

## TRANSITION AND BEYOND FOR INDIVIDUALS WITH AUTISM SPECTRUM DISORDERS (ASDs): A NEW JERSEY CASE STUDY OF THE ADULT SERVICE SECTOR, ITS INHERENT SHORTCOMINGS, AND HOPE FOR THE FUTURE

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### I. INTRODUCTION

Knowing that her young daughter with significant disabilities would face a lifetime of challenges, a mother diligently began preparing for the seemingly far-off day when the protection and consistency of school-provided services would end.<sup>1</sup> While her daughter was still a child, she met with the school district and a state agency that serves individuals with special needs to plan for her daughter's transition to adulthood.<sup>2</sup> Despite the mother's careful, long-term preparation for this transition, the agency could not guarantee continued day services following her graduation because of insufficient funding.<sup>3</sup> With shattered hopes, the mother confronted new fears that her adult daughter would likely regress without access to adequate care.<sup>4</sup>

After receiving educational and related services in a school setting until graduating from high school at the age of twenty-one, a young man with autism confronted a dramatic decrease in supportive services and found himself "sitting at home, lost."<sup>5</sup> Four years later, he continued to suffer from the absence of ongoing programming to

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<sup>1</sup> *Transitioning from School to Adult Life, Real Lives – On Hold . . .*, COUNCIL (N.J. Council on Developmental Disabilities, Trenton, N.J.), June 2008, at 4, available at <http://www.njcdd.org/Publications/Updates/thecouncil1C302-V1N9.pdf?FCItemID=S002EA306>.

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

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

<sup>4</sup> *Id.*

<sup>5</sup> Erica Harbatkin, *Autism's Challenges Continue into Adulthood*, HOME NEWS TRIB. (East Brunswick, N.J.), Apr. 29, 2007, at A18.

address his needs.<sup>6</sup> In New Jersey, a thirty-three-year-old man with autism added his name to a waitlist for adult services more than twelve years ago but is still waiting for a residential placement despite being a “priority” candidate.<sup>7</sup>

“Autism strikes in childhood”<sup>8</sup> when federal and state laws charge schools with the responsibility of providing special education services.<sup>9</sup> But children with autism grow up, and “a generation of teenagers and young adults is facing a new crisis: what happens next?”<sup>10</sup>

Nationwide, the number of individuals identified with autism spectrum disorders (ASDs) is growing.<sup>11</sup> Individuals with ASDs, who fall along a wide continuum of ability levels, “exhibit atypical, repeti-

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

<sup>7</sup> Fran Wood, *Hope for Disabled Waiting for Homes*, STAR-LEDGER (Newark, N.J.), May 4, 2008, at P3.

<sup>8</sup> Barbara Kantrowitz & Julie Scelfo, *What Happens When They Grow Up: Teenagers and Young Adults Are the Emerging Face of Autism as the Disorder Continues to Challenge Science and Unite Determined Families*, NEWSWEEK, Nov. 27, 2006, at 46, 47.

<sup>9</sup> See generally Individuals with Disabilities Education Act (IDEA) of 2004, 20 U.S.C. §§ 1400–1419 (2006); N.J. STAT. ANN. §§ 18A:46-1 to -53 (West 2009).

<sup>10</sup> Kantrowitz & Scelfo, *supra* note 8, at 47.

<sup>11</sup> See Ctrs. for Disease Control & Prevention (CDC), Autism Spectrum Disorders (ASDs): Autism and Developmental Disabilities Monitoring (ADDM) Network (Mar. 31, 2010), <http://www.cdc.gov/ncbddd/autism/addm.html> [hereinafter CDC, ADDM Network].

‘Autistic’ means a pervasive developmental disability which significantly impacts verbal and nonverbal communication and social interaction that adversely affects a student’s educational performance. Onset is generally evident before age three. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routine, unusual responses to sensory experiences and lack of responsiveness to others. . . . An assessment by a certified speech-language specialist and an assessment by a physician trained in neurodevelopmental assessment are required.

N.J. ADMIN. CODE § 6A:14-3.5(c)(2) (2009). Autism is one of three disorders falling under the umbrella of autism spectrum disorders (ASDs)—autistic disorder (or “classic” autism), Asperger syndrome, and pervasive developmental disorder—not otherwise specified (PPD-NOS or “atypical autism”). Ctrs. for Disease Control & Prevention (CDC), Autism Spectrum Disorders: Facts About ASDs (Mar. 31, 2010), <http://www.cdc.gov/ncbddd/autism/facts.html> [hereinafter CDC, Facts About ASDs]. ASDs “are a group of developmental disabilities that can cause significant social, communication and behavioral challenges.” *Id.* As “spectrum disorders,” ASDs “affect each person in different ways, and can range from very mild to severe. People with ASDs share some similar symptoms, such as problems with social interaction. But there are differences in when the symptoms start, how severe they are, and the exact nature of the symptoms.” *Id.*

tive behaviors and deficits in social and communication skills.”<sup>12</sup> According to an updated report by the Autism and Developmental Disabilities Monitoring (ADDM) Network, funded by the Centers for Disease Control and Prevention (CDC), the prevalence of autism is approximately 1 in 110 children;<sup>13</sup> the prevalence of autism in New Jersey is substantially greater, a staggering 1 in 94 children.<sup>14</sup> These high numbers present an enormous challenge as individuals with ASDs face lifelong challenges in the areas of independent living, vocational opportunities, and access to housing.<sup>15</sup>

The federal Individuals with Disabilities Education Act (IDEA)<sup>16</sup> and corresponding state laws and regulations<sup>17</sup> provide entitlements and services for individuals with special needs between the ages of three and twenty-one. Although many problems exist in providing special education to students with ASDs within this age group, these students have at least an entitlement on paper to support and access to a rapidly growing, albeit imperfect, range of services.<sup>18</sup> But services provided under IDEA and corresponding state mandates for those with disabilities do not extend beyond the age of twenty-one,<sup>19</sup> an age when many remain in need of some level of assistance to become productive members of society. IDEA and related state laws and regulations entitle individuals with special needs to transition services—services that prepare the students for post-school life.<sup>20</sup> Their educational programs must also contain assessment-based goals designed to

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<sup>12</sup> Autism N.J., About Autism, <http://autismnewjersey.org/AboutAutism.aspx> (last visited Jan. 10, 2010) (providing a comprehensive discussion of the major characteristics of individuals with ASDs); *see also* Autism N.J., FAQs, <http://autismnewjersey.org/FAQs.aspx> (last visited Jan. 10, 2010) (providing general information about ASDs, diagnosis, and treatment).

<sup>13</sup> CDC, ADDM Network, *supra* note 11 (“CDC considers ASDs to be an urgent public health concern. Increased concern in the communities, continued demand for services, and reports estimating a prevalence of about 1 percent underscore the need for a serious response to improve the lives of people with ASDs.”).

<sup>14</sup> *See* N.J. STAT. ANN. § 26:2-185(b) (West 2009).

<sup>15</sup> *See* John Reitmeyer, *New Jersey Gives \$4M Boost to Autism Research: Corzine Signs Bills to Expand Screening, Education, Aid*, RECORD (Bergen County, N.J.), Sep. 13, 2007, at A1.

<sup>16</sup> IDEA, 20 U.S.C. §§ 1400–1419 (2006).

<sup>17</sup> N.J. STAT. ANN. §§ 18A:46-1 to -53 (West 2009); N.J. ADMIN. CODE §§ 6A:14-1.1 to -10.2 (2009).

<sup>18</sup> *See* Harbatkin, *supra* note 5, at A18; John Duthie, *Roberts Tour of Bergen Facility Highlights Needs of Autistic Adults*, POLITICKERNJ.COM, Apr. 1, 2008, <http://www.politickernj.com/jduthie/17920/roberts-tour-bergen-facility-highlights-needs-autistic-adults>.

<sup>19</sup> § 1412; § 6A:14-1.1(d).

<sup>20</sup> §§ 1401(34), 1414(d)(1)(A)(i)(VIII); § 6A:14-3.7(e)(10), (e)(11).

prepare them for this transition.<sup>21</sup> Instead of serving as a bridge to the adult service sector, the transition period often ends with young adults losing access to the support they need to fulfill their goals.

In contrast to school-based programs, a vast and under-explored gap exists in the provision of services for adults with disabilities following graduation. Although federal<sup>22</sup> and state<sup>23</sup> laws and regulations govern the creation and responsibilities of agencies that provide services for eligible adults with special needs, challenges arise regarding the maintenance of support and access to services because of the scarcity and poor coordination of resources available for adults.<sup>24</sup> In spite of theoretical entitlements to adult services under these laws, in practice, individuals with special needs too often face a dramatic decrease in support once they exit school programs. Waitlists—where individuals typically remain for years and sometimes decades—block access to governmental services and create hardships at a time when these graduates need support for the transition to adulthood most.<sup>25</sup> Individuals with ASDs have distinctive needs and face unique challenges related to the transition to adulthood,<sup>26</sup> and their outlook grows even dimmer when they cannot continue with needed services once school-related entitlements cease. By failing to provide ample access to continuing services and programs at this point, the government is squandering its huge investment of time and resources spent during a child's school years.

Many current initiatives affecting individuals with ASDs focus on the needs of children<sup>27</sup> and thus ignore the dramatic drop-off in services for adults. While early identification and services for children are essential to improving the outcomes for individuals with ASDs, unduly skewed attention to the younger segment of the population neglects the concerns of the adult population, which is larger and will

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<sup>21</sup> § 1414(d)(1)(A)(i)(VIII); § 6A:14-3.7(e)(12).

<sup>22</sup> *E.g.*, Rehabilitation Act of 1973, 29 U.S.C. §§ 701–796 (2006); Developmental Disabilities Assistance and Bill of Rights Act of 2000, 42 U.S.C. §§ 15001–15009 (2006).

<sup>23</sup> *E.g.*, Developmentally Disabled Rights Act, N.J. STAT. ANN. §§ 30:6D-1 to -12 (West 2009); N.J. ADMIN. CODE §§ 12:45-1.1 to -1.16 (2009).

<sup>24</sup> *See* Tom Davis, *Are We Failing Autistic Adults? Group Urges More Services, Funding*, RECORD (Bergen County, N.J.), Dec. 15, 2006, at A1.

<sup>25</sup> *See id.*

<sup>26</sup> *See* EVE MÜLLER, PROJECT FORUM AT NAT'L ASS'N OF STATE DIRS. OF SPECIAL EDUC., INC., AUTISM: CHALLENGES RELATING TO SECONDARY TRANSITION 3 (2004), available at [http://www.projectforum.org/docs/autism\\_secondary\\_transition.pdf](http://www.projectforum.org/docs/autism_secondary_transition.pdf).

<sup>27</sup> *See* Linda H. Davis, *Autistic and Overlooked*, WASH. POST, Apr. 2, 2008, at A19; Karl Taro Greenfeld, Editorial, *Growing Old with Autism*, N.Y. TIMES, May 24, 2009, at 9; discussion *infra* Part V.

continue to expand.<sup>28</sup> Aiming the spotlight on issues that predominantly affect children often leads to insufficient consideration of the lifelong challenges facing those who age out of school-provided services.<sup>29</sup>

In states like New Jersey that have large, expanding populations of individuals identified with ASDs,<sup>30</sup> the shift from entitlements under IDEA to theoretical eligibility for scarce adult services has a severe impact and highlights the need for reform. New Jersey is unique, both in the size of its in-need population as well as its strong advocacy network.<sup>31</sup> Though imperfect, New Jersey has been a leader in improving children's access to school services compared to other states.<sup>32</sup> In recent years, the State has been proactive with policy and legislative initiatives relating to ASDs.<sup>33</sup> Former New Jersey Governor Jon Corzine signed seven bills pertaining to ASDs into law in 2007,<sup>34</sup> and since that time, the New Jersey General Assembly and Senate introduced a number of additional bills, several signed into law, that pertain to individuals with ASDs and other developmental disabilities.<sup>35</sup>

Despite the promising initiatives within New Jersey, three major challenges persist and dominate the landscape. First, insufficient go-

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<sup>28</sup> See Davis, *supra* note 27; Greenfield, *supra* note 27; discussion *infra* Part V.

<sup>29</sup> *Id.*

<sup>30</sup> N.J. STAT. ANN. § 26:2-185(b) (West 2009) ("According to the federal Centers for Disease Control and Prevention, or CDC, one of every 94 children in this State has autism, which is the highest rate among the states examined by the CDC in the most comprehensive study of the prevalence of autism to date."); N.J. CTR. FOR OUTREACH & SERVS. FOR THE AUTISM CMTY. (COSAC), MEETING THE NEEDS OF ADULTS WITH AUTISM: A BLUEPRINT FOR THE FUTURE 5 (2006), *available at* <http://autismnewjersey.org/doc/whitepaper.pdf> [hereinafter COSAC] ("New Jersey Department of Education data show a 183% increase from 1999 to 2005 in the number of students with autism age 3–21 who are eligible for special education services. In that time, the number of students with autism has tripled, from 2,355 in 1999 to 6,665 in 2005.").

<sup>31</sup> See discussion *infra* Part V.

<sup>32</sup> See Duthie, *supra* note 18.

<sup>33</sup> See discussion *infra* Part V.

<sup>34</sup> See Press Release, State of N.J. Office of the Governor, Governor Corzine Signs Bills on Autism (Sept. 12, 2007) (on file with author). One law created the New Jersey Adults with Autism Task Force ("Task Force"), which released a report with forty-four recommendations for reform in October 2009. See *id.*; see also discussion *infra* Part V. See generally N.J. ADULTS WITH AUTISM TASK FORCE, ADDRESSING THE NEEDS OF ADULTS WITH AUTISM SPECTRUM DISORDER: RECOMMENDATIONS FOR A PLAN OF ACTION FOR THE STATE OF NEW JERSEY (2009), *available at* <http://www.state.nj.us/humanservices/ddd/boards/AATFrpt.pdf> [hereinafter TASK FORCE].

<sup>35</sup> See discussion *infra* Part V.

vernmental funding pervades the service-delivery system at all levels. In addition to this major hurdle, a second significant impediment to successful lifelong outcomes for individuals with ASDs is inadequate transition planning and a lack of coordination between schools and other state agencies during the transition process. Finally, an enormous chasm exists between the completion of school programs and access to services for adults; inadequacies in both the quantity and quality of adult services hamper further development and skill attainment of individuals with ASDs and thus lessen their quality of life.

Within the past few years, the State took an important first step in confronting a complex and multifaceted challenge by commencing initiatives aimed at improving the outcomes for adults with autism.<sup>36</sup> Nevertheless, New Jersey is in need of a broad plan of attack to address the large and growing predicament faced by adults with ASDs. Despite the omnipresent funding challenges, the State must first ensure that transition planning effectively prepares individuals for post-school realities. The State also needs to develop a comprehensive interagency plan to bolster collaboration and coordination between schools and agencies to realize this aim. Additionally, amendments to existing regulations would clarify the duties and responsibilities of school districts and other state agencies during transition planning. Next, the State must address the staggering drop-off in services that occurs when individuals exit school programs as a result of the extensive waitlists for existing services. Because of limited financial resources, the State needs to expand access to adult programs to more individuals by encouraging service flexibility and supporting individuals who choose self-directed over government-provided services. Finally, the State needs to increase the efficiency of the current service-delivery system and ensure that the quality of available services adequately addresses the unique needs of adults with ASDs.

As New Jersey strives to succeed in its efforts, it can serve as a model for other states, which are also struggling to address the needs of a more visible ASD population, and demonstrate to the federal government that the investment of necessary federal resources can effectively and efficiently influence the quality of life for adults with ASDs.<sup>37</sup> Justice Louis D. Brandeis famously wrote, "It is one of the

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<sup>36</sup> See Reitmeyer, *supra* note 15; discussion *infra* Part V.

<sup>37</sup> See Editorial, *Tackling Autism; New Legislation Could Help*, RECORD (Bergen County, N.J.), Feb. 25, 2008, at L6 ("Despite New Jersey's financial problems, this state should be at the forefront of the quest to understand and treat this baffling and

happy incidents of the federal system that a single courageous State may, if its citizens choose, serve as a laboratory; and try novel social and economic experiments without risk to the rest of the country.”<sup>38</sup> To be a true leader among states, New Jersey must substantially improve the provision and coordination of transition services in the short term as well as commit to long-term changes in the adult-service sector.<sup>39</sup>

This Comment examines federal and state laws affecting individuals with ASDs as they transition to adulthood, discusses the shortcomings of available legal protections and the current service-delivery system with an emphasis on the impact in New Jersey, evaluates recent state initiatives, and offers proposals for further statewide reform. Part II describes the background of IDEA and related state laws affecting the provision of services for individuals with ASDs, ages three through twenty-one, and includes a discussion of transition planning and the development of post-secondary goals.<sup>40</sup> Part III describes federal and state laws and agency services affecting adults with ASDs, particularly vocational support, housing, and day services provided through the Division of Developmental Disabilities (DDD) and the Division of Vocational Rehabilitation Services (DVRS) in New Jersey.<sup>41</sup>

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frightening developmental disorder. New Jersey has the highest rate of autism in the nation, diagnosed in one of every 94 children. It makes perfect sense that we should become a model of what government can do to help families coping with all of its daunting aspects.”).

<sup>38</sup> *New State Ice Co. v. Liebmann*, 285 U.S. 262, 311 (1932) (Brandeis, J., dissenting).

<sup>39</sup> See Press Release, N.J. Assembly Democrats, Second Wave of Landmark Autism Support Measures Passes Assembly (May 19, 2008), available at <http://www.politickernj.com/teel/19864/second-wave-landmark-autism-support-measures-passes-assembly>.

<sup>40</sup> This Comment focuses on IDEA and not Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794 (2006), because if individuals are eligible for special education and related services and not merely “reasonable accommodations,” they will be covered under IDEA. Section 504 is a Civil Rights law prohibiting discrimination. See U.S. Dep’t of Educ., Protecting Students with Disabilities, <http://www.ed.gov/print/about/offices/list/ocr/504faq.html> (last visited Jan. 8, 2010) (providing background information about Section 504 and how it relates to IDEA).

<sup>41</sup> This Comment’s analysis focuses predominantly on vocational support, housing, and day services provided through DVRS and DDD; an examination of mental health services, Social Security programs, and Medicaid is beyond the scope of this Comment. For additional information on these issues, see Robert F. Rich, Christopher T. Erb, & Rebecca A. Rich, *Critical Legal and Policy Issues for People with Disabilities*, 6 DEPAUL J. HEALTH CARE L. 1 (2002); VALERIE POWERS SMITH & LESLIE LONG, N.J. CTR. FOR OUTREACH & SERVS. FOR THE AUTISM CMTY. (COSAC), MEDICAID & ITS IMPORTANT ROLE IN FUNDING SERVICES AND SUPPORTS FOR INDIVIDUALS WITH AUTISM,

Part IV examines and analyzes the implications of existing laws and available services with a focus on the effects in New Jersey, given its large population of individuals with ASDs and its relative receptiveness to providing services. Part V analyzes and critiques current statewide initiatives and proposals aimed at bolstering the support system and services available for adults with ASDs in the state. Finally, Part VI presents recommendations for legislative and policy changes needed to further address existing challenges and shortfalls in the system. The proposals focus on improving transitional planning and coordination of services provided by schools and state-run agencies and addressing weaknesses in the system regarding quantity, efficiency, and quality of services for adults. Recommendations include statutory and regulatory changes as well as other practical steps that New Jersey should take to expand access to needed services for adults with ASDs in a cost-effective and humane manner.

## II. LEGAL ENTITLEMENTS TO SERVICES FOR INDIVIDUALS WITH ASDS—AGES THREE THROUGH TWENTY-ONE

An interaction of federal and state laws and regulations governs the provision of services for individuals with disabilities, including ASDs, between the ages of three and twenty-one.<sup>42</sup> The laws and regulations create entitlements to educational programming and supplemental services designed to meet students' individualized needs.<sup>43</sup> Additionally, they require that schools begin planning for the transition to adulthood years before an individual exits the education system.<sup>44</sup>

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<http://autismnewjersey.org/doc/medfact.pdf> (last visited Jan. 8, 2010); and Autism N.J., Social Security Programs, <http://autismnewjersey.org/SocialSecurityPrograms.aspx> (last visited Jan. 31, 2010). Other agencies providing services in New Jersey include the Department of Human Services, the Division of Mental Health Services, the Division of Disability Services, and the Department of Labor and Workforce Development. See Autism N.J., Additional Adult Services Resources, <http://autismnewjersey.org/AdditionalAdultServicesResources.aspx> (last visited Jan. 8, 2010), for descriptions of these agencies. For additional proposals concerning funding and health care issues, see generally TASK FORCE, *supra* note 34.

<sup>42</sup> See IDEA, 20 U.S.C. §§ 1400–1419 (2006); N.J. STAT. ANN. §§ 18A:46-1 to -53 (West 2009); N.J. ADMIN. CODE §§ 6A:14-1.1 to -10.2 (2009).

<sup>43</sup> §§ 1400–1419; §§ 18A:46-1 to -53; §§ 6A:14-1.1 to -10.2.

<sup>44</sup> § 1414(d)(1)(A)(i)(VIII); § 6A:14-3.7(a)(10).



A. *Federal Protections*

Under IDEA, eligible children with disabilities receive a special education<sup>45</sup> and are entitled to receive a “free appropriate public education.”<sup>46</sup> Congress first enacted the Education of All Handicapped Children Act of 1975<sup>47</sup> and renamed it the Individuals with Disabilities Education Act in 1990.<sup>48</sup> To receive federal funding under IDEA, states must comply with the law’s mandates,<sup>49</sup> which apply to services and protections for individuals with disabilities between the ages of three and twenty-one.<sup>50</sup> Children with autism are eligible for services under IDEA,<sup>51</sup> which entitles them to an “individualized education program” (IEP).<sup>52</sup>

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<sup>45</sup> § 1401(29) (“Special Education’ means specially designed instruction, at no cost to parents, to meet the unique needs of a child with a disability.”).

<sup>46</sup> *Id.* § 1412(a)(1)(A).

The term ‘free appropriate public education’ means special education and related services that—

- (A) have been provided at public expense, under public supervision and direction, and without charge;
- (B) meet the standards of the State educational agency;
- (C) include an appropriate preschool, elementary school, or secondary school education in the State involved; and
- (D) are provided in conformity with the individualized education program required under [20 U.S.C. § 1414(d)].

§ 1401(9)(A)–(D).

<sup>47</sup> Pub. L. No. 94-142 (codified at 20 U.S.C. § 1400 (2006)).

<sup>48</sup> § 1400. Congress found that before the law’s enactment in 1975, “the educational needs of millions of children with disabilities were not being fully met.” § 1400(c)(2). Most recently amended in 2004, IDEA may also be referred to as the Individuals with Disabilities Education Improvement Act of 2004. *Id.* (see “History; Ancillary Laws and Directives, Short Titles”).

<sup>49</sup> *Id.* § 1407.

<sup>50</sup> *Id.* § 1412(a)(1)(A).

<sup>51</sup> *Id.* § 1401(3)(A)(i) (2006); *see also* MÜLLER, *supra* note 26, at 1 (“Autism was added to the list of federal disability categories in 1990.”).

<sup>52</sup> § 1414(d)(1)(A)(i).

The term ‘individualized education program’ or ‘IEP’ means a written statement for each child with a disability that is developed, reviewed, and revised in accordance with this section and that includes—

- (I) a statement of the child’s present levels of academic achievement and functional performance . . .
- (II) a statement of measurable annual goals, including academic and functional goals . . .
- (III) a description of how the child’s progress toward meeting the annual goals described in subclause (II) will be measured and when periodic reports on the progress the child is making toward meeting the annual goals . . . will be provided;
- (IV) a statement of the special education and related services and supplementary aids and services . . . to be provided to the

According to federal law, an IEP for individuals who are sixteen years old and above must include postsecondary goals and transition services,<sup>53</sup> which are a coordinated set of activities that are based on the student's needs and take into account the student's preferences and interests.<sup>54</sup> By law, an IEP team<sup>55</sup> must design transition services to "facilitate the child's movement from school to post-school activities."<sup>56</sup> When Congress amended IDEA in 2004, it required that transition services address a student's strengths,<sup>57</sup> an important change that can improve long-term planning of individualized goals. Nonetheless, Congress also increased the age for beginning transition services from fourteen to sixteen years.<sup>58</sup> Additionally, although other

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child . . . and a statement of the program modifications or supports for school personnel that will be provided for the child . . .

§ 1414(d)(1)(A)(i)(I)–(IV).

<sup>53</sup> § 1414(d)(1)(A)(i)(VIII). Congress made changes to the requirements for transition services when amending IDEA in 2004. See CRS REPORT FOR CONGRESS, RECEIVED THROUGH THE CRS WEB, INDIVIDUALS WITH DISABILITIES EDUCATION ACT (IDEA): ANALYSIS OF CHANGES MADE BY P.L. 108-446 (Jan. 5, 2005), [http://www.cec.sped.org/AM/Template.cfm?Section=Search&section=Policy\\_and\\_Advocacy1&template=/CM/ContentDisplay.cfm&ContentFileID=122](http://www.cec.sped.org/AM/Template.cfm?Section=Search&section=Policy_and_Advocacy1&template=/CM/ContentDisplay.cfm&ContentFileID=122) (last visited Mar. 18, 2010).

<sup>54</sup> Nat'l Dissemination Ctr. for Children with Disabilities, Transition to Adulthood, [http://www.nichcy.org/EducateChildren/transition\\_adulthood/Pages/Default.aspx](http://www.nichcy.org/EducateChildren/transition_adulthood/Pages/Default.aspx) (last visited Mar. 18, 2010).

<sup>55</sup> § 1414(d)(1)(B), (d)(3).

<sup>56</sup> IDEA, 20 U.S.C. § 1401(34) (2006).

The term 'transition services' means a coordinated set of activities for a child with a disability that—

(A) is designed to be within a results-oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child's movement from school to post-school activities, including post-secondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation;

(B) is based on the individual child's needs, taking into account the child's strengths, preferences, and interests; and

(C) includes instruction, related services, community experiences, the development of employment and other post-school adult living objectives, and when appropriate, acquisition of daily living skills and functional vocational evaluation.

§ 1401(34)(A)–(C).

<sup>57</sup> § 1401(34)(B).

<sup>58</sup> *Id.* § 1414(d)(1)(A)(i)(VIII). An IEP must include:

agencies outside a school district may provide transition services, such as vocational training, the amended language of IDEA removes the requirement that schools take steps to involve other agency representatives in transition planning.<sup>59</sup> Unfortunately, these two latter changes may have negative consequences by reducing the amount of time and resources spent per student on transition planning as well as weakening the coordination between schools and other agencies that serve individuals with ASDs.

In *Board of Education v. Rowley*, the Supreme Court of the United States interpreted the standard required under IDEA for “appropriate” special education services.<sup>60</sup> According to the Court, schools must provide an education that confers a benefit, but the law does not require that a special education program be optimal.<sup>61</sup> Case law has not fully developed how the *Rowley* test applies in the context of an IEP that includes transition services. In a recent problematic opinion, the U.S. Court of Appeals for the First Circuit applied the *Rowley* standard to IDEA-mandated transition services prior to the statute’s 2004 amendments.<sup>62</sup> The court held that “in considering the adequacy of a myriad of transition services, an inquiring court must view those services in the aggregate and in light of the child’s overall needs.”<sup>63</sup> Declining to analyze a student’s transition services separately from the adequacy of the IEP as a whole, the court stated that “[t]he test is whether the IEP, taken in its entirety, is reasonably calculated to enable the particular child to garner educational benefits.”<sup>64</sup> This decision placed an emphasis on current educational benefits rather than analyzing transition planning to determine if transition services are reasonably calculated to lead to post-school

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- (aa) appropriate measurable postsecondary goals based upon age appropriate transition assessments related to training, education, employment, and where appropriate, independent living skills;
  - (bb) the transition services (including courses of study) needed to assist the child in reaching those goals . . . .

§ 1414(d)(1)(A)(i)(VIII)(aa)–(bb).

<sup>59</sup> 34 C.F.R. § 300.321(b)(3) (2009).

<sup>60</sup> 458 U.S. 176, 198 (1982) (“[T]he requirement that a State provide specialized educational services to handicapped children generates no additional requirement that the services so provided be sufficient to maximize each child’s potential ‘commensurate with the opportunity provided other children.’”).

<sup>61</sup> *Id.*

<sup>62</sup> *Lessard v. Wilton-Lyndeborough Coop. Sch. Dist.*, 518 F.3d 18, 28 (1st Cir. 2008).

<sup>63</sup> *Id.* at 30 (citations omitted).

<sup>64</sup> *Id.* (citations omitted) (holding that “the IDEA does not require an ideal or optimal IEP, simply an adequate one”).

benefits. The First Circuit's holding, if applied by other courts, would preclude judicial evaluation of the quality of transition services if the student were deriving an educational benefit from the IEP as a whole while enrolled in school.

A recent federal district court case interpreted the language of IDEA subsequent to the 2004 amendments as placing more responsibility on a school for ensuring that transition services adequately address an individual's strengths and interests.<sup>65</sup> The U.S. District Court for the Eastern District of Pennsylvania found that a student's transition goals were inadequately "vague" and did "not capitalize on [the] [s]tudent's strengths or specific interests."<sup>66</sup> As such, the school "[d]istrict did not provide a meaningful transition plan for [the] [s]tudent once he turned sixteen."<sup>67</sup> Although this opinion does not set precedent for higher courts, its reasoning demonstrates that the revised language of IDEA could lead to a reconsideration of the *Rowley* standard as applied to transition services.

#### B. *Legal Protections in New Jersey*

State laws and regulations implement the mandates of IDEA at the local level.<sup>68</sup> In New Jersey, students diagnosed as "autistic" are eligible for special education and related services.<sup>69</sup> Within the State, "[a] program for students with autism shall maintain a student to staff ratio of three to one,"<sup>70</sup> which highlights the particular challenges involved in providing services to children with ASDs. In New Jersey, transitional planning begins for individuals with disabilities at the age of fourteen, two years earlier than federal law currently requires.<sup>71</sup>

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<sup>65</sup> *Marple Newtown Sch. Dist. v. Rafael N.*, No. 07-0558, 2007 U.S. Dist. LEXIS 62494, at \*31 (E.D. Pa. Aug. 23, 2007).

<sup>66</sup> *Id.*

<sup>67</sup> *Id.* at \*33.

<sup>68</sup> N.J. STAT. ANN §§ 18A:46-1 to -53 (West 2009).

<sup>69</sup> § 18A:46-1; N.J. ADMIN. CODE § 6A:14-3.5(c) (2) (2009).

<sup>70</sup> § 6A:14-4.7(e) n.1 ("For a secondary program, two classroom aides are required when the class size exceeds six students.").

<sup>71</sup> § 6A:14-3.7(c)(10) ("Beginning at age 14, or younger if determined by the IEP team, consider the need for consultation from the Division of Vocational Rehabilitation Services, Department of Labor and other agencies providing services for individuals with disabilities . . ."). A student's IEP must include:

Beginning with the IEP in place for the school year when the student will turn age 14, or younger if determined appropriate by the IEP team, and updated annually:

- i. A statement of the student's strengths, interests and preferences;

This illustrates that states may exceed the floor set by federal mandates. In other respects, New Jersey has adopted IDEA's definition of transition services.<sup>72</sup>

While still receiving school programming and special education, “[s]econdary level students may be placed in community rehabilitation programs for vocational rehabilitation services”<sup>73</sup> where they may receive training and support. Although agencies outside of a student’s school district may provide transition services in accordance with an individual’s IEP, if they fail to do so, New Jersey requires the school district to identify “alternative strategies” to meet a student’s “transition objectives.”<sup>74</sup> Yet the regulatory language does not explain what the phrase “alternative strategies” entails or whether agencies

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ii. Identification of a course of study and related strategies and/or activities that:

- (1) Are consistent with the student’s strengths, interests, and preferences; and
- (2) Are intended to assist the student in developing or attaining postsecondary goals related to training, education, employment and, if appropriate, independent living;

iii. As appropriate, a description of the need for consultation from other agencies that provide services for individuals with disabilities including, but not limited to, the Division of Vocational Rehabilitation Services in the Department of Labor; and

iv. As appropriate, a statement of any needed interagency linkages and responsibilities . . . .

§ 6A:14-3.7(e) (11) (i)–(iv). Moreover,

Beginning with the IEP in place for the school year when the student will turn age 16, or younger if deemed appropriate by the IEP team, a statement consisting of those elements set forth in (e)(11) above and appropriate measurable postsecondary goals based upon age-appropriate transition assessments related to training, education, employment and, if appropriate, independent living and the transition services including a course of study needed to assist the child in reaching those goals.

§ 6A:14-3.7(e) (12); *accord* IDEA, 20 U.S.C. § 1414(d)(1)(A)(i)(VIII) (2006) (federal requirements pertaining to postsecondary goals).

<sup>72</sup> § 6A:14-3.7(e) (12) (i).

<sup>73</sup> § 6A:14-4.7(i) (1) (“Community rehabilitation programs shall be approved by a State agency, including, but not limited to, the New Jersey Department of Labor, Division of Vocational Rehabilitation Services, the New Jersey Department of Human Services . . . and the Department of Human Services, Division of Developmental Disabilities, to provide vocational evaluation, work adjustment training, job coaching, skill training, supported employment and time-limited job coaching . . .”).

<sup>74</sup> § 6A:14-3.7(g) (“If an agency other than the district board of education fails to provide the transition services included in the student’s individualized education program, the district board of education shall reconvene a meeting of the IEP participants. Alternative strategies to meet the student’s transition objectives shall be identified.”).

can be compelled to provide services. As written, the vague regulations do not provide adequate guidance for schools and agencies and do not establish clear responsibilities for fulfilling state transition requirements. Ambiguity remains as to the particulars and scope of the regulatory directives as well as to which entities are ultimately responsible for compliance under the law.

Agency representatives may also participate in IEP planning for individuals receiving transition services. Moreover, “[i]f an agency invited to send a representative to the IEP meeting does not do so, the district board of education *shall* take other steps to obtain the participation of the other agency in the planning of any transition services.”<sup>75</sup> This New Jersey mandate differs from federal requirements, which do not demand that a district board of education take steps to secure the participation of other agencies.<sup>76</sup> While helpful, the New Jersey Code does not provide further guidance regarding what steps the district board of education must take to obtain this participation, and as a result, it fails to clearly establish a school’s responsibilities in this area and dilutes the effect of its mandate.

### III. ELIGIBILITY REQUIREMENTS AND PROVISION OF SERVICES FOR ADULTS WITH ASDS

The legal regime pertaining to adults with ASDs is complex and disjointed. Individuals with ASDs may benefit from agency services that provide continuing educational, vocational, and residential support to a sub-group of individuals with special needs, those with developmental disabilities.<sup>77</sup> In addition, individuals with ASDs may also be eligible for services through separate federal and state agencies specifically addressing vocational needs of individuals with a variety of disabilities.<sup>78</sup>

#### A. *Laws, Regulations, and Agency Services Affecting Individuals with Developmental Disabilities*

Once an individual exceeds the age of twenty-one, entitlements under IDEA and related state laws and regulations no longer apply.<sup>79</sup>

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<sup>75</sup> § 6A:14-3.7(h) (emphasis added).

<sup>76</sup> 34 C.F.R. § 300.321(b)(3) (2009) (“*To the extent appropriate . . . the public agency must invite a representative of any participating agency that is likely to be responsible for providing or paying for transition services.*”) (emphasis added).

<sup>77</sup> See 42 U.S.C. §§ 15001–15009 (2006); N.J. STAT. ANN. §§ 30:6D-1 to -12 (West 2009).

<sup>78</sup> See 29 U.S.C. §§ 701–796 (2006); N.J. ADMIN. CODE §§ 12:45-1.1 to -1.16 (2009).

<sup>79</sup> IDEA, 20 U.S.C. § 1412(a)(1)(A) (2006).

The federal Developmental Disabilities Assistance and Bill of Rights Act of 2000<sup>80</sup> concerns the rights and needs of all individuals with developmental disabilities,<sup>81</sup> which include ASDs.<sup>82</sup> Congress found that a significant number of individuals with developmental disabilities “do not have access to appropriate support and services”<sup>83</sup> and “often require lifelong community services, individualized supports, and other forms of assistance, that are most effective when provided in a coordinated manner.”<sup>84</sup> Additionally, Congress noted that “in almost every State, individuals with developmental disabilities are waiting for appropriate services in their communities.”<sup>85</sup> The Act authorizes the creation of State Councils on Developmental Disabilities and protection and advocacy systems in each state.<sup>86</sup> Services provided under this Act must meet a high standard—they must be “designed to maximize the potential of the individual and should be provided in the setting that is least restrictive of the individual’s personal liberty.”<sup>87</sup>

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<sup>80</sup> §§ 15001–15009 (noting that these sections fall under the heading “Developmental Disabilities Assistance and Bill of Rights: Programs for Individuals with Developmental Disabilities: General Provisions”).

<sup>81</sup> § 15002(8).

The term “developmental disability” means a severe, chronic disability of an individual that—

- (i) is attributable to a mental or physical impairment or combination of mental and physical impairments;
- (ii) is manifested before the individual attains age 22;
- (iii) is likely to continue indefinitely;
- (iv) results in substantial functional limitations in 3 or more of the following areas of major life activity:
  - (I) Self-care.
  - (II) Receptive and expressive language.
  - (III) Learning.
  - (IV) Mobility.
  - (V) Self-direction.
  - (VI) Capacity for independent living.
  - (VII) Economic self-sufficiency; and
- (v) reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

§ 15002(8)(A)(i)–(v).

<sup>82</sup> See CDC, Facts About ASDs, *supra* note 11.

<sup>83</sup> § 15001(a)(6).

<sup>84</sup> § 15001(a)(7).

<sup>85</sup> § 15001(a)(12).

<sup>86</sup> § 15001(b)(1)–(2).

<sup>87</sup> *Id.* § 15009(a)(2). This standard is higher than that for services provided under IDEA. See *Bd. of Educ. v. Rowley*, 458 U.S. 176, 198 (1982).

In New Jersey, the Developmentally Disabled Rights Act provides for services through the Division of Developmental Disabilities (DDD), which is part of the Department of Human Services (DHS).<sup>88</sup> The definition of developmental disability under this Act mirrors the federal definition;<sup>89</sup> it also states that a “[d]evelopmental disability includes but is not limited to severe disabilities attributable to . . . autism.”<sup>90</sup> DDD services may include treatment, day care, special living arrangements, training, education, sheltered employment, and information and referral services.<sup>91</sup> Like federal law,<sup>92</sup> New Jersey’s law requires that services “maximize the developmental potential” in the “least restrictive” way,<sup>93</sup> which is a higher standard for services than those provided under IDEA.<sup>94</sup> Those receiving services under this Act also receive an Individualized Habilitation Plan (IHP).<sup>95</sup>

Although an individual may be eligible for services under the Developmentally Disabled Rights Act, the Act expressly permits waitlists for services, which designate priority categories, because of limited resources and funding.<sup>96</sup> Thus, while the level of services provided is high when adults actually do manage to attain services through DDD, this does little to assist individuals who do not receive services during the lengthy waitlist interim. Unlike services provided under IDEA, individuals who receive DDD residential services must “contribute approximately 75% of their Social Security benefits and other unearned income, as well as 30% of their wages.”<sup>97</sup>

Instead of choosing to receive residential services through DDD, individuals may opt for “self-directed services,” which “are guided by the individual with a disability and his or her family.”<sup>98</sup> This option is

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<sup>88</sup> N.J. STAT. ANN. §§ 30:6D-1 to -12 (West 2009).

<sup>89</sup> 42 U.S.C. § 15002(8) (2006); § 30:6D-3(a).

<sup>90</sup> § 30:6D-3(a)(5).

<sup>91</sup> § 30:6D-3(b).

<sup>92</sup> See § 15009(a)(2).

<sup>93</sup> § 30:6D-9.

<sup>94</sup> See *Bd. of Educ. v. Rowley*, 458 U.S. 176, 198 (1982).

<sup>95</sup> § 30:6D-10; see also Autism N.J., The Division of Developmental Disabilities (DDD),

<http://autismnewjersey.org/TheDivisionofDevelopmentalDisabilitiesDDD.aspx> (last visited Apr. 26, 2010) (noting that an annual IHP is developed “regardless of whether the individual currently is receiving specialized services from DDD”).

<sup>96</sup> N.J. ADMIN. CODE § 10:46-1.1 to -6.1 (2009); see Autism N.J., *supra* note 95 (describing “priority categories”).

<sup>97</sup> Autism N.J., *supra* note 95.

<sup>98</sup> *Id.* “Real Life Choices (RLC) is one such self-directed service in New Jersey.” *Id.* “Individuals become eligible for RLC when they reach the top of DDD’s priority waiting list for residential services.” *Id.*



growing in popularity because of the lack of adequate residential and day programs provided by DDD and other state agencies. Based on need, individuals receive funding to help pay for their own services and have an “Essential Lifestyle Plan” (ELP) instead of an IHP.<sup>99</sup> The newly enacted law entitles individuals opting for self-directed services to the same rights and protections as those receiving government-provided residential services.<sup>100</sup>

*B. Laws, Regulations, and Agency Services Addressing Vocational Needs*

The federal Rehabilitation Act of 1973<sup>101</sup> also authorizes the creation of agencies within each state to provide services for individuals with disabilities, which assist with vocational needs.<sup>102</sup> But the definition of an eligible “individual with a disability” differs from definitions under IDEA and the Developmental Disabilities Assistance and Bill of Rights Act of 2000; the Rehabilitation Act focuses more on an individual’s ability to attain employment.<sup>103</sup> While many individuals remain eligible for services through IDEA, the Developmental Disabilities Assistance and Bill of Rights Act, and the federal Rehabilitation Act, the differing eligibility definitions may create barriers for some individuals who may be higher functioning in some areas and not qualify under a particular definition.

For example, an individual classified as autistic under IDEA might require coaching to improve on-the-job skills but be ineligible for vocational support if he or she cannot demonstrate a requisite deficit in securing employment. Even if individuals are ultimately eligible for vocational support services, the differing eligibility criteria add to the separation between agencies rather than facilitating an individual’s access to services throughout the system. Like the waitlist provisions under the Developmental Disabilities Assistance and Bill of Rights Act, the Rehabilitation Act of 1973 allows for the assignment

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<sup>99</sup> *Id.* (discussing how an ELP is “created to be more person-centered and strength-based than the traditional IHP document”).

<sup>100</sup> N.J. STAT. ANN. §§ 30:6D-12.1 to -12.6 (West 2009); *see also infra* Part V.

<sup>101</sup> 29 U.S.C. §§ 701–796 (2006).

<sup>102</sup> *Id.*

<sup>103</sup> § 705(20)(A)(i) (defining an individual with a disability as having a “physical or mental impairment which for such individual constitutes or results in a substantial impediment to employment”); § 705(20)(A)(ii) (stating that an eligible individual with a disability “can benefit in terms of an employment outcome from vocational rehabilitation services . . .”); § 705(21) (noting that the law has a separate definition for individuals “with a significant disability”).

of “priority for an order of selection” for services.<sup>104</sup> As a result, eligibility does not necessarily equal access to services.

New Jersey’s Administrative Code complies, as it must, with federal requirements under the Rehabilitation Act of 1973.<sup>105</sup> Title 12, Chapter 45 of the Code “applies to every individual who is seeking vocational rehabilitation services through the Division of Vocational Rehabilitation Services” (DVRS) in the state.<sup>106</sup> According to the Code, “Vocational rehabilitation services are any goods or services necessary to render an individual with a disability employable . . . .”<sup>107</sup> Services provided by the DVRS are temporary in nature<sup>108</sup> and may not be appropriately tailored to address the needs of individuals with ASDs.<sup>109</sup>

In New Jersey, eligibility requirements for DVRS services focus on an individual’s needs related to securing and maintaining a job. Individuals are eligible for vocational rehabilitation services if the following are present:

- (1) A physical or mental impairment which for the individual constitutes or results in a substantial impediment to employment;
- and (2) A need for vocational rehabilitation services to prepare for, enter, engage in, or retain gainful employment consistent with the applicant’s strengths, resources, priorities, concerns, abilities, capabilities and informed choice.<sup>110</sup>

Furthermore, individuals with disabilities are classified according to one of three categories based on severity of their disability.<sup>111</sup> This classification may affect the type, duration, and priority of services available.<sup>112</sup> Individuals with ASDs have varying degrees of need, and those with more severe disabilities may receive a higher priority classi-

<sup>104</sup> § 705(2)(A)(i)(II).

<sup>105</sup> N.J. ADMIN. CODE §§ 12:45-1.1 to -1.16 (2009).

<sup>106</sup> § 12:45-1.1(b).

<sup>107</sup> § 12:45-1.12 (noting that these services include “counseling, guidance, and work-related placement services,” “vocational and other training services,” “physical and mental restoration services,” “referral . . . to assist . . . in securing needed services from other agencies,” “transition services,” “on-the-job . . . services,” and “supported employment services.”).

<sup>108</sup> See Autism NJ., Division of Vocational & Rehabilitative Services (DVRS), <http://autismnewjersey.org/DivisionofVocationalRehabilitativeServicesDVRS.aspx> (last visited Mar. 20, 2010) (“DVRS services are not of lifelong duration.”).

<sup>109</sup> COSAC, *supra* note 30, at 18.

<sup>110</sup> § 12:45-1.4.

<sup>111</sup> *Id.* § 12:45-1.2 (noting that these categories are “with a disability,” “with a significant disability,” or “with a most significant disability”).

<sup>112</sup> *Id.*

fication in terms of waitlist placement and a greater likelihood of extended, though not indefinite, services.

Once an individual submits an application for DVRS's services, "[a] counselor shall determine eligibility within a reasonable time, not to exceed sixty days" absent "exceptional and unforeseen circumstances."<sup>113</sup> Thus, the eligibility determination is rapid, but the actual provision of assistance following a determination of eligibility can be much delayed. In the inevitable case of limited funding, a waitlist may be used with priority first determined by severity of disability and then by order of application for services.<sup>114</sup> DVRS develops an Individualized Plan for Employment (IPE), which a counselor monitors; this plan may be coordinated with an IEP for students still eligible for special education services.<sup>115</sup> Additionally, a "financial needs assessment" determines the amount that an individual must pay for services.<sup>116</sup>

#### IV. EFFECTS OF CURRENT LAWS AND AGENCY SERVICES ON INDIVIDUALS WITH ASDS IN NEW JERSEY

Provisions under IDEA and corresponding state regulations require that IEPs include transition planning. This planning must relate to educational and vocational goals and, if appropriate, independent living; and these goals must take students' strengths and interests into account.<sup>117</sup> But insufficient coordination between various agencies during transition planning reduces an individual's preparedness for adult life. Even if schools prepare diligently for an individual's transition, the lack of continuing services for adults needed to attain these goals frustrates the realization of post-secondary objectives and creates lifelong hardships.<sup>118</sup> This reality particularly affects

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<sup>113</sup> *Id.* § 12:45-1.3(f).

<sup>114</sup> *Id.* § 12:45-1.8.

<sup>115</sup> *Id.* §§ 12:45-1.10, -1.11.

<sup>116</sup> *Id.* § 12:45-1.14.

<sup>117</sup> IDEA, 20 U.S.C. § 1414(d)(1)(A)(i)(VIII) (2006); N.J. ADMIN. CODE § 6A:14-3.7 (2009).

<sup>118</sup> See Kantrowitz & Scelfo, *supra* note 8, at 49, 51.

Most government-sponsored educational and therapeutic services stop at the age of 21, and there are few residential facilities and work programs geared to the needs of adults with autism. 'Once they lose the education entitlement and become adults, it's like they fall off the face of the earth' as far as government services are concerned, says Lee Grossman, president and CEO of the Autism Society of America, a major national-advocacy group. . . . [U]ntil programs are widely available, families are left to cobble together a patchwork of solutions—from in-

individuals with ASDs, who often need ongoing support in many areas and rely on continuous access to services to maintain their skills.<sup>119</sup>

Congressional findings cite that “88[%] of individuals with developmental disabilities live with their families or in their own households,”<sup>120</sup> not in residential facilities provided by agencies such as DDD. Because of the scarcity of outside residential care, additional challenges arise if parents and families lose the resources or ability to continue taking care of individuals with ASDs.<sup>121</sup> This problem is readily apparent in New Jersey, which has a larger population of adults in need than other states have.<sup>122</sup> Inadequate coordination between services for school-aged individuals and adults as well as between agencies, such as DVRS and DDD, add to the challenge of securing continuing services.<sup>123</sup>

In addition to general access to support and services, adults with ASDs often require a greater specialization of services better tailored

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formal day care to hourly caretakers to private residential programs. But these are stopgap measures.

*Id.*

<sup>119</sup> See 42 U.S.C. § 15001(7) (2006) (noting that individuals with developmental disabilities, such as ASDs, “often require lifelong community services, individualized supports, and other forms of assistance that are most effective when provided in a coordinated manner”).

<sup>120</sup> § 15001(10).

<sup>121</sup> See § 15001(11)–(12).

[M]any service delivery systems and communities are not prepared to meet the impending needs of the 479,862 adults with developmental disabilities who are living at home with parents who are 60 years old or older and who serve as the primary caregivers of the adults . . . and in almost every State, individuals with developmental disabilities are waiting for appropriate services in their communities.

*Id.*; see also *Effort Highlights Needs of Youth Transitioning from School to Adult Life*, COUNCIL (N.J. Council on Developmental Disabilities, Trenton, N.J.), June 2008, at 1, available at <http://www.njcdd.org/Publications/Updates/thecouncil1C302-V1N9.pdf> [hereinafter *Needs of Youth*] (“Although these students have transition plans, the adult services they need are contingent on state funding.”).

<sup>122</sup> See Davis, *supra* note 24. According to COSAC, in 1996,

[C]iting state [N.J.] Division of Developmental Disabilities statistics . . . the number of people applying for autism-related services has increased by 186 percent since 1999. More than 60 percent of the 50,000 New Jerseyans with an autism-related disorder are adults. . . . Less than 13 percent of the 6,021 people with autism served by the Division of Developmental Disabilities attend day programs. . . . 89 percent of those live at home with families.

*Id.*

<sup>123</sup> See Press Release, N.J. Assembly Democrats, *supra* note 39 (“[N]avigating the myriad services and offices that aim to help autistic individuals has proven equally baffling for too many families.”).

to meet their individualized needs.<sup>124</sup> Services through DVRS, for example, often do not account for unique characteristics of individuals with ASDs<sup>125</sup> and may fail to address socialization needs that accompany employment difficulties.<sup>126</sup> Further, services must be “delivered in a consistent, predictable manner.”<sup>127</sup> Adults with autism have distinctive needs regarding vocational training and maintaining employment.<sup>128</sup> One “study found that adults with autism often experienced high levels of unemployment and under-employment, and that lack of social skills frequently led to poor outcomes including being fired from jobs.”<sup>129</sup>

Numerous obstacles prevent access to services for adults with ASDs. Insufficient funding permeates each issue affecting the provision of services, but additional flaws in the system exacerbate the difficulties and create further challenges. First, New Jersey lacks a comprehensive interagency plan, and inadequate coordination exists between school agencies and agencies servicing adults with ASDs.<sup>130</sup> Second, the statutory language of IDEA and corresponding state regulations do not establish adequate linkages between agencies during transition planning. School and agency responsibilities pertaining to the provision of services are unclear, and the duties of each entity are defined inadequately. Furthermore, although transition services begin while individuals are under the purview of IDEA, individuals face

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<sup>124</sup> See COSAC, *supra* note 30, at 4 (“There is an urgent need to develop more specialized services for adults with autism in all areas of the service delivery system including: in-home and family support; day programs and job supports; and out-of-home residential supports.”).

<sup>125</sup> See *id.*

<sup>126</sup> See MÜLLER, *supra* note 26, at 3.

<sup>127</sup> COSAC, *supra* note 30, at 6.

<sup>128</sup> See Kathleen Carroll, *Helping Adults with Autism into Gainful Jobs; Landmark Plan Looks Beyond School Years*, RECORD (Bergen County, N.J.), Apr. 2, 2008, at A1.

Many adults with the disability require extra help in the workplace, including hands-on job coaches that are funded by the state. But it makes more financial sense to provide support there rather than in adult day care or other costly social programs . . . because employing those adults may help close gaps in the labor pool and contribute to income taxes.

*Id.*

<sup>129</sup> MÜLLER, *supra* note 26, at 3 (citing Eve Müller et al., *Meeting the Vocational Support Needs of Individuals with Asperger Syndrome and Other Autism Spectrum Disabilities*, 18 J. VOCATIONAL REHABILITATION 163, 163–75 (2003)).

<sup>130</sup> See *id.* at 6 (“The lack of early and sustained collaboration between schools and outside agencies makes it difficult to facilitate a seamless transition to post-school life for many students with autism.”).

an enormous drop-off in the quantity and quality of services once they surpass the age of twenty-one.

Limited funding, a deficit in available services, and inefficient use of existing resources create extensive waitlists for adults' access to support.<sup>131</sup> Many individuals remain on waitlists for residential placements through DDD for years, sometimes for more than a decade, even when they are considered "priority candidate[s]."<sup>132</sup> Waitlist numbers underestimate the magnitude of the problem because many individuals have yet to register for services.<sup>133</sup> For those who do manage to secure day programming or residential placements, the overall quality of services requires improvements so that programs better meet the needs of individuals with ASDs and maximize their potential.

#### V. CURRENT ATTEMPTS AT REFORM—NEW JERSEY'S INITIATIVES TO ADDRESS THE NEEDS OF INDIVIDUALS WITH ASDS

New Jersey is at the forefront of multiple legislative and policy initiatives addressing the needs of individuals with autism. Within the state, advocacy groups drove many of the current proposals and much of the newly enacted legislation.<sup>134</sup> One organization, the New Jersey Center for Outreach and Services for the Autism Community (COSAC), now known as Autism New Jersey, drafted a report to provide guidelines for state action regarding adults with ASDs.<sup>135</sup> In addi-

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<sup>131</sup> See Autism N.J., *supra* note 95.

In special education, a student with a disability is immediately entitled to receive services specified in the Individual Education Plan (IEP) regardless of cost. Unlike a local school, DDD is allowed to establish waiting lists for services. Therefore, even when an individual is eligible for services, DDD can require that a person waits for services. There are exceptions—for instance, DDD must provide immediate residential services when an emergency exists.

*Id.* More than 8000 individuals are listed on a group-home waiting list with the Division of Developmental Disabilities with nearly 4000 on the priority list. Harbatkin, *supra* note 5; see also Virginia Rohan, *Child-Care Quandary: Aging Boomers Fear for the Future of Their Disabled Offspring*, RECORD (Bergen County, N.J.), Nov. 11, 2008, at F1 ("In 2007, there were just 24 new placements.").

<sup>132</sup> See Wood, *supra* note 7.

<sup>133</sup> See *id.* ("As of 2004, there were 22,743 DDD (Division of [f] Developmental Disabilities) clients living with a caregiver over the age of 60, which tells you there are many parents who have not even put their kids on the waiting list.").

<sup>134</sup> See Carroll, *supra* note 128. The Alpine Learning Group, a private school serving individuals with autism, "released a new 'how-to' guide for businesses seeking to employ adults with autism . . . . The 22-page guide was funded by a grant from the Ridgewood-based Daniel Jordan Fiddle Foundation." *Id.* See generally COSAC, *supra* note 30.

<sup>135</sup> COSAC, *supra* note 30, at 4–5.

tion, *The Record's* 2006 series on autism served as a catalyst for a group of Assembly bills related to autism.<sup>136</sup> On September 12, 2007, former Governor Corzine signed seven bills related to autism into law.<sup>137</sup> The New Jersey General Assembly and Senate subsequently introduced multiple bills during the 2008–2009 legislative session relating to individuals with ASDs and developmental disabilities.<sup>138</sup>

Of the seven autism bills that Governor Corzine signed into law in September 2007, three directly or potentially affect the needs of adults with ASDs.<sup>139</sup> One law established the New Jersey Adults with Autism Task Force (“Task Force”) in the Department of Human Services (DHS).<sup>140</sup> Its purpose was “to study, evaluate, and develop recommendations relating to specific actionable measures to support

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COSAC convened an historic gathering of more than 50 stakeholders from the public and private sector including parents, service providers, planners and others to develop a blueprint to help guide the State of New Jersey in serving adults with autism. The group generated nearly 30 findings and more than 80 specific recommendations.

*Id.*

<sup>136</sup> See Press Release, N.J. Gen. Assembly, Assembly Passes Sweeping Autism Package: Measures Would Assist Adults with Autism, Advance Research, Promote Awareness (Mar. 15, 2007), available at <http://www.assemblydems.com/pdf/prautism031507.pdf>.

<sup>137</sup> Press Release, State of N.J. Office of the Governor, *supra* note 34.

<sup>138</sup> See, e.g., Gen. Assem. 975, 213th Leg., 2008–2009 Sess. (N.J. 2008) (“Requires DHS to provide functional services to certain persons with developmental disabilities.”); Gen. Assem. 1238, 213th Leg., 2008–2009 Sess. (N.J. 2008) (“Supplemental appropriation of \$5 million to DHS to develop community residences for Division of Developmental Disabilities clients on the waiting list.”); Gen. Assem. 2258, 213th Leg., 2008–2009 Sess. (N.J. 2008) (“Requires Commissioner of Human Services to create identification card for use by persons with autism.”); Gen. Assem. 2040, 213th Leg., 2008–2009 Sess. (N.J. 2008) (“Establishes Task Force on the Oversight of Group Homes for Persons with Developmental Disabilities.”); Gen. Assem. 2442, 213th Leg., 2008–2009 Sess. (N.J. 2008) (“Requires certification and establishes registry in DHS of community agency employees working with persons with developmental disability.”); Gen. Assem. 105, 213th Leg., 2008–2009 Sess. (N.J. 2008) (“Urges State Board of Education and Commission on Higher Education to encourage establishment of programs to provide student partners for students with autism spectrum disorder.”); S. 768, 213th Leg., 2008–2009 Sess. (N.J. 2008) (“Requires candidates for teaching certificates and current teachers to receive instruction in autism awareness and methods of teaching students with autism.”); see also Press Release, N.J. Assembly Democrats, *supra* note 39. According to New Jersey Assembly Speaker Joseph J. Roberts, Jr. (D-Camden), “New Jersey is forging ahead by taking a multidimensional approach to tackle some of the most significant challenges facing individuals with autism and their families.” *Id.*

<sup>139</sup> See *infra* notes 140, 153, 159 and accompanying text.

<sup>140</sup> Act of Sept. 12, 2007, ch. 173, 2007 N.J. Laws 1304.

and meet the needs of adults with autism,” which “include job training and placement, housing, and long-term care.”<sup>141</sup>

While many of New Jersey’s initiatives directly address the needs of children with autism who receive early intervention and school-provided services,<sup>142</sup> creation of the Task Force brought needed attention to the concerns of adults with autism.<sup>143</sup> Additionally, the Task Force’s multi-disciplinary composition enabled it to address the diverse needs of the autism community in areas such as education, housing, and medical research.<sup>144</sup> This coordination is essential for developing effective statewide initiatives, and the Task Force’s recommendations can aid in long-term planning and reform.

The members of the Task Force released their recommendations and a comprehensive report on October 8, 2009.<sup>145</sup> Acknowledging the difficult economic realities confronting the State, the Task Force’s forty-four recommendations include both initiatives that can

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<sup>141</sup> Press Release, State of N.J. Office of the Governor, *supra* note 34.

‘New Jersey faces new challenges created by the rise in adults classified with autism including the need for job training and placement, housing and long-term care,’ said Assemblyman Gary Schaer (D-Passaic/Bergen/Essex). ‘It’s critical that we strengthen the community of support for adults with this lifelong disease.’

*Id.*

<sup>142</sup> *See id.*

<sup>143</sup> *See* Press Release, N.J. Assembly Democrats, *supra* note 39 (“The lawmakers said it is crucial that the state take a comprehensive approach that includes both autistic adults and children, especially since the swelling numbers of children diagnosed with autism since 1991 will begin aging out of the education system over the next several years.”).

<sup>144</sup> State of N.J. Office of the Governor, Boards, Commissions, and Authorities, [https://wwwnet1.state.nj.us/GOV/APPT/GOV\\_APPT\\_WEB/Default.aspx](https://wwwnet1.state.nj.us/GOV/APPT/GOV_APPT_WEB/Default.aspx) (follow “View Details” hyperlink under “New Jersey Adults with Autism Task Force”) (last visited Mar. 14, 2010).

The Task Force shall consist of 13 members as follows: the Commissioners of Human Services, Health and Senior Services, Education, and Labor and Workforce Development, as well as the Chair of the Governor’s Council for Medical Research and Treatment of Infantile Autism or their designees who shall serve ex-officio; and 8 public members who shall be appointed no later than 30 days after the signing of this legislation of which 6 shall be appointed by the Governor—including one person upon the recommendation of the New Jersey Center for Outreach and Services for the Autism Community, one person upon the recommendation of Autism Speaks, one person upon the recommendation of ASPEN, one person who is an adult with autism and two public members with demonstrated expertise in issues relating to the work of the Task Force; one person appointed by the President of the Senate; and one person appointed by the Assembly Speaker.

*Id.*

<sup>145</sup> *See generally* TASK FORCE, *supra* note 34.



commence in the short term with minimal additional funding and others that will require more extensive legislative and financial reform.<sup>146</sup> The top recommendation was “the establishment of an Office of Autism Services (OAS) within the Department of Human Services, Division of Disability Services.”<sup>147</sup> As envisioned by the Task Force, “The OAS will provide a concentrated focus and responsibility for implementing the state strategic plan to address both existing adults with ASD and residents who now are children with ASD but soon will enter the adult service system.”<sup>148</sup> Other recommendations pertain to day programs, employment, healthcare, housing, life skills, and transportation.<sup>149</sup>

Despite the significant work of the Task Force, upon presentation of its final report, the Act creating it was set to expire.<sup>150</sup> While the aim is to use the Task Force’s report to create new legislative and policy initiatives, no guarantee that the government will follow through with the recommendations exists, particularly during a time of tremendous economic unrest in the State.<sup>151</sup> Moreover, while the Task Force compiled a comprehensive plan during its relatively brief tenure, more time will likely be necessary to research ongoing developments and problems thoroughly and to design, revise, and implement integrated and effective solutions.<sup>152</sup>

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<sup>146</sup> *Id.* at 6–10.

<sup>147</sup> *Id.* at 4.

<sup>148</sup> *Id.* (noting that the numerous responsibilities of the OAS would include continuing legislative efforts and “[c]oordinating and promoting inter-agency collaboration of client-centered service delivery across the lifespan”).

<sup>149</sup> *Id.* at 16–41.

<sup>150</sup> Act of Sept. 12, 2007, ch. 173, 2007 N.J. Laws 1304.

<sup>151</sup> A severe economic crisis and transition to a new administration create greater uncertainty about the fate of many of the Task Force’s recommendations, including the creation and/or maintenance of an OAS. See Claire Heining, *Christie Facing Harsh Options: Extreme Measures Outlined for ‘Broke’ New Jersey*, TIMES OF TRENTON, Jan. 23, 2010, at A1 (describing the dire economic climate in New Jersey). But even as Governor Christie’s proposed state budget includes drastic cuts to education aid, “[f]or the first time, the budget includes funds for day programs for developmentally disabled 21-year-olds who will ‘age out’ of their school programs this year.” Lindy Washburn, *Young People with Autism Get ‘Ray of Hope’: Christie Plan Helps Those Who ‘Age Out,’* RECORD (Bergen County, N.J.), Mar. 23, 2010, at A1.

<sup>152</sup> An entity such as the proposed OAS would be pivotal to this endeavor. See TASK FORCE, *supra* note 34, at 16–18. In the fall of 2009, former Governor Corzine announced plans to open an Office for Autism Services. See Cynthia Henry, *Reaction Mixed to New Jersey Office on Autism: Governor Corzine Wants to Give the Disability More Attention. Some Fear It Will Dilute the Focus on Other Special Needs*, PHILADELPHIA INQUIRER, Oct. 18, 2009, at B1. Presently, however, whether the State in fact acted or intends to act on that pledge is unclear.

Another of the September 2007 laws established an Asperger's Syndrome Pilot Initiative in DHS:<sup>153</sup>

The initiative will provide vocational, educational and social training services to persons with Asperger's Syndrome. This will be accomplished through community-based service sites which offer appropriate support; guidance and education that will enable these individuals to further their education [and] achieve gainful employment and become broadly competent adults who are able to lead fulfilling lives.<sup>154</sup>

Individuals with Asperger's Disorder are often able to function with greater independence if given the appropriate support.<sup>155</sup> Because of their strengths, individuals with Asperger's Disorder may not be eligible for support from DDD or DVRS if they do not fit within the definitional criteria for these agencies;<sup>156</sup> yet many of these individuals would nonetheless greatly benefit from continued support and face significant difficulties without it.<sup>157</sup>

Focusing on improving the productivity of individuals with Asperger's will work to maximize outcomes and to reduce lifelong dependence on statewide services.<sup>158</sup> Additionally, integration of educational and vocational goals is essential to effective transition planning

<sup>153</sup> N.J. STAT. ANN. §§ 30:6D-62.3 to -62.4 (West, Westlaw through 2009).

(a) Asperger's Syndrome is a Pervasive Developmental Disorder often characterized by autistic-like behaviors and marked by deficiencies in social and communication skills;

(b) Children with Asperger's Syndrome tend to be self-absorbed, have difficulty making friends, are often preoccupied with their own interests and easily become the victims of teasing or bullying . . . ;

(e) Although those with Asperger's Syndrome have a better prognosis than those with other Pervasive Developmental Disorders, people with Asperger's Syndrome often continue to demonstrate difficulties in social interactions well into their adult lives . . . .

§ 30:6D-62.3(a)-(b), (e).

<sup>154</sup> Press Release, State of N.J. Office of the Governor, *supra* note 34 (According to Assemblywoman Joan Voss (D-Bergen), "This pilot program will be a model to help people with Asperger's acquire the socialization skills they need so they can enjoy productive and happy lives.").

<sup>155</sup> § 30:6D-62.3(f).

<sup>156</sup> § 30:6D-62.3(g).

<sup>157</sup> See § 30:6D-62.3(h) ("The range of support needs for persons with Asperger's Syndrome typically includes: social skills training; social supports, including supported employment; housing supports; and psychiatric and psychological services for the treatment of Obsessive Compulsive Disorder and other neurological disorders[.]" ); see also Kathleen Lynn, *Job Search Program Aids Disabled: Those with Asperger's Getting Help*, RECORD (Bergen County, N.J.), Mar. 2, 2009, at L6 (describing a program started by Jewish Family Service in Teaneck, New Jersey to provide employment support, including mentoring, to individuals with Asperger's).

<sup>158</sup> See N.J. STAT. ANN. § 30:6D-62.4(a) (West, Westlaw through 2009).

and support services as both components impact an individual's capacity to attain independence. If the pilot program is successful, it may lead to an expansion of programs and increased opportunities for individuals across the autism spectrum. Because it is a pilot program, however, the short-term impact will not reach the majority of those in need, and like the Adults with Autism Task Force, nothing guarantees that New Jersey will commit to long-term initiatives in this area.

A third law requires the Department of Health and Senior Services (DHSS) to maintain an anonymous registry of reported autism diagnoses in the state and appropriates funding for this purpose.<sup>159</sup> Although, in the short term, the registry will more directly address school-related needs and planning,<sup>160</sup> the registry can assist with long-term planning for the needs of all individuals with ASDs. By compiling data related to the number of individuals with ASDs in the state, New Jersey can better anticipate future demands for services and support. At the same time, ASDs cover a wide range of behaviors and characteristics. This makes assessing and evaluating individual needs difficult when the only data collected is related to the initial diagnosis alone. The original law was child centered,<sup>161</sup> but 2010 amendments, as recommended by the Task Force, provide for the voluntary inclusion of information pertaining to adults to better plan for and meet the needs of individuals of all ages.<sup>162</sup>

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<sup>159</sup> N.J. STAT. ANN. §§ 26:2-185 to -188 (West 2009). According to Assemblyman John McKeon (D-Essex), "This registry will serve as an invaluable tool for the state to monitor autism cases while ensuring that New Jersey continues to provide services to meet the needs of the state's growing autism community." Press Release, State of N.J. Office of the Governor, *supra* note 34.

The DHSS, in consultation with the Department of Human Services, will maintain an up-to-date registry to include a record of all reported cases of autism that occur in New Jersey . . . to enable analysis of this problem, and to plan for and provide services to children with autism and their families.

*Id.*

<sup>160</sup> § 26:2-185(d).

<sup>161</sup> *Id.* ("A . . . requirement for reporting diagnoses of autism and maintaining a registry of that information is needed to improve current knowledge and understanding of autism . . . and to plan for and provide services to *children* with autism and their families.") (emphasis added).

<sup>162</sup> Act of Jan. 15, 2010, ch. 204, 2009 N.J. Laws (West, Westlaw through 2009 Sess.) (codified at N.J. STAT. ANN. §§ 26:2-185 to -188). Another Task Force recommendation precipitated an amendment to New Jersey's Law Against Discrimination (LAD) "to prohibit discriminatory acts against persons with ASD and other developmental disabilities." TASK FORCE, *supra* note 34, at 5; *see also* N.J. STAT. ANN. § 10:5-5(q) (West, Westlaw through Jan. 15, 2010).

Former Governor Corzine signed four additional bills addressing the needs of children with autism into law in September 2007.<sup>163</sup> One law provides “for teacher training in awareness and instruction methods for students with autism and other developmental disabilities.”<sup>164</sup> Another focuses on early intervention related to early identification of ASDs and referrals for services for toddlers.<sup>165</sup> The final two laws extended New Jersey’s commitment to medical research for autism.<sup>166</sup> Nearly two years later, in the summer of 2009, Governor Corzine signed a bill into law requiring “health benefits coverage for certain therapies for the treatment of autism and other developmental disabilities.”<sup>167</sup> While this legislation is an important development, its coverage does not extend to adults over the age of twenty-one.<sup>168</sup>

In early 2009, Governor Corzine signed a bill into law expanding the legal protections of individuals with developmental disabilities who opt for self-directed services over state-provided residential programs.<sup>169</sup> With self-directed services, state agencies provide funding to individuals who choose to reside in their own homes or with their

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<sup>163</sup> Press Release, State of N.J. Office of the Governor, *supra* note 34 (“Today, we are enhancing New Jersey’s pioneer status in the fight against autism spectrum disorders by bolstering our arsenal of programs, training, education, and research,” said Governor Jon S. Corzine. “This is an opportunity for New Jersey to become a model for other states in researching the nature of autism and its causes as well as in treating those with these disorders.”).

<sup>164</sup> *Id.*; N.J. STAT. ANN. §§ 18A:26-2.8 to -2.10 (West 2009).

<sup>165</sup> N.J. STAT. ANN. §§ 26:1A-36.7, -36.7a (West 2009). The law focuses on

- (a) developing, in consultation with autism experts and advocates . . . guidelines for health care professionals to use in evaluating infants and toddlers for autism, ensuring the timely referral by health care professionals of infants and toddlers suspected of being on the autism spectrum to the Early Intervention Program . . .
- (b) referring affected children who are identified as having autism or suspected of being on the autism spectrum and their families to schools and agencies . . . which offer programs specifically designed to meet the unique needs of children with autism;
- (c) collecting data on statewide autism screening, diagnosis, and intervention programs and systems . . . and
- (d) disseminating information . . . to health care professionals and the general public.

§ 26:1A-36.7a(a)-(d).

<sup>166</sup> N.J. STAT. ANN. §§ 30:6D-56 to -62 (West, Westlaw through 2009); N.J. STAT. ANN. § 39:5-41(f) (West, Westlaw through 2009) (retaining practice of collecting a one-dollar surcharge for motor vehicle fines and traffic violations within the state to contribute to the Autism Medical Research and Treatment Fund).

<sup>167</sup> Act of Aug. 13, 2009, ch. 115, 2009 N.J. Sess. Law Serv. 699 (West) (to be codified as amended in scattered sections of N.J. STAT. ANN. §§ 17, 17B, 26, 52).

<sup>168</sup> *Id.*

<sup>169</sup> N.J. STAT. ANN. §§ 30:6D-12.1 to -12.6 (West 2009).

families, allowing them “to determine the nature and scope of services to be provided, in lieu of the department placing the person with a developmental disability in a residential program operated by the department directly or by contracting with a residential provider of services for persons with developmental disabilities.”<sup>170</sup> The law calls for an expansion of self-directed services and creates an entitlement for individuals opting for these services to “retain the rights guaranteed to them under the Developmentally Disabled Rights Act.”<sup>171</sup> In addition, individuals will benefit from the development of an individualized habitation plan as part of their self-directed services.<sup>172</sup>

Taken together, these new laws demonstrate New Jersey’s efforts toward combating the difficulties facing individuals with ASDs and their families. Those focusing on early intervention and research can lead to more positive long-term gains for individuals with ASDs and may create better outcomes as individuals will be more likely to reach adulthood with greater skills, better equipped to face the challenges of post-school life. While initiatives focusing on children are essential, more attention must focus on the needs of adults with ASDs as well.<sup>173</sup>

#### VI. RECOMMENDATIONS AND PROPOSALS FOR FURTHER STATEWIDE REFORM—NEW JERSEY AS A MODEL

Despite New Jersey’s current efforts and recently enacted legislation, the State is in need of a multi-dimensional and comprehensive plan to amply meet the lifelong needs of adults with ASDs. While inadequate funding will most likely persist across the service delivery sector, the State can take many steps toward meaningful reform; several recommendations and proposals are explained below. New Jersey must strengthen agency collaboration and transition planning for individuals while they remain under the protection of school-provided services to give them the greatest chance of attaining their goals. At the same time, the State must meaningfully address its wait-list problem, provide wider and more flexible access to adult services, and continually strive to bolster service quality and efficiency.

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<sup>170</sup> § 30:6D-12.3.

<sup>171</sup> § 30:6D-12.2(d).

<sup>172</sup> § 30:6D-12.4(b).

<sup>173</sup> See MÜLLER, *supra* note 26, at 1, 5.

A. *Improving Interagency Coordination and Collaboration to Achieve Better Transition Planning Outcomes*

As early intervention programs strive to improve outcomes for individuals by giving them a jump start in receipt of benefits from therapy and education, effective transition planning can better prepare individuals for dealing with the challenges of post-school life and can decrease future reliance on outside support.<sup>174</sup> Because so many factors come into play during transition, including preparation for the workforce, residential life, and independent care, students must experience learning opportunities apart from traditional educational classroom models.<sup>175</sup> Improving coordination and collaboration between agencies—as well as clarifying roles, obligations, and responsibilities related to planning, communicating with families, determining eligibility for each agency, and providing supportive services—can optimize the learning experiences for students with ASDs to better equip them for the transition to adulthood.<sup>176</sup>

1. Developing Comprehensive Interagency Agreements

Schools and other state agencies must work jointly toward improving the outcomes for individuals with ASDs. Rather than a unified network designed to address the varied needs of individuals on the spectrum, schools and other state agencies, such as DVRS and DDD, operate and understand each other as discrete entities; New Jersey is in need of a comprehensive interagency plan to enhance collaboration.<sup>177</sup> Each agency has its own definition for eligibility for services,<sup>178</sup> which effectively puts more red tape in the way of accessing services from each agency. Some individuals may fit eligibility requirements for one agency but not others<sup>179</sup> and may need assistance in determining where they can turn for services. Although it is reasonable for each agency to have different standards, better planning and coordination could nonetheless improve the service delivery system. For example, eligibility for particular services provided by one

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<sup>174</sup> See Duthie, *supra* note 18. See generally MÜLLER, *supra* note 26.

<sup>175</sup> See Morris-Union Jointure Comm'n, <http://www.mujs.org/> (last visited Jan. 21, 2010), for an innovative regional public school model designed to expand learning opportunities for individuals with ASDs.

<sup>176</sup> See MÜLLER, *supra* note 26, at 6–7.

<sup>177</sup> See COSAC, *supra* note 30, at 10 (“New Jersey must establish a single point of entry into the adult service system, which cuts across arbitrary Department lines.”).

<sup>178</sup> See *supra* Parts II, III.

<sup>179</sup> See N.J. STAT. ANN. § 30:6D-62.3(g) (West, Westlaw through 2009).

agency could automatically result in eligibility for services with less stringent requirements provided by another agency.

Better coordination and interdisciplinary efforts can maximize the use of current resources and create a more integrated network of support for individuals with ASDs.<sup>180</sup> Clearly delegating agency roles and the sharing of information between agencies could result in improved communication to families regarding the specifics of differing eligibility standards. Additionally, agency coordination could facilitate a process where an individual submits a single, comprehensive application for various agency services for screening to determine eligibility under the differing standards, which would lessen the burden on applicants and their families.

Other states' models of interagency agreements may be instructive in designing a parallel plan in New Jersey. In Wisconsin, various agencies, including the Department of Public Instruction, the Division of Vocational Rehabilitation, and the Department of Health and Family Services, created an agreement to "clarif[y] their relationship in order to establish a common understanding regarding their roles, policies, and procedures related to providing transition services and supports for students with disabilities entering employment."<sup>181</sup> Wisconsin interpreted federal regulations related to IDEA and the Rehabilitation Act<sup>182</sup> as mandating a comprehensive interagency agreement.<sup>183</sup> Its plan focuses on the transition from education to employment,<sup>184</sup> and its goals include compliance with federal mandates; providing guidance to school districts, service providers, and students and families; and clarifying roles and responsibilities.<sup>185</sup> The plan created a network involving Transition Coordinators, Transition Action Teams, Transition Advisory Networks, and Transition Advisory Councils.<sup>186</sup> It clearly articulates roles, responsibilities, and collaborative activities and includes procedures for conflict resolution.<sup>187</sup>

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<sup>180</sup> See COSAC, *supra* note 30, at 21.

<sup>181</sup> DIV. OF LEARNING SUPPORT: EQUITY & ADVOCACY, WIS. DEP'T OF PUB. INSTRUCTION ET AL., INTERAGENCY AGREEMENT 2 (July 5, 2007), *available at* [http://dwd.wisconsin.gov/dvr/pdf\\_files/dpi\\_interagency\\_agreement.pdf](http://dwd.wisconsin.gov/dvr/pdf_files/dpi_interagency_agreement.pdf) [hereinafter INTERAGENCY AGREEMENT].

<sup>182</sup> See 34 C.F.R. §§ 300.154, 361.22 (2009).

<sup>183</sup> INTERAGENCY AGREEMENT, *supra* note 181, at 3.

<sup>184</sup> *Id.* at 2.

<sup>185</sup> *Id.* at 3.

<sup>186</sup> *Id.* at 6.

<sup>187</sup> *Id.* at 6–10.

Pennsylvania also developed a comprehensive statewide transition plan with interagency collaboration.<sup>188</sup> Its “IDEA Memorandum of Understanding . . . identifies how services for youth with disabilities will be provided and coordinated in the state by identifying agency responsibility for services, financial responsibility, conditions and terms of reimbursement, procedures to address interagency disputes, and procedures for coordinating services.”<sup>189</sup> Pennsylvania also developed a mini-grant program through its Bureau of Special Education to implement “research-based practices related to improving special education services for students with disabilities” and to encourage agency participation.<sup>190</sup>

Like Wisconsin and Pennsylvania, New Jersey must work to establish an agreement between school districts and agencies regarding their responsibilities, coordination of services, and dispute resolution procedures. Although federal regulations do not explicitly define requirements for interagency agreements,<sup>191</sup> Wisconsin’s interpretation correctly exceeds minimum standards, creating a workable agreement that can positively influence the system, and New Jersey should follow suit. Clarification of roles and responsibilities within an interagency agreement can aid individuals and their families by establishing accountability measures to better ensure that individuals receive sufficient transition services.

As part of a comprehensive interagency agreement, New Jersey must provide a better communication network, such as an electronic database, that is accessible to both schools and agencies serving individuals with ASDs. This network should include information related to children, individuals in transition, and adults. Additionally, shared opportunities for professional development and training can work to strengthen relationships between agencies. To further this aim, state funding should directly target transition planning and joint efforts between agencies. Some advocates suggest a “modest, on-going line item in the state budget for those transitioning from special education to the Division of Developmental Disabilities (DDD) adult day

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<sup>188</sup> See Ellen Romett, *Pennsylvania’s Secondary Transition Initiative: Communities of Practice*, COUNTERPOINT (Nat’l Assoc. of State Directors. of Special Educ., Alexandria, VA), Fall 2003, at 1, 1, available at <http://www.ideapartnership.org/documents/3D.Trans.4.18.05.PennaCoP%20UP.Primary.pdf>.

<sup>189</sup> *Id.* at 1.

<sup>190</sup> *Id.* at 5.

<sup>191</sup> See 34 C.F.R. §§ 300.154, 361.22 (2009).



services.”<sup>192</sup> Also, grant programs, such as the Pennsylvania grant program, that use shared resources should target collaborative pilot programs and initiatives.

To facilitate execution of an interagency agreement, New Jersey should create liaison positions to assist families who seek support from various agencies and relieve some of the burdens on school and agency personnel. In the spring of 2008, Senator Robert Menendez (D-N.J.) submitted a bill to the U.S. Senate, the “Helping HANDS for Autism Act of 2008”, that would have created “navigators” to fill this role.<sup>193</sup> Although this bill did not pass at the federal level,<sup>194</sup> New Jersey may emulate its model. As part of Senator Menendez’s proposal, the State “would assign trained ‘navigators’ to families soon after diagnosis to help them sort through medical, educational and social service options.”<sup>195</sup> Navigators would assist individuals and their families in a wide variety of areas, including securing initial services subsequent to an autism diagnosis as well as supporting later housing needs.<sup>196</sup> A navigator program in New Jersey could facilitate interagency coordination throughout an individual’s transition to adulthood. For example, a navigator can assist with the application process for differing agency services and monitor an individual’s wait-list status.

Administrative and financial burdens make the creation of a comprehensive and workable agreement between state agencies challenging to achieve in practice. Nevertheless, a plan can begin by clarifying existing roles and legal responsibilities, such as which entity supplies funding for a particular service or who is responsible for

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<sup>192</sup> *Needs of Youth*, *supra* note 121; *see also* MÜLLER, *supra* note 26, at 7 (“Earmark state funds for transition-aged students with autism, in addition to generic funds for autism and/or secondary transition.”) (internal quotations omitted).

<sup>193</sup> S. 2950, 110th Cong. § 101 (2008). The full title of the federal bill, proposed by Senator Bob Menendez (D-N.J.), was the “Helping Housing, Awareness, and Navigation Demonstration Services for Individuals With Autism Spectrum Disorders Act of 2008.” *Id.*

<sup>194</sup> Menendez reintroduced this bill on March 25, 2009, but it stalled in committee. *See* S. 706, 111th Cong. (2009); GovTrack, S.706: Helping HANDS for Autism Act of 2009, <http://www.govtrack.us/congress/bill.xpd?bill=s111-706> (last visited Mar. 19, 2010).

<sup>195</sup> Kathleen Carroll, *Menendez Bill Helps Families Deal with Autism*, RECORD (Bergen County, N.J.), Apr. 29, 2008, at A1. Similarly, the New Jersey Adults with Autism Task Force seeks creation of a centralized Office for Autism Services that would, among other responsibilities, take on the role of helping individuals and families navigate the service delivery system, promote interagency collaboration, and serve as an information clearinghouse. TASK FORCE, *supra* note 34, at 16–18; *see also* discussion *supra* Part V.

<sup>196</sup> S. 2950 § 101.

communications and giving status updates to families. As in Wisconsin, leaders from schools and other agencies should participate in the development of the agreement; their multi-disciplinary expertise can help to refine priorities and expectations.<sup>197</sup> An agreement should also include benchmarks for expanding responsibilities and joint initiatives to continue over time with frequent reassessment of current efforts.

## 2. Clarifying State Regulatory Requirements Relating to Agency Responsibilities and Expectations

The current statutory language in the New Jersey Administrative Code provisions<sup>198</sup> raises questions about a school's responsibilities regarding agency participation in transition planning. As part of a student's transition, New Jersey requires that a school "shall" take steps to involve the participation of outside agencies, such as DVRS;<sup>199</sup> however, these required steps remain undefined. Moreover, the Code requires that schools identify "alternative strategies" to meet a student's objectives if an outside agency fails to provide services.<sup>200</sup> This provision is vague and sets a low standard for compliance. Statutory or regulatory revisions could better articulate expectations and provide more guidance for service providers,<sup>201</sup> which would also lead to more consistency in practice throughout the state.

The State must strengthen this regulatory language and delineate more detailed, objective requirements of this provision for schools and agencies. The Commissioner of Education and the legislature must communicate minimum standards and should incorporate contingencies into the regulations for failure to meet these standards. For example, if agencies fail to provide transition services, regulations may specify that they must facilitate access to comparable private sector services by furnishing contact information and descriptions of outside programs. If agency representatives fail to attend IEP meetings, schools should be required to take remedial action—such as arranging phone conferences or securing written commitments from agencies that will be providing services for a given individual—and to document their efforts. Regulations can also specify that agency representatives must work with schools to ensure that stu-

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<sup>197</sup> See INTERAGENCY AGREEMENT, *supra* note 181, at 2–4.

<sup>198</sup> N.J. ADMIN. CODE § 6A:14-3.7(g)–(h) (2009).

<sup>199</sup> § 6A:14-3.7(h).

<sup>200</sup> § 6A:14-3.7(g).

<sup>201</sup> See MÜLLER, *supra* note 26, at 7 (recommending strong "legal requirements for the participation of outside agencies in transition planning").

dents' eligibility for agency services is determined prior to exiting the school system and that individuals place their names on waitlists early on in their school careers. Additionally, they can clarify which entity is responsible for identifying and securing outside services when a particular agency is unable to provide them.

Critics of amending New Jersey's regulatory language may argue that the current structure permits needed discretion and flexibility for school districts. They may also posit that further steps or alternative strategies will not be required in every case. Nonetheless, in drafting regulations, the State can work with schools and outside agencies to design guidelines and reasonable expectations based on pre-existing legal responsibilities and best practices related to transition planning.

*B. Transitioning from Entitlements to Eligibility—Addressing the Drop-Off of Services Awaiting Adults with ASDs*

1. Tackling the Problems of Waitlists and Insufficient Quantity of Adult Services

New Jersey must commit to reducing the “burgeoning” number of individuals on waitlists for services.<sup>202</sup> In 2008, the New Jersey General Assembly introduced a bill that would have created mandates for reducing DDD's priority waitlist by ten percent each year.<sup>203</sup> The Assembly proposed this bill in response to the failure of an earlier mandate requiring the elimination of the waitlist by 2008.<sup>204</sup> The bill called for “reallocating federal matching dollars” to fund “community placements” or to “provide family support services.”<sup>205</sup> Additionally, the bill required an annual evaluation, which would “be made available to the public upon request.”<sup>206</sup>

This measure was a positive sign that New Jersey recognized the need to take steps to ameliorate the waitlist problem within the state

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<sup>202</sup> See Wood, *supra* note 7.

<sup>203</sup> Gen. Assem. 2855, 213th Leg., 2008–2009 Sess. (N.J. 2008), available at [http://www.njleg.state.nj.us/2008/Bills/A3000/2855\\_I1.PDF](http://www.njleg.state.nj.us/2008/Bills/A3000/2855_I1.PDF); see also Wood, *supra* note 7 (noting that a lawsuit has been filed by New Jersey Protection and Advocacy Inc. arguing for “community-based services” and placements in the “most integrated setting possible . . . [n]ot isolated, self-contained institutions”) (internal quotations omitted); Complaint for Declaratory and Injunctive Relief at 3, New Jersey Protection & Advocacy, Inc. v. Velez, No. 05-01784 (D.N.J. Apr. 16, 2008) (seeking a court ruling “that New Jersey’s practice of ‘waitlisting’ eligible citizens is not a substitute for providing services that the State is required to provide”).

<sup>204</sup> N.J. Gen. Assem. 2855.

<sup>205</sup> *Id.*

<sup>206</sup> *Id.*

and to create transparency in the system. But following its introduction in May 2008, the bill never advanced out of committee in the Assembly.<sup>207</sup> Going forward, waitlist proposals need to be part of a coordinated effort to improve the service infrastructure and to make service delivery more flexible and accessible to all. Without additional reforms to address the inefficiencies of the present system, which by design cannot accommodate the thousands in need, and to better allocate existing resources, a reduction in the number of individuals on waitlists is not realistic.

Another manner of increasing access to services would be to provide greater support to families who select self-directed rather than government-provided services for day programs and residential placements. Currently, New Jersey has a limited but expanding program of self-directed services, which has the dual benefits of giving individuals more options and reducing the reliance on scarce state-provided residential facilities.<sup>208</sup> In early 2009, the General Assembly introduced a bill seeking “to rebalance State resources to provide community services and supports for persons with developmental disabilities.”<sup>209</sup> The multi-faceted proposal aims to dramatically reduce the population of individuals residing in state developmental centers within the next five years while redirecting resources toward strengthening and expanding community services.<sup>210</sup> Although the measure failed to advance in 2009, the Assembly reintroduced the bill in early 2010.<sup>211</sup>

Senator Menendez’s proposed Helping HANDS for Autism Act of 2008 also contained a provision for increasing the number of self-directed residential programs.<sup>212</sup> Like the proposed autism navigator positions, New Jersey may benefit from adopting this housing initia-

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<sup>207</sup> *Id.*

<sup>208</sup> See TASK FORCE, *supra* note 34, at 33; N.J. Dep’t of Human Servs., Div. of Developmental Disabilities, Self-Directed Services, <http://www.state.nj.us/humanservices/ddd/programs/selfdirected/> (last visited Apr. 7, 2010).

<sup>209</sup> Gen. Assem. 3625, 213th Leg., 2008–2009 Sess. (N.J. 2009).

<sup>210</sup> *Id.* The New Jersey Adults with Autism Task Force found the following: [T]he cost of living in the community is approximately half of the cost of living in an institution. If savings could be obtained by transition the disabled out of the institution, while still providing a safe and successful life for those would be transitioned, the Task Force supports closing a majority of the developmental institutions. This also would allow the DHS-DDD to develop community support programs.

TASK FORCE, *supra* note 34, at 33.

<sup>211</sup> See Gen. Assem. 1673, 214th Leg., 2010–2011 Sess. (N.J. 2010).

<sup>212</sup> S. 2950, 110th Cong. § 301 (2008).

tive at the state level. Senator Menendez's bill sought to create a housing task force and award grants "with the goal of providing individualized housing and services" to adults with ASDs.<sup>213</sup> Such a task force in New Jersey could study the shortage of residential placements for adults with ASDs, develop strategies to assist individuals seeking private placements, and target available funds to support flexibility in the housing system. In the long term, federal funding may be able to further bolster state efforts in this area.

Supporting individuals who opt for self-directed and community services eases strains on the public system and reaches more adults in need of day programs and residential placements.<sup>214</sup> It also promotes choice and gives individuals and their families more autonomy and control over their care.<sup>215</sup> Moreover, qualifying private service providers could be funded directly to reduce bureaucratic expenses and to maximize resources by matching providers to individual needs.

## 2. Improving Efficiency Within the Service Delivery System

Under federal and state laws and regulations, the quality of services is quite high for those who actually have access to the services;<sup>216</sup> however, a system that directs its limited resources to meet fully the needs of a few who make it off of the waiting list while leaving a large number without any services is not acceptable. Waitlists for government-provided services are a current reality in the short-term so New Jersey needs to support private efforts to close gaps and to assist those in need. COSAC's report recommends more flexibility in funding for services and alternate financial support strategies, including "establishing tax credits, tax-exempt savings plans and other vehicles that would facilitate a family's contribution to the cost of services."<sup>217</sup> The New Jersey Adults with Autism Task Force proposes legislation to

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<sup>213</sup> *Id.* In light of the high waitlist numbers for housing and related services, the New Jersey Adults with Autism Task Force also recommends the creation of a grant program. TASK FORCE, *supra* note 34, at 32 ("Awards would be based on: 1) specific needs of the ASD population[,] 2) ability to decrease service costs[,] 3) community involvement[,] 4) partnerships[,] 5) sustainability, and 6) ability to be replicated.").

<sup>214</sup> See Alison Lozano, *What Are We Waiting For? It's Time to Revisit the State's Over Reliance on Developmental Centers*, PEOPLE & FAMILIES (N.J. Council on Developmental Disabilities, Trenton, N.J.), Winter 2008, at iv.

<sup>215</sup> See N.J. Gen. Assem. 1673; N.J. Dep't of Human Servs., *supra* note 208.

<sup>216</sup> See 42 U.S.C. § 15009(a)(2) (2006); N.J. STAT. ANN. § 30:6D-9 (West 2009).

<sup>217</sup> COSAC, *supra* note 30, at 10 ("Programs that exclusively rely on public funding are not a sustainable solution to the funding crisis.").

“[e]stablish a New Jersey Tax-Free Savings Account so that families can save for lifespan expenses related to ASD.”<sup>218</sup>

To improve efficiency of services, New Jersey must improve oversight and planning at all levels. A current New Jersey bill may lead to better organization and planning related to both transition and adult services specifically for individuals with ASDs.<sup>219</sup> It would establish an “Autism Education Council in, but not of, the Department of Education.”<sup>220</sup> The bill would appropriate funding, and the Council would make program recommendations and award grants related to professional development and “supplemental education services for children with autism in the public schools including . . . transitional planning services.”<sup>221</sup> This type of council could better target limited resources to fund needed programs while providing direct oversight relating to the needs of individuals with ASDs.

Another bill proposed that the Public Advocate designate an Autism Advocate, who could “serve as the primary advocate within the Division of Advocacy for the Developmentally Disabled [in the Department of the Public Advocate] for persons with autism and their families who are seeking to obtain services or otherwise contact the division in order to request information or assistance.”<sup>222</sup> Furthermore, the Autism Advocate would have “communicate[d] with, and provide[d] guidance to, departments of State government that provide services which impact persons with autism.”<sup>223</sup> The Autism Advocate’s work could have complemented the council in the Department of Education by creating more efficient linkages between agencies serving transitioning students and adults with ASDs as well as strengthening the nexus between the public and private sectors.

Improved access to information related to transition and adult services will also improve system efficiency and benefit individuals

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<sup>218</sup> TASK FORCE, *supra* note 34, at 18.

<sup>219</sup> Gen. Assem. 1313, 214th Leg., 2010–2011 Sess. (N.J. 2010).

<sup>220</sup> *Id.*

<sup>221</sup> *Id.*

<sup>222</sup> Gen. Assem. 475, 214th Leg., 2010–2011 Sess. (N.J. 2010). Governor Christie’s proposed budget sought to consolidate state agencies and eliminate the Public Advocate. See *Christie’s Budget, Cut by Cut*, STAR-LEDGER (Newark, N.J.), Mar. 17, 2010, at 18. Upon finalizing the state budget, the Public Advocate was eliminated. State of N.J. Dep’t of the Public Advocate, <http://www.state.nj.us/publicadvocate/> (last visited Sept. 12, 2010). Thus the Autism Advocate Bill is no longer viable.

<sup>223</sup> N.J. Gen. Assem. 475. Under the proposal, the Autism Advocate’s responsibilities would have also included “serving persons with developmental disabilities other than autism.” *Id.*

with ASDs and their families.<sup>224</sup> A proposed bill would create a “New Jersey Autism Website’ in consultation with the various autism advocacy and service organizations in the State.”<sup>225</sup> As drafted, the bill designates that a website would predominantly focus on dissemination of information related to diagnosis, early intervention, and services for children.<sup>226</sup> The legislature should amend or supplement this bill to include information pertaining to adults with ASDs as well. If New Jersey is going to invest in this project, it should commit adequate resources to provide information for all age groups affected by ASDs. Adults, whose services do not flow largely or entirely from a single entity such as a local school district, are in some ways even more in need of a centralized repository of information than are children first entering the system.

### 3. Improving the Quality of Services

To improve the quality of available services and to improve administration of current programs, New Jersey should direct more efforts toward increasing professional development and training of those employed to help adults with ASDs.<sup>227</sup> As more individuals are identified with ASDs and later transition out of school-provided programs, a growing demand for professionals in a field that is often plagued with high staff turnover will continue.<sup>228</sup> COSAC proposed that “two and four year colleges . . . work with families and providers to offer supervised, direct care practicum experience for students who plan to work with adults with autism.”<sup>229</sup> While providing experience

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<sup>224</sup> See Editorial, *supra* note 37 (“The more information and support parents have, the better they can cope with the devastating diagnosis—and the better the outcome for their children.”); see also COSAC, *supra* note 30, at 4 (“The adult service system must be integrated, seamless and transparent to users; it must encourage decision-making on the part of families and consumers. The State of New Jersey must establish a system for the coordination and dissemination of accurate information on the support needs of adults with autism.”).

<sup>225</sup> Gen. Assem. 361, 214th Leg., 2010–2011 Sess. (N.J. 2010).

<sup>226</sup> *Id.*

<sup>227</sup> See COSAC, *supra* note 30, at 11 (“New Jersey institutions of higher education should establish a college-level curriculum for ‘Community/Life Coach’ direct care professionals with measurable standards in areas such as safety skills, assessment and interventions for challenging behavior, crisis intervention, community integration and general knowledge of autism spectrum disorders.”); TASK FORCE, *supra* note 34, at 18 (recommending a requirement that “teachers and case managers involved in transition planning . . . attend training on transitioning students with Autism Spectrum Disorders (ASD)”).

<sup>228</sup> See Kate Debevois, *Letting Go: Transitioning Your Adult Child to Independent Living*, 51 AUTISM ADVOC. 8, 10 (2008).

<sup>229</sup> COSAC, *supra* note 30, at 12.

for students and professionals, these programs can also create more service delivery options for individuals with ASDs at institutions of higher education. Any combination of grants, subsidized tuition, and tax incentives contingent on work commitments upon graduation may aid in recruitment of professionals in this area.

Individuals on the autism spectrum encompass a broad range of strengths and disabilities.<sup>230</sup> Some may have severe language deficits and difficulties with communication; other individuals may have relatively minor socialization challenges.<sup>231</sup> As a result, no single program design can meet the needs of all; however, one area of concern for many on the spectrum is underemployment.<sup>232</sup> Many individuals with ASDs have the intellectual and physical capacity to work but may require ongoing training and on-site coaching.<sup>233</sup> Yet inadequacy of job-training programs and lack of supported employment opportunities create few workforce opportunities.<sup>234</sup>

Although providing employment coaches requires financing in the short term, a program that supplies on-the-job mentoring saves costs in the long term by better equipping individuals for future independence, reducing their reliance on sustained governmental support. Some propose creating incentives for businesses and employers to provide this support by establishing tax incentives.<sup>235</sup> Private advocacy groups seek to prioritize supported employment and can supply additional resources. The Alpine Learning Group, a private, not-for-profit school serving individuals with ASDs, prepared a “how-to” guide for businesses that employ individuals with ASDs with funding from the Daniel Jordan Fiddle Foundation.<sup>236</sup> The State should encourage the production of similar publications, possibly with targeted grants, to distribute to businesses in an effort to educate and inform prospective employers. The present efforts of not-for-profits within

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<sup>230</sup> See Harbatkin, *supra* note 5; Carroll, *supra* note 128.

<sup>231</sup> See Harbatkin, *supra* note 5; Carroll, *supra* note 128.

<sup>232</sup> See Carroll, *supra* note 128.

<sup>233</sup> *Id.*

<sup>234</sup> See *id.* In early 2010, the New Jersey Senate introduced a bill aiming to create county-based transition centers for young adults with developmental disabilities that would provide support and guidance related to employment. S. 771, 214th Leg., 2010–2011 Sess. (N.J. 2010). Services would include “mentoring, job coaching, skill training, or any other appropriate wrap-around services to help achieve a successful transition into adult work life.” *Id.*

<sup>235</sup> Kristina Chew, *What Our Kids (Who Will Be Adults Tomorrow) Need: Listening Tour with Sen. Robert Menendez’s Staff*, AUTISM VOX, Jan. 2, 2008, <http://www.autismvox.com/what-our-kids-who-will-be-adults-tomorrow-need-listening-tour-with-sen-robert-menendezs-staff/> (last visited Mar. 19, 2010).

<sup>236</sup> Carroll, *supra* note 128.



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the state illustrate the willingness of the advocacy community to bear some of the burdens in this endeavor, and these groups may be more likely to expand their role with added State support, such as assistance with pilot programs and the dissemination of publications.

## VII. CONCLUSION

A growing number of autism diagnoses and a continually expanding population of adults with ASDs in need of lifelong support will continue to stretch a system that is not currently prepared to fulfill demand. New Jersey has a greater population of those in need than any other state in the country, and as a result, it must develop a multi-layered approach to address the many facets of the challenges affecting the ASD community. While school mandates require services for individuals through the age of twenty-one, New Jersey is vastly unprepared to meet the needs of those aging out of the educational system who often find themselves on seemingly perpetual waitlists. Theoretically available services do nothing to assist individuals who do not benefit from them in practice because they are mired indefinitely on a waitlist. Inadequate funding, of course, is a primary limitation on the scope of services provided, but even in the absence of a significant infusion of money, New Jersey can work to maximize the current service delivery system and to improve the quality and effectiveness of transition planning and adult services.

New Jersey took the first steps toward broadening its attention beyond childhood and confronting shortcomings in the system by establishing a task force targeting the needs of adults with ASDs. Hopefully, the New Jersey Legislature and current administration will work toward implementing the Task Force's recommendations and continue to work toward providing increased support and resources for the adult population. Additionally, New Jersey's pilot initiative for adults with Asperger's Syndrome may create models for further programming available to other individuals on the autism spectrum. By establishing a statewide autism registry, New Jersey can better anticipate the growing need for continued resources and account for increased diagnoses in its long-term planning. At the same time, it must commit to comprehensive short- and long-term reform to adequately address the challenges facing individuals with ASDs within New Jersey.

In particular, New Jersey must improve transition planning for teenagers and young adults to better equip them for the impending difficulties associated with exiting the school system. The State must strengthen interagency relationships and develop agreements that

clearly delineate school and agency roles, responsibilities, and dispute resolution procedures. Regulations must clarify mandates related to transition planning and include accountability measures.

Next, New Jersey must address the pervasive waitlists and lack of services awaiting adults with ASDs when they exit school programs. Encouraging flexibility of service delivery and supporting individuals who opt for self-directed or community-based services in the private sector can extend support to more individuals in a cost-effective manner. Improving information access, establishing governmental positions to help individuals navigate the system, and creating oversight mechanisms will further benefit individuals with ASDs and their families by increasing system efficiencies. Finally, New Jersey must strive to strengthen professional development opportunities and to improve the quality of services available, which includes appropriately matching programs to individual needs.

A statewide initiative requires multi-disciplinary planning, continual oversight and monitoring, and ongoing reassessment. By demonstrating that invested money and resources can lead to successful changes, New Jersey can serve as a model to other states and place itself in a better lobbying position for federal support. Although not a simple task, reform will lead to promising lifelong outcomes for New Jersey residents with ASDs and will provide valuable opportunities and a better quality of life for those in need.