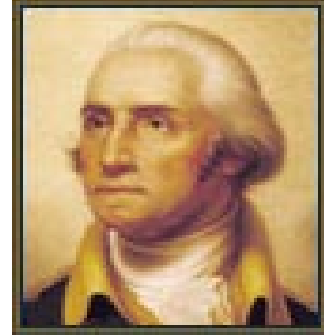# Planning for Post School Outcomes and Emerging into Adulthood: A Resource Guide for Parents of Youth with Intellectual Disabilities

By: Donna Martinez

In the forward to his New Freedom Initiative for People with Disabilities (2007) [1] President George W. Bush assures

> Today, people with disabilities have greater access to assistive and universally designed technologies, receive broader opportunities to excel in the classroom, are integrating themselves into the workplace, and are participating actively in every facet of life in their communities. We are fighting against low expectations, and we are winning. Individuals and organizations of every description are answering the clarion call to make things better, not just for people with disabilities, but for everyone.(http://tinyurl.com/yt9pka [2])

This same vision of opportunity and raised expectations are also set out in federal education laws such as Individuals with Disabilities Education Act (IDEA) [3] and No Child Left Behind Act [4]. With these laws as our guide, we may better envision a future full of opportunity and potential for youth with intellectual disabilities. Along with their graduating classmates, many youth with intellectual disabilities are ready to launch into their adulthood with plans for continued postsecondary learning, expectations of personal choice in meaningful employment, and the anticipation of establishing a home in their community.

However, steps needed to claim a life in the community can be not only daunting, but also confusing and frustrating. Today, as many as 90% of persons with intellectual disabilities remain unemployed (President's Committee for People with Intellectual Disabilities 2004). Young people with disabilities and their families must leave behind the familiar protections and supports of IDEA to venture into a myriad of often befuddling regulations on health, employment, housing, and support services, each with their specific and separate legislation, policies, and personnel.

John O'Brien in his forward to *Make the Day Matter! Promoting Typical Lifestyles for Adults with Significant Disabilities* by Pamela Walker and Patricia Rogan (2007) suggests seven qualities of leadership that will aid in changing skeptical and sometimes hostile audiences to rethink assumptions, inform practice, and deepen their appreciation

about the potential found in our family members and friends with intellectual disabilities. Those seven qualities in need of encouragement are:

1. Impossibly high expectations for what we can learn in order to assist people with substantial disabilities to achieve
2. Close personal partnership with people with substantial disabilities
3. Priority on creating a pathway to success for the people with the least access to opportunity
4. Relentless belief in people's capacity…
5. Opportunism: seizing any opportunity to actually demonstrate what people with substantial disabilities can do
6. Fanatic commitment to show and tell an passion to debate the merits of different approaches
7. Willingness to abandon ineffective or outmoded practices and structures, even when you invented them yourself (Walker and Rogan 2007, p. xvi-xvii.)

What follows are suggested goals for young adults with disabilities and their families that will guide them towards their "New Freedom" in adulthood. These suggested goals may help keep the bar of expectations high for young adults with intellectual disabilities as they strive to have a life like ours. At the end of the article a listing of online resources provides added information and guidance.

Self Determination and Self Advocacy for Successful Futures Planning

People with intellectual and developmental disabilities are capable of determining their wants and needs when provided opportunities to express themselves. Leadership opportunities, the right to self determination or choice making, and person-centered planning characterize successful components of educational and school experiences that provide youth with intellectual disabilities the necessary skills for a smooth emergence into adulthood. Coupling high expectations with consistent opportunities for self determined choice making at home, in school, and in the community sets the stage for a future of greater independence.

One of the first places students can try out their advocacy skills is in leading their own Individual Education Plans (IEP) and their Transition Planning (ITP). Emerging adults use their personal dreams and desires to guide them in planning their transition from public school and childhood into their self determined, personal choice making life as an adult with the support of family and professionals. However moving rhetoric into reality does not happen successfully without the self determined commitment of the team of individuals involved in the process (e.g., students, teachers, parents, paraprofessionals, supports service personnel, administrators) skilled in collaboration and risk-taking "to be facilitators and not enablers" (Price, Wolensky et al. 2002 , p. 109.) To learn more about IEPs and special education visit the National Dissemination Center for Children with Disabilities (NICHCY) (www.nichy.org).

Transition into Life Long Learning

There has been an increased realization that postsecondary education is necessary for meaningful participation in the modern economy. In 2004, 2.8 percent of all entering freshmen at four-year colleges reported having a learning disability. At community colleges, it is estimated that nearly 4 percent of the 11 million students enrolled in two-year institutions identify themselves as learning disabled. In 1985, only 1.1 percent of first-time, full-time freshmen in the U.S. had done so (Ward and Merves 2006, Summer).

However, while Title I of the Americans with Disabilities Act (ADA) has assured students' their civil rights to access postsecondary education with needed accommodations, the National Council on Disability notes students with disabilities (estimated to represent nearly 10 percent of all college students) may experience postsecondary outcomes far inferior to those of their non-disabled peers (Frieden 2004).

Despite the challenges students with disabilities face, college education opportunities are emerging for an increasing number of people, including for students with intellectual disabilities (Blackorby and Wagner 1996; Hart, Zimbrich et al. 2005). Currently, over 100 postsecondary education options exist nationwide for students with intellectual disabilities utilizing a variety of models (Hart, Grigal et al. 2006; Neubert and Moon 2006; Smith and Walker 2007). Students who enroll in postsecondary education experience show growth in the areas of academic and personal skill-building, employment, independence, self-advocacy, and self-confidence. (Hart, Zimbrich et al. 2005; Hart, Grigal et al. 2006). A significant barrier to the dream of postsecondary education is obtaining adequate support and services to participate in postsecondary educational opportunities both in the community of the college and on the political scene (Hart, Grigal et al. 2006). Amendments proposed in bills by both Houses of Congress for the reauthorization of the Higher Education Act of 1968 include new incentives and supports such as work study programs for students with intellectual disabilities who are enrolled in college (H.R. 609, the College Access and Opportunity Act of 2005), funding for model programs, and provision of technical assistance as universities and colleges explore the addition of and improve postsecondary options on their campuses (S. 1642 Higher Education Amendments of 2007). By keeping college as a future option for students with intellectual disabilities to explore after high school, the statement is clear that there is a strong belief in their potential for success.

Self-Directed Employment Success and Satisfaction

For most adult Americans, their life's goal of gainful and productive employment provides them a source of dignity, purpose, and identity. Steps taken to secure self-directed employment for people with disabilities requires planning and brainstorming, "thinking out of the box," to develop not only the job, but also the supports needed to be successful and to address the inevitable changes that occur over time (Rogan, Callahan et al. 2007). The fundamental principal of ADA assures that people who want to work have an equal opportunity to do so. One option, supported employment, is paid employment for the person with the most significant disabilities whom competitive employment has not traditionally occurred in an integrated, real-work setting. One-Stop Centers provide employment-related services within all states through a single seamless system of service

networks. The goal of One-Stop Centers is to conveniently and efficiently make accessible to job seekers and the employer customers, employment identification and recruitment, education, and training services.

Overcoming the Disincentives to Work

Ticket to Work and Work Incentives Act provides a means to over come the historic barriers to the independence and full inclusion of persons with disabilities. The Ticket Programs permits people receiving Social Security Benefits to obtain employment without loss to those benefits. Since 2002, Ticket packages have been sent to approximately 75,000 new beneficiaries each month. The voluntary program allows individuals who use the ticket to
1. Access employment services and supports to help them start or return to work;
2. Hold on to their document to use at a later time; or
3. Choose not to use it.
Either way, SSDI and SSI benefits are not affected.

Ticket to Work packages includes instructions, information and the actual read, white, and blue Ticket document. An individual's Ticket serves as proof of Social Security Administration's (SSA) agreement to pay an Employment Network or EN (SSA-approved organizations that provide job training and other employment services and supports to Ticket holders who want to work) for needed services. Payments are structured to encourage ENs to provide the best possible assistance. Individuals interested in the Ticket to Work Program should call the toll-free helpline at 1-866-968-7842 (V) or 1-866-833-2967 (TTY).

Another SSI provision to help people with disabilities save some money and return to work is the Plan to Achieve Self-Support or PASS. Individuals with disabilities set aside money and/or things he or she owns to pay for items or services need to achieve a specific work goal. Examples of items that may be paid through the PASS include training or education, services needed, supplies to start business, equipment and tools, transportation and uniform requests. The PASS also allows people to set aside money for installment payments as well as a down payment for things like a vehicle, wheelchair or computer if needed to reach work goal. Once the individual has determined his or her goal for employment and what items or services will be needed to meet that goal, the cost of those needs, a friend or various agencies may assist in setting up the PASS. A business plan is needed for those individuals planning for self-employment. Agencies may included vocational rehabilitation (VR) counselor; an organization that helps people with disabilities; Benefits Specialists or Protection and Advocacy organizations who have contracts with SSA; Employment Networks involved in the Ticket to Work program; the local Social Security office. The PASS is submitted to the SSA for approval.

At the time of this writing, the Ticket to Work and Work Incentives Advisory Panel established within the Social Security Administration under legislation to advise the President, the Congress and the Commissioner of Social Security is hard at work gathering information about the issues related to work incentive programs, planning and

assistance for individuals with disabilities and the Ticket to Work and Self-Sufficiency Program established under this Act. The panel, a bipartisan group of twelve private citizens, four of whom were appointed by the President, four by the Senate and four by the House of Representatives, is gathering information from consumers and stakeholders across the nation to inform their final report expected to be released Monday, December 3, 2007. To learn more about the panel and how you may share your experiences in the Ticket to Work process please visit their website at: http://www.ssa.gov/work/panel/index.html [5]

Moving into the Neighborhood

Learning the skills to live independently may seem easier than actually finding a place to call ones own when the potential home owner is an individual with a disability. A crucial service that helps support people with disabilities to live independently and in the community is Medicaid. A state's Medicaid program and its various waivers pays for a comprehensive range of home and community services that provide alternatives to unnecessary institutional care. Services and amount of funding are determined by the states. Each state has a mix of programs and funding sources combined with other sources of federal, state and local dollars that fund home and community based services.

Purchasing or renting a home is often significant passage into adulthood and a pivotal piece of federal disability policies found in the ADA and Fair Housing Act. Federal regulations and state initiatives assure access to public housing providing people with disabilities greater opportunities to live in the home of their choice. Through creative builders and universal design, any private residence may be made accessible to people with disabilities.

Financial Security

The Social Security and Supplemental Security Income disability programs administered by the Social Security Administration provide assistance to people with disabilities. Social Security Disability Insurance (SSDI) pays benefits to the individual with a disability and certain members of the family if they are "insured," meaning that they worked long enough and paid Social Security taxes. On the other hand, Supplemental Security Income (SSI) pays benefits based on financial need to meet basic needs of food, clothing, and shelter and Medicaid to pay doctor and hospital bills. A child from birth to age 18 may receive monthly payments based on disability or blindness if he or she has an impairment or combination of impairments that meets the definition of disability for children; and the income and resources of the parents and the child are within the allowed limits. Under both of these programs, the child must not be doing any "substantial" work, and must have a medical condition that has lasted or is expected either to last for at least 12 months, or to result in death.

At age 18, for disability purposes in the SSI program, a child is considered an adult. Different medical and nonmedical rules apply when deciding if an adult can get SSI disability payments. The income and resources of family members no longer count when

deciding whether an adult meets the financial limits for SSI, only the young adult's income and resources. The child's medical condition is reviewed when he or she turns age 18 usually during the one-year period that begins the child's 18th birthday. If the child was not eligible for SSI before his or her 18th birthday because of family income and resources, he or she may become eligible for SSI at age 18.

Individual Development Accounts (IDA) is one way of saving towards purchasing an asset - most commonly buying their first home, paying for post-secondary education, or starting a small business. IDAs are designed to help low income people invest in their future through special matched savings accounts. Similar to an employer match for 401 (k) contributions, the match incentive contributions are provided through a variety of government and private sector sources. Organizations that operate IDA programs may include financial literacy education, training to purchase their asset, and case management.

Recognizing that family contributions or building up ones savings accounts can only improve the over all quality of life of an individual with a disability, supporters are cautioned to be aware of how added income affects possible government benefit programs (e.g. SSI, Medicaid Waivers/Home Based Community Supports). Supplementary contributions are generally permitted as long as they do not duplicate government benefit programs. Because the government regulations are very strict, and carefully monitored, it is advisable to first check with a financial advisor well versed in estate planning for people with special needs (e.g. special needs trusts).

Emerging into Adulthood

Transition into adulthood for youth with disabilities is an exhilarating time of hope and expectations of independence when wrapped in a clear vision that a meaningful and productive life is possible. As O'Brien states in his forward to *Make the Day Matter! Promoting Typical Lifestyles for Adults with Significant Disabilities*, "We humans have a breathtaking capacity to invent when we choose to step into the tension between our vision of a desirable future and our current reality" (Walker and Rogan 2007, p. xv). Planning for a home, finding the job that fits is not always easy. There will be barriers encountered and creativity demanded on the part of service providers, families, and supporters. And while we may face perplexing and at times even painful challenges to surmount the issues standing in our way, they need not be a worry when commitment to valued social roles for our friends and family members with intellectual disabilities frame our planning for a meaningful and self determined post school life in the community.

Online Resources

Laws and Policies for Young Adults with Disabilities
The New Freedom Initiative: http://www.hhs.gov/newfreedom/ [6]
IDEA, 2004: http://www.ed.gov/policy/speced/guid/idea/idea2004.html [7]

NICHCY's Building the Legacy: A Training Curriculum on IDEA 2004
http://www.nichcy.org/training/contents.asp [8]
The Rehabilitation Act Of 1973, P.L. 93-112, Section 504 (ADA):
http://www.usdoj.gov/crt/ada/adahom1.htm [9]
Security Supplemental Income (SSI): http://tinyurl.com/275bgl [10]
Americans with Disabilities Act: http://www.usdoj.gov/crt/ada/adahom1.htm [11]

Transition and Person Centered Planning
NICHCY: http://www.nichcy.org/resources/transition101.asp [12]
TASH: http://www.tash.org/mdnewdirections/planning.htm [13]
Person Centered Planning Education Site: http://www.ilr.cornell.edu/edi/pcp/ [14]
Sample Person Centered Plan: Postsecondary Education
http://www.thinkcollege.net/families/index.php?page=plans [15]
Sample Person Centered Plan: Job Seeker
http://www.communityinclusion.org/article.php?article_id=54 [16]

Self Determination and Self-Advocacy
Center for Self Determination http://www.self-determination.com/ [17]
Self Advocates Becoming Empowered http://www.sabeusa.org/ [18]
Kids as Self Advocates http://www.fvkasa.org/ [19]
Self-Determination: Supporting Successful Transition:
http://www.ncset.org/publications/viewdesc.asp?id=962 [20]
American Association on Intellectual and Developmental Disabilities Fact Sheet:
http://www.aamr.org/Policies/faq_movement.shtml [21]
Self Advocacy Speaking for Yourself: http://thechp.syr.edu/saspeak.htm [22]

Student Led IEP
Student Guides to IEP: http://www.nichcy.org/stuguid.asp [23]
Research: Student-Led IEPs and Self Determination:
http://hawbaker.pls.iowapages.org/id2.html [24]
Council for Exceptional Children's Division on Career Development and Transition-
Student Involvement in the IEP Process:
http://www.dcdt.org/pdf/DCDT_Fact_Sheet_IEP_Process.pdf [25]

Transition and Postschool Outcome Reports
National Postschool Outcomes Center: http://www.psocenter.org [26]
The Postoutcomes Network: http://www.ncset.hawaii.edu/default.htm [27]
National Transition Longitudinal Study 2 Reports: http://www.nlts2.org/gindex.html [28]
National Council on Disabilities report:
http://tinyurl.com/2aa6x2 [29]
Impact: Transition http://ici.umn.edu/products/impact/163/163.pdf [30]

Postsecondary Education Resources
Think College: http://www.thinkcollege.net [31]
Transition Coalition: http://www.transitioncollation.org [32]
HEATH: http://www.heath.gwu.edu [33]

Transition to College/ Post-Secondary Education Research Center (PERC):
http://tinyurl.com/2hlnvx [34]
Disability.gov, The New Freedom's Initiative for Online Resource for Americans with
Disabilities-Colleges and Universities: http://tinyurl.com/2bgpdb [35]

Resources for Employment Planning
Supported Employment: http://www.dol.gov/odep/archives/fact/supportd.htm [36]
National Center on Secondary Education and Transition (NCSET):
http://www.ncset.org/default.asp [37]
OSERS: http://tinyurl.com/2xtxq5=>http://tinyurl.com/2xtxq5 [38]
One-Stop Centers: http://www.onestops.info [39]

Ticket to Work:
http://www.yourtickettowork.com/index [40]
http://www.ssa.gov/work/Ticket/ticket_info.html [41]
http://www.dol.gov/odep/pubs/ek00/ticket.htm [42]

PASS Plans:
http://ruralinstitute.umt.edu/transition/SSAworkincent.asp [43]
http://www.passplan.org/ [44]
http://www.socialsecurity.gov/disabilityresearch/wi/pass.htm [45]
National Collaborative on Workforce and Disability: http://www.ncwd-
youth.info/about_us/index.html [46]
Association for Persons in Supported Employment: http://www.apse.org [47]

Living a Life Like Yours in Home and Community
Home Community Based Services Clearinghouse: http://www.hcbs.org [48]
Centers for Independent Living: http://www.ilusa.com/links/ilcenters.htm [49]
Community Life: http://tinyurl.com/yv69xv [50]
Community Imperative:
http://thechp.syr.edu/community_imperative.htm [51]
Understanding Medicaid Home and Community Services: A Primer:
http://aspe.hhs.gov/daltcp/reports/primer.htm [52]
Social Services Block Grant (SSBG) Program:
http://www.acf.hhs.gov/programs/ocs/ssbg [53]
Office of Education and Rehabilitative Services (OSERS)
http://www.ed.gov/about/offices/list/osers/index.html [54]
Home Ownership for People with Mental Retardation:
http://www.aamr.org/Policies/pdf/homeownership.pdf [55]
Accessible and Affordable Housing Options: http://tinyurl.com/2rhqc2 [56]
Center for Universal Design: http://design.ncsu.edu/cud/ [57]
Webcast-Symposium on Homeownership for Persons with Disabilities:
http://www.hhs.gov/od/webcast.html [58]
Disability.gov, The New Freedom's Initiative for Online Resource for Americans with
Disabilities-Housing: http://tinyurl.com/2rhqc2 [59]

Disability.gov, The New Freedom's Initiative for Online Resource for Americans with Disabilities-Community Life: http://tinyurl.com/yv69xv [60]

Financial Supports
What You Need to Know When You Get Supplemental Security Income: http://www.ssa.gov/pubs/11011.pdf [61]
Benefits for Children With Disabilities: http://www.ssa.gov/pubs/10026.pdf [62]
Individual Development Accounts:
http://tinyurl.com/ypc5zp
http://tinyurl.com/367k6c [63]
http://tinyurl.com/367k6c [64]
Estate Planning and Special Needs Trusts:
http://www.familyvillage.wisc.edu/general/estate.htm [65]
Planning for Children with Special Needs: http://tinyurl.com/yqqj86 [66]

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Donna Martinez is a doctoral candidate at The George Washington University and Director of The GW-HEATH Resource Center Online Clearinghouse for Postsecondary Education for Students with Disabilities. Her research is in Parent Involvement in the Transition of Their Young Adult Child with Intellectual Disabilities. Donna has been a special education teacher for 13 years. She has participated in invitational conferences and committees on transition. She is a strong advocate providing testimony related to IDEA, Medicaid, and Ticket to Work. She is Government Relations Committee Chair for the Council for Exceptional Children, Division on Career Development and Transition, represents her School Board on the Fairfax County Public Schools Advisory Committee on Students with Disabilities, and is a Board Member of The Arc of VA, TASH-VA and National Coalition on Self Determination. She is also a parent of two young adults, one a young man with Down syndrome.

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Smith, V. and P. M. Walker (2007). Creating inclusive postsecondary educational environments: 57-73.

Walker, P. and P. Rogan (2007). Make the day matter! Promoting typical lifestyles for adults with significant disabilities. Balitmore, MD, Paul H. Brookes.

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Source URL:
http://www.heath.gwu.edu/node/376

Links:
[1] http://www.hhs.gov/newfreedom/
[2] http://tinyurl.com/yt9pka
[3] http://idea.ed.gov/
[4] http://www.ed.gov/nclb/landing.jhtml
[5] http://www.ssa.gov/work/panel/index.html
[6] http://www.hhs.gov/newfreedom/
[7] http://www.ed.gov/policy/speced/guid/idea/idea2004.html
[8] http://www.nichcy.org/training/contents.asp
[9] http://www.usdoj.gov/crt/ada/adahom1.htm
[10] http://tinyurl.com/275bgl
[11] http://www.usdoj.gov/crt/ada/adahom1.htm
[12] http://www.nichcy.org/resources/transition101.asp
[13] http://www.tash.org/mdnewdirections/planning.htm
[14] http://www.ilr.cornell.edu/edi/pcp/
[15] http://www.thinkcollege.net/families/index.php?page=plans
[16] http://www.communityinclusion.org/article.php?article_id=54
[17] http://www.self-determination.com/
[18] http://www.sabeusa.org/
[19] http://www.fvkasa.org/
[20] http://www.ncset.org/publications/viewdesc.asp?id=962
[21] http://www.aamr.org/Policies/faq_movement.shtml
[22] http://thechp.syr.edu/saspeak.htm
[23] http://www.nichcy.org/stuguid.asp
[24] http://hawbaker.pls.iowapages.org/id2.html
[25] http://www.dcdt.org/pdf/DCDT_Fact_Sheet_IEP_Process.pdf
[26] http://www.psocenter.org/
[27] http://www.ncset.hawaii.edu/default.htm
[28] http://www.nlts2.org/gindex.html
[29] http://tinyurl.com/2aa6x2
[30] http://ici.umn.edu/products/impact/163/163.pdf
[31] http://www.thinkcollege.net
[32] http://www.transitioncollation.org
[33] http://www.heath.gwu.edu
[34] http://tinyurl.com/2hlnvx
[35] http://tinyurl.com/2bgpdb
[36] http://www.dol.gov/odep/archives/fact/supportd.htm
[37] http://www.ncset.org/default.asp
[38] http://tinyurl.com/2xtxq5
[39] http://www.onestops.info/
[40] http://www.yourtickettowork.com/index
[41] http://www.ssa.gov/work/Ticket/ticket_info.html
[42] http://www.dol.gov/odep/pubs/ek00/ticket.htm

[43] http://ruralinstitute.umt.edu/transition/SSAworkincent.asp

[44] http://www.passplan.org/

[45] http://www.socialsecurity.gov/disabilityresearch/wi/pass.htm

[46] http://www.ncwd-youth.info/about_us/index.html

[47] http://www.apse.org/

[48] p://www.hcbs.org/

[49] http://www.ilusa.com/links/ilcenters.htm

[50] http://tinyurl.com/yv69xv

[51] http://thechp.syr.edu/community_imperative.htm

[52] http://aspe.hhs.gov/daltcp/reports/primer.htm

[53] http://www.acf.hhs.gov/programs/ocs/ssbg/

[54] http://www.ed.gov/about/offices/list/osers/index.html

[55] http://www.aamr.org/Policies/pdf/homeownership.pdf

[56] http://tinyurl.com/2rhqc2

[57] http://design.ncsu.edu/cud/

[58] http://www.hhs.gov/od/webcast.html

[59] http://tinyurl.com/2rhqc2

[60] http://tinyurl.com/yv69xv

[61] http://www.ssa.gov/pubs/11011.pdf

[62] http://www.ssa.gov/pubs/10026.pdf

[63] http://tinyurl.com/ypc5zp

[64] http://tinyurl.com/367k6c

[65] http://www.familyvillage.wisc.edu/general/estate.htm

[66] http://tinyurl.com/yqqj86

[67] http://www.luminafoundation.org/

[68] http://www.gwu.edu