person with a cognitive disability. These components must be diagnosed prior to age 22. (Give an example)

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### **We Want to Highlight 12 Current State Conditions**

#### Focusing on People with Intellectual and Developmental Disabilities

1. Dianne just explained that people with I/DD are living longer, as a result we know they age faster than peers without disabilities. This is the first generation of people with I/DD to have the opportunity to grow old. Because of that there will be challenges ahead which we have not yet encountered.
2. Employment opportunities for many people with I/DD have been slow in coming so most have very limited incomes and limited or no options for retirement. It's not that they don't want to work it is that they have a hard time competing for jobs in the workforce.

#### **The next 4 are true for both people with I/DD and older adults**

3. Isolation is no stranger to people with I/DD even though they are in the community they often are not a part of the community and have fewer connections. Isolation also happens to older people without disabilities.
4. While the numbers are growing for people needing assistance as they age, numbers are shrinking for providers that would be able to assist them. This would be true for both people with I/DD and other older people.
5. Since many adults with I/DD grew up in families with siblings some of these siblings are getting increasingly involved with their lives, this also happening with other older people. So you can see in some instances there are real similarities between aging adults with I/DD and older people in general.
6. Between eligibility and limited funding seeking services can be confusing as well as challenging.
7. As aging adults with I/DD outlive their parents, many no longer have family's involved. If no preparations have been made to assist this person, a crisis just may be unfolding.
8. Many parents with a child with I/DD continue to care for them throughout their adult lives. The parents are lifetime caregivers. Many times adult children care for parents as they grow older though this can be challenging the caregiving time frame is shorter.
9. Burnout among caregivers is not uncommon. Many of these families age faster because of wear and tear on their bodies, ongoing stress, lack of sleep and seldom getting a break.
10. People find it difficult to plan or discuss legal issues like guardianship, Power of Attorneys, end of life wishes and especially death. Not being prepared will just make a hard situation more difficult.
11. The need for more education on aging issues of people with I/DD and their parents is vitally important.
12. Last but not least people need people in their lives who are available and not paid.