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Research

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Challenges Facing Older Adults with Intellectual Disabilities

Joan is a 62-year-old woman with mild mental retardation and a disc disease. She has been on and off public assistance for twenty years and has worked sporadically in home care jobs since 1965. Now she is physically unable to perform those duties and has no further skills. Joan needs part-time work that is less physically demanding.

Joan is one of an estimated 2.5 million people in the United States who has an intellectual disability according to the U.S. Equal Employment Opportunity Commission. Moreover, she is one of the estimated 526,000 adults age 60 and older with mental retardation and other developmental disabilities. The numbers will double to 1,065,000 by 2030 when the post World War II baby boom generation born between 1946 and 1964 will be in their sixties (Heller and Factor, 2004).

Current and Future Challenges

The 2004 report from The President's Committee for People with Intellectual Disabilities (PCPID) stated that in 1970 only about eleven percent of people with intellectual disabilities in the United States were over 55. It is expected that by 2040 the percentage will increase to twenty-two percent. Because of the many improvements in health care, the life expectancy of people with intellectual disabilities is close to that of the general population.

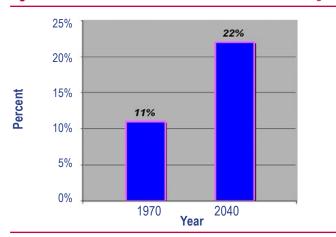


Figure 1. Percent of Persons with Intellectual Disabilities Over Age 55

Source: Data from the President's Committee for People with Intellectual Disabilities (PCPID) A Charge We Have to Keep. 2004. In 2002 approximately 2.79 million of the 4.56 million people with intellectual disabilities lived with family caregivers (Braddock, et al., 2004), and more than twenty-five percent of people with intellectual disabilities lived with parents age 60 or older (PCPID, 2004). What are some of the special challenges of this group, and why should we be concerned?

Increasing Longevity

The increasing longevity of people with intellectual disabilities and the aging and death of caregivers culminate in tremendous challenges for the future. These caregivers/parents fear that their children will not have adequate services to meet their needs and may not have a place to live (Llewellyn, et al., 2004). What individuals with intellectual disabilities need most is the income required to support them financially.

Meeting Housing Needs

Persons with intellectual disabilities who live with a parent/ caregiver age 60 or older will face a housing crisis when their caregiver dies. Even though most qualify and are receiving federal Supplemental Security Income (SSI) benefits, in 2002, for the first time ever, the average national rent was greater than the income received by SSI recipients. Housing affordability and the need for housing assistance are measured by the percentage of income that a low-income household pays each month for housing costs, including utilities. In Wisconsin this percentage was 113 percent, in California 116 percent, and in New York 143 percent (O'Hara and Cooper, 2003).

Meeting Educational Potential

Adults age 55 and older with intellectual disabilities have not had the educational and employment advantages that are now available to their younger cohorts. The Education for All Handicapped Children Act (Public Law 94-142), passed in 1975, required public schools to provide education for students with disabilities, and therefore, special education programs were created through the public school systems. Later concerns regarding these students as they entered adult life, especially adult employment, led to emphasis on school-towork transition and the passage of the Individuals with Disabilities Education Act Amendments of 1997 (IDEA). This bill was reauthorized (IDEA, Individuals with Disabilities Improvement Act) on December 3, 2004 (H. R. 1350).

Education for school-age individuals with intellectual disabilities has since moved from reliance on hard-core academics based on an IQ test to a system of educational supports. These supports include functional life skills based assessment and curriculum frameworks based on a theory of multiple intelligences, with the focus permeating all levels of educational programming from preschool to adult education. In addition, performance-based assessment moves beyond paper-and-pencil tasks and tests student ability to [apply] knowledge (Wehmeyer, 2002).

Expanding Employment Opportunities

Because the older generations of people with intellectual disabilities were born prior to special education, transition programs, and supported employment, many work in sheltered workshops earning very little. Their options in life were to be in a day program, an adult activity center, in a sheltered workshop, stay at home, or perhaps even live in institutions. Supported employment gives people, regardless of their disability, the opportunity to do meaningful work (Wehman, 2000).

A recent comparison study of earnings of both a supported employment group and a group in sheltered employment during a seven-year period showed that the mean cumulative earnings of the supported employment group were \$18,945.00, while the sheltered employment group earned \$8,364 (Kregel and Dean, 2003). Supported employment also gives individuals more of a choice in the labor force than sheltered employment provides. Employment in supported, integrated settings provides greater job satisfaction and a higher quality of life (Beckman, et al., 2004).

Realizing Adult Life Outcomes

Included in the IDEA were requirements for transition to postschool education for students with disabilities. Under the IDEA, 1997, schools are required to incorporate transition planning in the Individual Education Plan (IEP) by age sixteen. Transition services provide education beyond high school and typically include vocational training and employment, so that students can become successful, productive members of the adult community.

As early as 1985, research was already showing that students with disabilities who experienced paid work as a part of their

high school transition program were four times more likely to be employed as adults (Hasazi, et al., 1985). A more recent study indicated that those who received transition services beyond graduation experienced significantly higher earnings for two years after the termination of services than did youth who did not receive such services. This same group continued to have positive outcomes and was employed at higher rates four to six years later than those youth who did not receive transition services (Izzo et al., 2000). Transition programs give students opportunities to work with community agencies and have paid work experiences at employer work sites.

The Gap in Services for Older Adults

So what about the older person with an intellectual disability who did not have the advantages of transition services in high school, paid work experience, functional academics, and employment opportunities? While unemployment rates, low earnings, and dependence on income benefit programs are concerns for all persons with intellectual disabilities, these problems are more pronounced among the senior population. Their low rates of employment demonstrate the need for improved employment services (Yamaki and Fujuira, 2002).

A Strategy for Improvement

The Senior Community Service Employment Program (SCSEP) is a surviving portion of the War on Poverty and is designed to assist low-income persons who are 55 and older and unemployed to survive in the short term and re-enter the competitive labor market in the medium term.

Funding sources such as SCSEP could provide services similar to special education and, in particular, transition services to seniors with intellectual disabilities. These older individuals could provide a much-needed resource in the workplace. The President's Committee for People with Intellectual Disabilities (PCPID, 2004) reports that there is a projected shortage of 4.8 million workers in the labor market over the next ten years. People with intellectual disabilities can work and want to work. Work gives a dimension and meaning to one's life, but more importantly, it generates income, and this income assists the person in achieving economic independence (Davies, et al., 2000).

SCSEP accomplishes this through a program of subsidized work experience, paid training, and job placement assistance. Most of the participants in the program have significant and often multiple barriers to employment that include a lack of current work experience and employable skills. Older adults with intellectual disabilities are underemployed and underserved by programs such as SCSEP, and this type of program has the capacity to incorporate more of these individuals and provide meaningful employment outcomes.

The concept of "host sites" through programs such as SCSEP could replicate transition services. This type of program sets no artificial time limits as to when an individual must leave the host site and enter unsubsidized employment. The individuals learn not only work skills, but also learn social skills and workplace behaviors at their host sites. In addition, host sites would enable another important part of transition services — assessment — to take place. Assessment for career development, vocational decision-making, and transition planning is an essential process (Sitlington et al., 1997).

From a public policy perspective, the employment of individuals with intellectual disabilities would reduce dependence on public assistance now and in the future. Employment can enable these individuals to live on their own rather than in a residential facility, which is not only more cost effective but also allows for a better quality of life. Recent studies on deinstitutionalization in Australia found that most individuals who had moved from institutions were enjoying lifestyles similar to those without intellectual disabilities (Young and Ashman, 2004).

Employment for people with intellectual disabilities allows them the opportunity to contribute to society by producing a product or providing a service, as well as by paying taxes instead of receiving long-term financial public assistance. For both economic and qualityof-life reasons, the replication of transition services through programs such as SCSEP and host sites would enable seniors with intellectual disabilities to live independent, fulfilled lives.

Joan was enrolled in a SCSEP program and was assigned to a senior center as her host site. Joan worked 20 hours a week in the nutrition program at the senior center as part of the food service staff. After a year, as the result of her experience at the senior center, Joan was offered a part-time job as food service worker at a local military base. Her new job pays her \$8.65 per hour with benefits. Her employment allows Joan to live with dignity and independence.

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