Facing the Challenge of Full Participation – Lifespan Perspective

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Quality of Life for Older Adults with Down Syndrome

- Wellbeing
  - Physical Wellbeing
  - Social Wellbeing
  - Emotional Wellbeing
  - Productive Wellbeing
Quality of Life – **Physical Wellbeing**

- **Health Challenges –**
  - Ultimately, as with all of us, the lifespan of an individual with Down syndrome depends on any medical conditions he or she may be living with.
  - Alzheimer disease is an important contributing cause of death in adults with Down syndrome.
  - The average age of onset is 51-54 with an average survival from diagnosis of about 5 years.
Quality of Life – **Physical Wellbeing**

- **Health Challenges** –
  - Individuals with Down syndrome also experience medical conditions such as osteoporosis, leukemia, heart problems, chronic respiratory conditions, arthritis, and premature aging.
  - Medication to help with managing symptoms of these conditions may be difficult for an individual to understand - as some medications come with complicated methods of administering the medication.
Quality of Life – Physical Wellbeing

- Health Resources-
  - Medical and supportive services should be initiated with specialists in the field of geriatrics as well as developmental disabilities – a team approach must be implemented with parents and caregivers of adults with Down syndrome.
  - Medication management must be tailored to the individual.
Quality of Life – **Physical Wellbeing**

- **Health Resources**-
  - Adequate nursing and medical planning are critical to wellness and management.
  - Often the first signs of Alzheimer’s in individuals with Down syndrome are changes in behavior and loss of daily living skills – regular health checks and screening can identify treatable conditions.
  - Connect with area community health centers to encourage exercise.
Quality of Life – Physical Wellbeing

- Issues of personal choice
  - Taking medications-
  - Looking after basic hygiene needs-
  - Privacy is important-
  - Staff and community resources with expertise in dementia and Alzheimer’s in individuals with Down syndrome.
Quality of Life – Social Wellbeing

- Because quality of life and general health have improved, individuals with Down syndrome have many choices available – now more than ever.
- This means that good information, experiences and support are crucial for social wellbeing.
Quality of Life – **Social Wellbeing**

- **Challenges –**
  - Older people with Down syndrome are a growing population but their age-related needs are a new frontier as many community services are still geared towards the younger age group.
Quality of Life – Social Wellbeing

- A vision of life for the older adult with Down syndrome.
  - This vision focuses on the individual’s interests, abilities, and dreams.
  - Person-centered planning is important during this life-stage to develop a series of action plans to reach the goals and vision.
Quality of Life – **Social Wellbeing**

- General areas to consider:
  - Romantic and committed relationships
    - Self-determination in social relationships is critical.
    - Caring for another and sexual expression.
  - Maintaining friends and social relationships
    - Maintaining a satisfying and sustainable social network.
    - This can include a social network of work friends, friends with disabilities, paid staff, and family members.
Quality of Life – **Social Wellbeing**

- General areas to consider:
  - Enabling adults to "age in place":
    - The growing numbers of older adults with Down syndrome will increase the need for services and supports that will enable individuals to maintain functioning and continue living as independently as possible, whether they are living with family or in other residential settings.
Quality of Life – Social Wellbeing

- General areas to consider:
  - Examples of such services and supports that can help an individual ‘age in place’ include:
    - personal care services,
    - assistive technologies,
    - home health care and other in-home supports,
    - Assistive technologies could include mobility and communication devices, environmental accommodations, and techniques for maintaining and improving functioning.
  - Ensuring continuity of care in community living
    - Privately personally owned housing,
    - Roommates, house routines.
Quality of Life – Social Wellbeing

- Social opportunities afforded to adults with Down syndrome are correlated with being healthy.
- Regular assessment is suggested to determine the level of activity to meet the changing level of skill of individuals as they age -
  - Regular, small changes seem beneficial to meet the changing needs.
Quality of Life – **Productive** Wellbeing

- Supporting productive and meaningful lives -
  - Older adults with Down syndrome differ widely in their desire to retire, with many preferring to continue participation in work or vocational activities.
  - Given that many of adults are unemployed, underemployed, or participating in day or sheltered programs with little or no pay, the prospect of retirement may take on a different meaning than it does for persons who have been employed most of their adult life and who may have retirement income.
Quality of Life – **Productive** Wellbeing

- Supporting productive and meaningful lives -
- Community inclusion models for individuals in the retirement stage of development can include:
  - links with aging services, such as senior center/companion programs, and adult day care;
  - recreational programs in the general community; and
  - later-life planning educational programs - many community service agencies are developing individualized options, including preferences for working part-time.
  - The success of these options depends on the follow-up support from community service agencies, families, and friends available in the community
  - Development of “alternative-to-work” programs.
Quality of Life – Emotional Wellbeing

- Providing support to families who are primary caregivers and are experiencing diminished capacity: Families continue to be the primary providers of care for adults with Down syndrome.
- Older families become less able to provide care as parents and siblings deal with their own aging, careers, and other caregiving responsibilities.
- Key unmet service needs reported by older family caregivers are for information regarding residential programs, financial plans, and guardian and respite services.
Quality of Life – **Emotional Wellbeing**

- Older family caregivers have concerns about planning for the future when they can no longer provide care to their relative.
  - Future planning entails providing for future residential, legal, and financial arrangements in addition to health care, vocational/leisure activities, and community supports.
  - Many families do not discuss future plans with their relatives with developmental disabilities or other family members.
Quality of Life – Emotional Wellbeing

- Choice-making of individuals with Down syndrome and intellectual impairments is critically important – as challenges have been identified which include:
  - The top barriers identified -
    1) difficulty trusting the service system and professionals;
    2) difficulty affording financial costs of attorney;
Quality of Life – Emotional Wellbeing

○ 3) difficulty finding helpful contact persons within the service system;
○ 4) emotional barriers fighting the service system; and
○ 5) emotional barriers involved with thinking about own mortality.
Quality of Life – *Emotional* Wellbeing

- **End of Life Care**
  - Discuss end-of-life care planning and options
    - These options should mirror the options available to the general public.
  - End-of-life decision making is not a single event that occurs when faced with a critical illness but rather . . .
    - An on-going series of choices
    - Based on life experiences
    - Family and friends support systems
    - As well as health issues
Quality of Life – Emotional Wellbeing

- End of Life Care
  - Individuals with Down syndrome face unique barriers to end-of-life choices
    - Many are often in dependent conditions where others are making decisions on the behalf of the individual.
    - This can result in a range of legal and ethical issues particularly in the legal and health care arenas.
Quality of Life – Emotional Wellbeing

End of Life Care
  - Resources
    - Individuals and their families can receive training and support they need to make choices regarding end-of-life care.
    - Education should be provided to the health care community as well as the general public regarding the differences in facing a terminal illness and living with a chronic disability.
Quality of Life – Emotional Wellbeing

- End of Life Care
  - Resources
    - Help in understanding that end-of-life planning begins well in advance of a terminal illness.
    - Planning for end-of-life care must begin with the understanding of state law and the individual’s capacity to give consent.
Quality of Life – Emotional Wellbeing

- End of Life Care
  - Making decisions
    - Be clear in advocating for individuals with Down syndrome that each person has the right to life, despite the level of disability.
    - Every person has the right to choose curative care, even in the face of a dismal prognosis.
    - The right to palliative care should also be fully extended to individuals who choose this end-of-life treatment option.
Quality of Life – Emotional Wellbeing

- End of Life Care
  - Making decisions
    - The right to palliative care should also be fully extended to individuals who choose this end-of-life treatment option.
    - Healthcare providers must recognize and value the difference between disability management and prolonging the end of life.
Quality of Life – Emotional Wellbeing

- **Recommendations**
  - Discussions regarding end-of-life care should not be a formalized one-time event – it should be a natural discussion that takes place over time.
  - Opportunities for learning should be maximized and individuals should be allowed to participate in their culture’s rituals around death, including funerals, remembrances and other activities.
Quality of Life – **Emotional Wellbeing**

- **Recommendations**
  - Training should be provided to legal guardians as well as family members who may be asked to make decisions regarding end-of-life care.
  - Training should include information that is available to the general public such as:
    - Hospice
    - Pain management
    - Treatment options
Quality of Life – Emotional Wellbeing

- Recommendations
  - Legal needs such as advance directives, guardianship paperwork and related issues should be discussed.
- The Medicaid system must allow for the flexibility for an individual to exercise their choices regarding end-of-life care.
Quality of Life – **Emotional Wellbeing**

- **Financial Resources . . .**
  - Funding must be available to support the use of hospice or related services within the individual’s normal living environment.
  - Confusing and conflicting regulations must be eliminated.
  - Natural deaths must be treated with dignity and respect . . .
  - Rather than with suspicion and investigation.


References


