

The Lives of persons who are Aging with Life Long Disabilities

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Persons with disabilities:

- What is your recollection of a person with a disability when you were young?

Living with a life long disability- what we'll learn:

- Early to mid 1900's: trends, changes
- Outliving doctor's predictions
- (Down Syndrome and Aging)
- Many still living with aging parent
- (Double Jeopardy)
- People coming to agencies in crisis

1900's: trends, changes

- Persons who had IDD were:
 - Often not allowed to go to school due to failure to learn
 - Institutionalized or hidden for shame
 - Used as guinea pigs, tests
 - Abused in all manner of the word
 - Put in fields to die
 - Treated like eternal infants or children

1900's: trends, changes

- Institutions became dumping grounds for any deviant behavior and no longer “schools” to teach persons with IDD
- Pres. Kennedy brought disability to light in the 60's
- PL 94-142 for compulsory education in 1975
- Deinstitutionalization trends in the 80's
- Now a pioneer generation of aging persons with IDD

Outliving doctors predictions

- Parents told to institutionalize or hide their child as they won't live to be more than 10
- Most prevalent with persons with Down Syndrome (obvious disability)
- Because of medical technology, life expectancy is nearly the same as regular population (less with those with DS)

Results of aging with IDD

Professionals not prepared for aging in residential and day program arenas

Nursing homes not prepared for the increase in admissions for persons w/IDD

Aging issues common to the general population including cancer, heart disease, arthritis, Alzheimer's disease, etc.

Community as whole unprepared (medical care providers, senior centers, etc.)

Double Jeopardy...oh my!

- Parents of older population of persons with IDD:
 - Generation believes all doctors say
 - Feel threatened at times by professionals
 - Fear losing their homes and control
 - Feel it's a "life sentence" or lot in life
 - Often don't care for their own needs
 - Fail to pre-plan for the future

Double Jeopardy...oh my!!!

- Issues that arise:
 - Parent becomes less able to care for the person yet will not plan
 - Parent becomes ill, breaks a hip, MI, etc. and the person with IDD's put in emergency home
 - Person w/IDD becomes the caregiver
 - Sibling/family member inherits person
 - Hidden cases called in from other agencies

Double Jeopardy: studies

- 2 major studies:
 - 2001: statewide study and project to attempt to find the hidden cases and assist families in making future plans
 - 2006: Welcome House grant to find the needs of the older person with IDD and to find hidden persons
 - Both studies did not meet the goal of finding the hidden persons in communities
 - Will continue to see growth as generation ages

What we need to know!

- Persons with IDD are aging
- Learn about aging issues as well as IDD issues
- Advocate on behalf of the older population
- Be sensitive to family members who are caring for or releasing their family member to your care

What we need to know!

- How to change our reactions and interventions as people age
- See the person as a person who is aging
- Assist them in the aging process
- Learn about grief issues as the persons you support grieve
- How to assist with end of life issues

Nuts and Bolts of Aging w/IDD

- Alzheimer's Disease:
 - What to watch for: changes in mood, routine, forgetting basic things
 - How to intervene: support, keep directives simple, keep in mind their fear
 - When to go to alternative living arrangement: when safety cannot be provided, when care is out of realm of agency scope

Nuts and Bolts of Aging w/IDD!

- Health care issues:
- professionals not familiar with aging issues or how to handle them (broken hip)
- Incontinence issues as behavioral, not aging
- Chemo, etc. treatment challenges
- Health care POA, guardian needs

Nuts and Bolts of Aging w/IDD!

- Grieving issues:
- Constant changes
- Losses in all areas
- People with IDD grieve all losses too
- Prepare for end of life issues
 - Arrangements, planning, distribution of possessions

Nuts and Bolts of Aging w/IDD!

- Retirement options:
 - Planning to retire from work
 - Transition plans
 - Senior centers
 - Volunteering
 - Adult Day Programs
 - No pensions!
 - Creative planning

Community integration:

- Barriers faced:
 - Fear: general population fearful of person with IDD
 - Apathy: don't care to have relationship with "those" people
 - Stigma: see persons with IDD as lower class citizen

Community integration:

- How to make it happen:
 - Cross training, advocacy, develop relationship
 - Offer to visit each other's sites (WIIFM)
 - Highlight the ABILITIES as opposed to the DISABILITIES
 - Find out the options available in the community besides just senior options (i.e. YMCA, rec programs, etc.)

Do's & Don'ts of Community Integration:

The 10 Steps of Successful Integration:

1. Treat the person with ID as you would treat any other participant.
2. If there are questions, ask the person to help you understand
3. Seek the support, help, advice, guidance of person's care provider/main contact.
4. Get to know the person-their interests, likes, dislikes, history, dreams...
5. Offer the person the opportunity to serve others if they are able and willing.

Do's & Don'ts of Community Integration:

- Focus on what the person can do rather than what they can't do.
- Invite the person to attend a special occasion outside the usual activity (ie: annual picnic)
- Introduce the person to others in the group
- If possible, ask another participant to be a buddy to the person with ID.
- give the person the opportunity to be a star in some activity.

Do's & Don'ts of Community Integration:

What Not to do in Integrating Persons w/ID

- 1.** Don't allow the care provider/staff to force more than one or two persons to start at the same time.
- 2.** Don't provide a special room or place for the person with ID (don't segregate)
- 3.** Don't introduce them as a person with ID
- 4.** Don't talk to them as children or ignore them, talking only through their care provider
- 5.** Don't feel sorry for them because they have ID or allow behaviors that would typically not be allowed by others.

TRIUMPHS:

- For years I have seen persons with ID:
 - Start a real life in their senior years
 - Rise to the occasion of becoming a senior and making friends with non-disabled peers
 - Begin to offer themselves as a servant to the society that has served them all their life.
 - State that they didn't know they could retire and live happily ever after!!!