

## **The Transition of Children with Disabilities From the Public School System**

*By Megan G. Morrissey*

One morning in 1988, Nathaniel, an active and healthy ten year old Eagle Scout, went on a hike with his family to Red Rock Canyon, a national park outside of Las Vegas, Nevada.<sup>1</sup> Hiking was just one of the many activities that Nathaniel enjoyed—he also loved sports, music, and had recently become an alter server at his church.<sup>2</sup> Little did he or his family expect on that fateful morning that on that hike, Nathaniel would venture too close to the edge of the cliff where he would trip and fall close to 100 feet, leaving him severely mentally and physically disabled. In the ensuing months, the devastating reality of Nathaniel’s condition became increasing and achingly clear; Nathaniel’s life and the lives of all of his family members would never be the same.

Programs made available for school aged children offered the first round of opportunities to help Nathaniel and his family cope with his disabilities, however, on the eve of his 22<sup>nd</sup> birthday, Nathaniel was no longer eligible to participate in the school system, and Nathaniel had nowhere to go—he was forced to stay at home.<sup>3</sup> On Nathaniel’s 22<sup>nd</sup> birthday, his parents felt they were on the edge of another kind of cliff with Nathaniel, knowing that his life, and theirs, were about to go through a huge transition. On this day, instead of dealing with the prospect of a doctor’s medical diagnosis, Nathaniel’s parents were contemplating Nathaniel’s future in another context. This time they were all poised on the edge of a free fall through a dizzying maze of information and decisions to be made in finding and accessing the right program that could address Nathaniel’s unique and long term needs now that he had “aged out” of the school system.

## **I. Introduction**

While the school system provides a framework to implement the guaranteed right for a child to receive care and education from the government until age 21, parents have the persistent fear that their developmentally disabled or handicapped young adult may fall through the cracks and languish after “aging out” of the school system.<sup>4</sup> Families confronted with this fear have no choice but to educate themselves about the options available for the care of their child. In an attempt to discover the best program for their child, these families may experience a period of trial and error. It is difficult for families to balance their desire to find the least restrictive environment feasible for their child against their child’s need for specialized care and attention. Given these competing concerns, it becomes increasingly complex for families to choose the right program amidst the confusing array of public and private programs and service providers. Even if such a plan or program is found, many such programs are frequently under-funded and often result in a long waiting list to obtain services. In addition, the programs that are offered often do not tailor their services to the individuals, which ultimately results in the inefficient use of taxpayer funds. The lack of available government services, coupled with the failure to provide effective assistance of trained personnel to educate the mentally and physically disabled individuals and their families as to the various programs and viable alternatives, may be considered tantamount to a denial of the disabled individual’s right to exercise and enjoy the basic civil rights to which we are all entitled.

This note will explore how the treatment of the disabled person has evolved historically and how society’s acceptance of disabled individuals has changed over the years. That perception is but one aspect of the problem that disabled youngsters face when transitioning from the nuclear family to participation in programs as aging adults who seek to be assimilated into

the larger society. Where local, state, and federal programs have been effective in solving the problems associated with shelter, employment, and the medical needs of those with disabilities, there are scattered examples where specialized programs have succeeded in filling the gaps. Those programs that are innovative and focused on providing the additional services and needs should serve as models for further implementation. Part II of this article will address the history of government involvement with the disabled and the progress and problems associated with the current education system. Traditionally, it will be seen that the public schools often fail in facilitating the transition needs of their young disabled population when those individuals are at their most confusing and vulnerable crossroad. Part III will describe what legal rights and governmental assistance are available to the disabled individual and his or her family after “aging out” of the public school system and state financed residences. And Part IV will focus on how states and communities have attempted to address the interrelated issues of transition from school to adult services through a series of primarily privately funded programs. In addition, this section will highlight one program that has been particularly successful for mentally and physically disabled individuals, their families, as well as for the community.

## **II. History of Education Legislation for Individuals with Disabilities**

Throughout history, people with disabilities have been viewed as incompetent in their capacity for decision-making and development. Prior to the mid 19<sup>th</sup> century, the United States’ citizens with disabilities were generally kept in the family home, with little or no support from the government or their local communities.<sup>5</sup> Then for over a hundred years, lifelong placement in large residential facilities or “institutions” was the predominant approach of dealing with the mentally disabled.<sup>6</sup> By the mid 1950’s, public opinion shifted from the belief that mentally disabled individuals should be institutionalized to the conviction that habilitative intervention

would better serve the State's moral obligation.<sup>7</sup> In the 1960's, President Kennedy called for more community-based care for the disabled, heralding the "deinstitutionalization" movement, which was followed by the Nixon's Administration concerted effort to reduce the population of public institutions, which housed nearly 200,000 mentally disabled.<sup>8</sup>

The movement of discouraging institutionalizing the mentally disabled gained momentum with the civil rights movement and the *Brown v. the Board of Education* decision, when many parents of children with disabilities turned to the courts to seek redress. Two U.S. District Court cases provided the foundation for a state and local obligation to educate children with disabilities appropriately. In *Pennsylvania Association for Retarded Children (PARC) v. Pennsylvania* (PA, 1971) and *Mills v. Board of Education* (DC, 1972), the courts established the right of children with disabilities to a free, appropriate public education in the least restrictive environment by virtue of the equal protection guarantee of the 14th Amendment.<sup>9</sup> Then in 1973, Congress passed §504 of the Rehabilitation Act guaranteeing civil rights for the disabled in the context of federally funded institutions or any program or activity receiving federal financial assistance, such as schools.<sup>10</sup>

The commitment to create opportunities and protections for people with disabilities continued to strengthen as more and more disabled youth left institutions and were placed in public schools. "Prior to 1975, there was not an aging out problem at all," said New York's Lieutenant Governor Alfred B. DelBello, "that is not because there were no disabled children, but rather because society had no organized care programs for them to age out of."<sup>11</sup> It was not until the enactment of the Education for All Handicapped Children Act (changed to the Individuals with Disabilities Education Act "IDEA" in 1990) that mentally disabled children were guaranteed the right to a free and appropriate education.<sup>12</sup> Although some states and local

school districts had provided services to children with disabilities and received limited federal special education reimbursement, as of 1975 approximately 1.75 million with disabilities were excluded from public school and 2.5 million were in programs that did not meet their needs.<sup>13</sup>

Since the enactment of the IDEA, grave discretion has been left to the schools to determine what assessments are to be made in determining if a child is disabled and is entitled to services under the Act. Once an evaluation indicates that the student is eligible for special education, the school district is required to create an individualized education program (IEP) for that child.<sup>14</sup> An IEP is a report that includes, among other things, the school's annual goals and short term instructional objectives for a student, as well as the related services to be provided.<sup>15</sup>

Although the IDEA was noteworthy for its acknowledgment that each child is entitled to an education, there are no requirements that the services should meet a particular standard. Furthermore, even though a child's IEP must include some statement of the type of transition services needed, there is no mandatory condition that a transition plan be fully incorporated into the schooling process or carried out, focusing on goals for the future, living, and employment after school. This lack of guidance from the public school system leaves many parents in a state of crisis once their child turns 21 and is no longer eligible for school services asking "where can I place my child?" and "what is the best and fullest life that my child can live?"<sup>16</sup>

### **III. Transition from School to Employment and Legislation for the Disabled "Adult"**

The transition from school to adulthood is often a particularly challenging process for youth with disabilities and their families. National unemployment rates for adults with disabilities have been at extremely high levels for the last 20 years, reaching nearly 70% and there are few indications that rates will soon improve.<sup>17</sup> National data indicate that, in spite of the

educational opportunities created by the IDEA, the nation still has not achieved full participation of persons with disabilities in the economic and social mainstream of their local communities.<sup>18</sup>

In response to this the government has ensured that persons with disabilities have the ability and right to real employment choices in fully integrated environments through the Americans with Disabilities Act (“ADA”) of 1990.<sup>19</sup> Furthermore, public agencies have attempted to promote policies and practices to improve the transition from youth to adulthood for persons with disabilities, even though there is no guaranteed legal right to continued services beyond the age of 21.<sup>20</sup> The most predominant financial support that the government has provided for the mentally disabled has been administered through Social Security Income (“SSI”) or Social Security Disability Income and Medicaid Programs, such as Home and Community Based Services. The benefits and incentives included in the SSI program can be used as a source of support for an individual making the transition from school to adult life. However, SSI is not beneficial unless parents of disabled children are informed by the school of the details of this program and how to connect with their local Social Security Office, prior to “aging out”.

Despite the efforts of the government to create these programs, many mentally disabled individuals and their families miss out on their benefits upon leaving the school system due to a lack of coordinated transition services, providing them with the instructions on how to attain them. One reason for this result is because educators are inadequately prepared to provide the services required under the IDEA.<sup>21</sup> The issues and challenges of providing coordinating transition services are multifaceted and urgent, yet few special education personnel preparation programs include even one course devoted to transition.<sup>22</sup> Moreover, state departments of education often identify that primary training takes place on the job rather than through comprehensive professional development. Thus, the very purpose of planning accordingly for a

transition is lost and many individuals are not prepared to manage the tasks associated with their assigned workplace. As a result, state departments of education have targeted transition professional development as a priority for special education improvement grants and statewide planning.<sup>23</sup> Unfortunately, transition professional development is often hampered by a lack of clear policies and limited resources to fund systems for planning, delivery, and evaluation.

Due to inadequate funding, many governmental integrated support programs designed to aid disabled youth and their families with a view to maximizing the chances of successful transitions have failed. Effective collaboration during transition is critical for employment success and failure to do so often results in long-term negative consequences for employment.<sup>24</sup> There has been progress in developing transition manuals, resource directories, and working agreements to help youth and families maneuver the service maze, but overall the process is still daunting. Alisa Sinnott the mother of Patrick, a 24 year old Down syndrome individual, recently expressed her opinion about public programs for the mentally disabled youth exiting the school system:

Our experience in working with the different programs has been disappointing. There are so many clearing houses to work through to get the services. I am not sure how people with disabilities who are without family members to advocate for them make it. It is really a challenge to get everything lined-up and on track for services to be in place once the person is ready to leave the school system. Perhaps if the state would provide a coordinator to facilitate the transition from school to life it would be better. The school did have someone, but it really was not sufficient enough to get things done and ultimately we just took it into our own hands to figure out Patrick's job situation. Bottom line, if the services are out there—there are too many hoops, loops, and people to go through to get to them, and ultimately, as we became increasingly frustrated, we just gave up and did our own thing.<sup>25</sup>

This account describes the plight of numerous families who are trying to determine where to go and how to get services for their aging disabled child. Even though federal programs, such as Social Security, provide financial assistance, it is often difficult to figure out how to retrieve

those benefits, in conjunction with finding the disabled young adult a suitable living and working situation. Schools, human service agencies, and governmental programs that are responsible for serving individuals with disabilities have typically operated in isolation or from uncoordinated agendas.<sup>26</sup> It is due to this lack of cohesiveness that many disabled youth fall through the cracks unable to find a place to work, live, and ultimately carry on a productive life.

The IDEA Amendments of 1997 attempted to address this problem by requiring a sharing of transition programming responsibilities among special, vocational, general, and postsecondary education; employment services, vocational rehabilitation, social services, and mental health services. However, the Act merely requires general transition services and lacks direction, thus it would be beneficial to create some more tailored transitional approach options for implementation beyond the mandate of the IDEA.

#### **IV. Successful Transition Programs for Individuals with Disabilities**

An important and unique solution to bridging the gap between the variety of agencies and services for the mentally disabled is the promotion of interagency coordination. Interagency collaboration for students with disabilities brings together community agencies to focus their joint expertise and pooled resources to improve the quality of transition planning.<sup>27</sup> Interagency planning and coordination may be supported through an array of means, which include a transition coordinator assigned to work with other participating agencies, and guidelines for working with other agencies identified as potential service providers.<sup>28</sup> The implementation of agreements outlines agencies' duties and funding responsibilities, which maximizes resources for transitioning youth.<sup>29</sup> The rationale behind interagency partnerships, through the use of agreements among various agencies, is to smooth the progress of transitions for youth and information sharing among educators, adult service providers, and families.<sup>30</sup>

The agreements that are the most efficient include statements regarding the ultimate purpose of the collaboration, procedures and policies, reviews of existing services and funding sources, dispute resolution, cross-agency training, and service coordination.<sup>31</sup> If correctly implemented interagency coordination at the state and local levels can also reduce the gap in service duplication and unnecessary expenses—ultimately preserving taxpayer dollars. Interagency transition teams not only implement interagency agreements, but they provide a mechanism for the school to access and share information and draw on community resources and services, improving outcomes for youth with disabilities.<sup>32</sup>

An example of successful implementation of interagency cooperative agreements for the purpose of improving the quality and coordination of services for youth with disabilities in transition occurred in the state of Delaware. The agreement was formed between the Delaware Department of Education and the Delaware Division of Vocational Rehabilitation.<sup>33</sup> Both of these agencies appointed directors who identified staff with transition service planning as their primary responsibility, and had each school district's superintendent sign the agreement. Since the implementation of the collaborative agreement, most districts now have full time employees, whose sole job is to carry out these responsibilities, conducting annual reports and data to aid in ensuring continuous improvements during the disabled individuals' transition. Ultimately the interagency agreement was a success and significantly improved outcomes for students.<sup>34</sup>

Even the best transition program is inadequate if suitable adult services are unavailable in the community. Parents are progressively seeking not merely a transition system but a package of adult services comparable in quality to the services they were receiving under the IDEA and school systems. Their search is affected by the fact that service providers and other professionals in the field are still determining what a suitable set of services for the mentally disabled should

look like.<sup>35</sup> In a number of places around the country, cost effective, usually smaller, programs are emerging which offer alternatives to the traditional service delivery system or which seek, in interesting ways, to make the traditional system work better. These programs place heavy emphasis on independent or semi-independent living, community integration, on the job training and competitive employment. Much of their effort is based on the philosophy of moving the individual into the real world, rather than building a sheltered environment. Although not all disabled young adults are able to take full advantage of these opportunities for independence, these programs have a record of often accepting clients others have refused and have moved them to levels of achievement that are beyond previous expectations.

The following example is just one of the many organizations that offer flourishing programs focused upon ensuring that disabled youth are efficiently transitioned out of the school system and are granted the opportunities to be contributing members of society, which could ultimately serve as model for implementation by other states and communities. The organization, widely known throughout the state of Nevada, is Opportunity Village (“OV”). This not-for-profit organization serves varying aged adults who reside in the Las Vegas and surrounding communities who have intellectual disabilities. OV is a valuable asset to the mentally disabled population and their families in Las Vegas because it not only offers vocational training, employment, day services, advocacy, and social recreation, but is also a place where people with disabilities are able to find new friends, realize future career paths, and become fully integrated into the community.<sup>36</sup> As if those attributes were not enough, OV pays the disabled adult, otherwise known as their client, a wage that enables each participant to enjoy a sense of pride that comes from being productive and a feeling of being included as part of a team, a welcome

departure to the feeling of isolation that often comes from being different than other individuals who live in the mainstream.

OV offers vocational training and employment programs so that people with severe disabilities have a chance to develop job skills that offer opportunities for individual advancement.<sup>37</sup> Upon completion of vocational training, mentally disabled individuals can be placed in long term stable employment positions with local businesses and can also opt to work within the OV Work Centers, if they do not find an adequate fit within the community.<sup>38</sup> In conjunction with providing many mentally disabled individuals with jobs, OV also saves taxpayer funding—by paying wages that reduce the need for governmental benefits.<sup>39</sup> Work at OV's three work centers is often the first and sometimes the only option available to people with severe disabilities.<sup>40</sup> Earning wages allows them to become productive members of society and to join the ranks of the taxpayers of Nevada.

Furthermore, OV has created special programs such as ENABLE, which provides training and assistance to individuals in developing socialization skills, communications skills, assertiveness skills, self-advocacy skills and behavior self-management skills that are needed in any community-based supported employment program.<sup>41</sup> Project ENABLE ultimately offers adults with severe multiple disabilities a chance to become active and contributing members of the community and is a program highly utilized by parents whose disabled children “age out” of the Clark County school system.

## **V. Conclusion**

The Congressional intent behind programs such as the IDEA, that provide educational services to the disabled, was to ensure that these individuals became contributing members of society, so as not to be solely dependent on subsistence payments from public funds for the

duration of their life.<sup>42</sup> Senator Williams discussed the purpose of such legislation and the hopeful effects for the education opportunities of the mentally disabled population when he stated that “The time, I hope has come when we look no longer upon persons with disabilities as charitable objects, unable to make significant contributions. Action on this legislation will establish a public policy which will break the chains of ignorance once and for all.”<sup>43</sup> Senator William’s aspirations are a work in progress, as now these same hopes transcend the school system and apply to the next step of disabled individuals transitioning into the adult world; all the while ensuring that they achieve a life of meaning, equality, dignity, opportunity, and inclusion in the community.

Ultimately, success in the arena of transitional services for the disabled depends on the available financial resources, general social philosophies, existence of local centers of innovation and expertise, and the strength of local advocacy or parent organizations. No single agency has the fiscal resources, the knowledge, or the legislative mandate to plan and deliver the multitude of services essential for effective transition planning. It is through an integrative collaboration amongst an array of services that progress is made and effective placements of mentally and physically disabled individuals are secured. Since an innovative approach that works well in one situation may not be appropriate in another, it is necessary to consider a variety of program models for implementation by the states. However, a starting point is ensuring that transition plans are fully incorporated in the educational experience, which provides an accessible and distinct plan for an individual upon “aging out” of a school district.

The process of transitioning implies that there is a destination or evolution for all of us who generally prefer to direct our own path. The charting of the disabled adult’s future often falls upon family members and advocates to pursue the information and secure the benefits of the

programs that will fit the need. If coordination of efforts and interagency cooperation develops with time, successful placement of individuals in programs that are well suited to their special needs may be realized more often. Innovative programs such as those described in this note, may also play an increasing role in the future of providing an alternative to governmental programs that are unwieldy, inaccessible or unknown. Transitioning is a process, however, the fear and frustration felt by families such as Nathaniel's should not be a part of that process.

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<sup>1</sup> Interview with Lynda Smith, Chief Development Officer, Opportunity Village, in Las Vegas, N.V. (Nov. 6, 2005).

<sup>2</sup> *Id.*

<sup>3</sup> *Id.*

<sup>4</sup> See HR. REP. NO 94-332, at 11-12 (1975) [hereinafter HR. REP.]; Generally “aging out” occurs at the age of 21, however the target age for transitioning out of the public school system vary amongst the states.

<sup>5</sup> Issue Brief: Developmental Disabilities. Office for Citizens with Developmental Disabilities, <http://www.dhh.state.la.us/OCCD> (last visited May 6, 2009). [hereinafter Issue Breif].

<sup>6</sup> *Id.*

<sup>7</sup> Jennifer Saba, *Undue Deference: Toward a Dual System of Burdens under the Individuals with Disabilities Education Act*. 57 DEPAUL L. REV. 133, 135 (2007).

<sup>8</sup> Issue Brief, *supra* note 5; Leonard Cross, *Useful Lives Useful People*. Parade Magazine (Aug. 25, 1985).

<sup>9</sup> See *Generally* PARC v. Pennsylvania, 334 F.Supp. 1257 (E.D. PA 1972); *Mills v. Board of Education, DC*, 348 F.Supp. 866 (D. DC 1972).

<sup>10</sup> 29 U.S.C. §794 (2007).

<sup>11</sup> Sam Roberts, *Additional Care for the Disabled at Age 21 Urged*, N.Y. TIMES, Nov.1, 1983.

<sup>12</sup> See 20 U.S.C.A. §1411(i) (West 2008).

<sup>13</sup> HR. REP., *supra* note 4.

<sup>14</sup> Susan Luger & George Zelma, *Understanding Special Education and the Law*, NYU Child Study Center. <http://www.aboutourkids.org>. (last visited May 6, 2009).

<sup>15</sup> *Id.*

<sup>16</sup> Richard P. Kusserow, *A Program Inspection on Transition of Developmentally Disabled Young Adults from School to Adult Services*, Dept. of Health and Human Services, <http://www.mnddc.org/parallels2/pdf/84-API-DOH.pdf>.

<sup>17</sup> See Robert Stodden & Jean Johnson, *2 Decades of Making a Difference Annual Summary Report*, Center of Disability Studies (Apr. 2008).

<sup>18</sup> *Id.*

<sup>19</sup> 42 U.S.C. §12101.

<sup>20</sup> David Leake & Megan Conway, *Transition to Adulthood: Supporting Individuals with Disabilities across Secondary, Postsecondary Education, and Employment*, (July 8, 2002).

<sup>21</sup> Anderson, D., Kleinhammer-Tramill, P. J., Morningstar, M. E., Lehmann, J., Bassett, D., Kohler, P., et al. (2003). *What's happening in personnel preparation in transition? A national survey*. Career Development for Exceptional Individuals, 26(2), 145–160.

<sup>22</sup> Mary Morningstar and Jeannie Kleinhammer-Tramill, *Professional Development for Transition Personnel Current Issues and Strategies for Success*. National Center on Secondary Education and Transition. (Aug. 2005) Vol. 4, Issue 4.

<sup>23</sup> *Id.*

<sup>24</sup> *Id.*

<sup>25</sup> Email from Alisa Sinnott, Director of Christian Services for Central Catholic High School, to Megan Morrissey (February 21, 2009, 4:09 CST) (on file with author).

<sup>26</sup> S Hadden., S. Fowler, D. Fink., & M. Wischnowski, (1995). *Writing an Interagency Agreement on Transition: A Practical Guide*. Champaign, IL: FACTS/LRE. (ERIC Document Reproduction Service No. 391328), <http://www.facts.crc.uiuc.edu/facts5/facts5.html>. [hereinafter S. Hadden].

<sup>27</sup> *Id.*

<sup>28</sup> *Id.*

<sup>29</sup> Kelli Crane, Meredith Gramlich, & Kris Peterson, *Putting Interagency Agreements Into Action*, Examining Current Challenges in Secondary Education and Transition, Issue 4, Vol. 3 (Sept. 2004).

<sup>30</sup> *Id.*

<sup>31</sup> S. Hadden, *supra* note 26.

<sup>32</sup> S. B Hasazi, K. Furney, & L. DeStephano, *Implementing the IDEA transition mandates*. Exceptional Children, 65, 555–566 (2000).

<sup>33</sup> Kelli Crane, *supra* note 29.

<sup>34</sup> *Id.*

<sup>35</sup> Richard P. Kusserow, *supra* note 16.

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<sup>36</sup>Opportunity Village, <http://www.opportunityvillage.org/content> (last visited May 6, 2009).

<sup>37</sup>*Id.*

<sup>38</sup>*Id.*

<sup>39</sup>*Id.*

<sup>40</sup>*Id.*

<sup>41</sup>*Id.*

<sup>42</sup>Nancy Lee Jones, *The Individuals with Disabilities Education Act: Congressional Intent* (May 19, 1995).

<sup>43</sup>*Id.*