



Barriers and Policy Goals

Children and adults with Down syndrome and other significant disabilities can live in their own homes, work in the community, vote, recreate and enjoy all the benefits of living in a free society. This is a profound shift from a model whereby individuals were segregated into institutional settings, received no education or training and were confined to a life in which all the benefits of society were denied. In spite of the fact that much progress has been made in our recognition of the rights of and treatment of individuals with Down syndrome, many barriers remain.

Barriers

Education

Our public school system continues to reflect poor public attitudes for individuals with Down syndrome as reflected in the continued segregation and has low expectations in educating students with Down syndrome from preschool to postsecondary opportunities. In fact, challenges grow in the implementation of education laws, specifically the Individuals with Disabilities Education Act (IDEA) and No Child Left Behind (NCLB). In spite of the fact that some quality postsecondary program opportunities on college campuses exist, these opportunities are, for the most part, financially and programmatically unavailable to most teen-agers with Down syndrome.

Adult Services – Community Living and Employment

Currently, Medicaid provides the lion share of funding for adult support services needed by individuals with Down syndrome to create meaningful and independent lives in the community. These services are needed throughout our children's lives, particularly when parents are aging and unable to provide the support needed.

However, current public policy promotes dependence on public benefits, discourages work and prohibits individuals from saving and developing assets. The Medicaid program promotes expensive institutional care while long waiting lists exist for Medicaid waiver, community based support services that promote consumer choice, work and independence.

Health Care

Individuals with Down syndrome face discrimination in health care coverage because of "preexisting condition" clauses. In many parts of the country, the health care that is available is inadequate. In



particular, there is a lack of comprehensive clinical care with a focus on the specific needs of children and adults with Down syndrome. Past research has more than doubled the lifespan of individuals with Down syndrome. Researchers would like to continue that work and also improve life quality by addressing cognitive issues. However, these efforts cannot occur at a meaningful level because funding for NIH research has significantly decreased in the past five years.

Policy Goals

From infancy to adult live, changes need to occur that remove the barriers discussed above. This includes

- Changing Medicaid law so that consumers and families can choose, through a self-determination model control over their own resources. This will enable families and individuals to better meet their individual needs, promote maximum economic independence through work and savings and remove the institutional bias from the current Medicaid program.
- Promoting quality inclusive educational opportunities throughout children's lives from preschool through post-secondary education. This includes access to the general curriculum, greater accountability in educational programs, better implementation of current education laws (NCLB and IDEA) and fostering development of post-secondary programs.
- Promote health care and research efforts that provide access to much needed services and offer the opportunity to improve the quality of life for individuals with Down syndrome.