Exploring Transition in New Jersey: Research into the Experiences of Emerging Adults with IDD and their Families

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Overview
Students with disabilities should begin preparing for adult life by the time they turn 16. During this time of transition, a coordinated, results-oriented process should take place to improve the academic and functional achievement of the child with a disability and facilitate movement from school to post-school activities including, postsecondary education, employment, independent living, and community participation. The services provided during transition must be based on the child’s strengths, interests, preferences and needs and may focus around academic instruction, community experiences, employment skills, and or daily living skills (US DOE OSEP, 2007).

This final report provides an overview of activities conducted through the research project titled Exploring Transition in New Jersey: Research into the Experiences of Emerging Adults with IDD and their Families and summarizes the study’s findings.

This study used a four-pronged approach to learn about the current state of transition in New Jersey. The strategies implemented include:
1) Literature review
2) Survey of school districts statewide
3) Regional focus groups
4) Phone interviews with transition age youth and their families

The following describes findings from data gathered through each of these strategies.

Literature Review
A review of national and state-based literature focused on the topic of transition to adulthood for youth with disabilities was conducted as a part of this research project. Much of the literature about transition focuses on school-based efforts. Both national (Newman, et.al., 2011) and state data (NJ OSEP, 2013) on post-school outcomes for youth with disabilities are readily available online. Research has been conducted across the country to determine the most effective strategies in helping students to achieve preferred outcomes such as post-secondary education, employment, increased independence, and social relationships. While the literature focuses predominately on school activities, many of the recommended best practices found in the literature can be applied across school, home, and community environments, and would likely optimize success in achieving preferred outcomes after graduation.

State and National Data
New Jersey’s Office of Special Education Programs monitors activities and compliance with state special education regulations and the Individuals with Disabilities Education Act (IDEA). As part of this monitoring, data is collected on a set of performance indicators, two of which specifically relate to transition. Indicator 13 addresses the percentage of students aged 16+ who have IEPs that contain each of the required components for secondary transition; during the period of July 2013-June 2014, 90.41% of those reviewed in New Jersey’s sample did. Indicator 14 addresses post-school outcomes. Data from the same time period demonstrate that of youth with disabilities in New Jersey, 49% were enrolled in higher education, 74% were enrolled in higher education or were competitively

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employed, and 84% were enrolled higher education, were participating in some other post secondary education or training program, were competitively employed, or were in some other employment setting within one year of leaving high school. It is important to note that this data does not delineate between types of disabilities. The data presented is reflective of disabilities including speech/language impairments, specific learning disabilities, orthopedic impairment, intellectual disabilities and other disability categories eligible for service under IDEA (NJ OSEP, 2015).

Information from the National Longitudinal Transition Study – 2 (NLTS-2), a collection of the country’s largest and most widely used transition study data and reports, were reviewed for purposes of this study. Some key findings show that overall, youth with disabilities are less likely than the young adults in the general population to be enrolled in postsecondary education, be employed, live independently, be married, or have a checking account/credit card. When the general young adult population is compared to that of young adults with intellectual and/or multiple disabilities, these disparities are even greater (Newman et. al., 2011).

Evidence-Based Practices
The research demonstrates a number of in-school predictors that lead to improved post-school outcomes for children with disabilities. Self-determination, career preparation and work experience, and parental involvement/expectations are commonly identified as important indicators of post-school success. Other common predictors described in the literature include:

- career awareness,
- community experiences,
- exit exam requirements/high school diploma status,
- inclusion in general education,
- interagency collaboration,
- occupational courses,
- paid work experiences,
- parental involvement,
- program of study,
- self-advocacy/self-determination,
- self-care/independent living,
- social skills,
- student support,
- transition program,
- vocational education, and
- work study (Test et al., 2009)

National Priorities for Policy and Practice
Efforts have been made across state and federal organizations to set priorities to improve transition for youth with disabilities. These priorities are derived from published research findings. The following describes two publications that present frameworks for improving transition policy and practice.
In April 2013, the Association of University Centers on Disability (AUCD) published a manuscript to trigger conversation among stakeholders aimed at facilitating a more comprehensive and successful transition process for youth with disabilities. This report further emphasizes some of the predictors to post-school outcomes, but also promotes core concepts necessary to develop and implement effective transition processes. These include:

- Self-determination as the foundation for transition planning
- The importance of viewing transition through a cultural lens
- Interagency collaboration as essential
- The inclusion of all perspectives, disciplines (e.g. educators, healthcare, social work, etc.), and organizations that will impact the student (Antosh, et. al., 2013).

In February 2015, The 2020 Federal Youth Transition Plan: A Federal Interagency Strategy was published (FTP Workgroup, 2015). This document provides the rationale for continued interagency efforts by acknowledging recent initiatives, defining national outcome goals for transition, and describing policy areas for future strategic focus. The workgroup defined five priority outcome goals for transition programs and policies to ensure that youth with disabilities have equal opportunity to:

- Access health care services and integrated work-based experiences in high school
- Develop self-determination and engage in self-directing individualized planning
- Be connected to programs, services, activities, information, and supports
- Develop leadership and advocacy skills
- Have involvement from families and other caring adults with high expectations.

**School District Surveys**

Responses from $N = 248$ school districts in New Jersey were received by the time of data analysis. Many of the districts that sent in information were school districts that did not have high schools within the district.

Because the goal of the survey was to better understand barriers for youth with intellectual and developmental disabilities as they transition out of the school system as they reach adulthood, those school districts that did not have a high school ($n = 41$) were dropped from the dataset. All reported descriptive and predictive analyses used the subsequent $N = 207$, except when specifically noted.

In addition, some data points were not available for all questions (see Appendix A for full list of school survey questions). For example, some schools skipped questions or only responded partially to questions. Missing data were not imputed because the variables are discrete in nature. In addition, it was not always clear whether the responses were left blank because the respondent did not know how to respond to the question, felt that the question was not relevant to their own school or district, or simply did not notice the question. All reported descriptive and predictive analysis were conducted with missing data dropped from the analysis of each question to maximize the number of schools and districts included in each analysis. As a result, different analyses include different numbers.
of schools or districts. In order to take this into account, percentages are reported whenever possible rather than raw numbers.

**Descriptive Information**

Data were received from all counties within New Jersey: Atlantic (n=1), Bergen (n=25), Burlington (n=10), Camden (n=17), Cape May (n=2), Cumberland (n=1), Essex (n=21), Gloucester (n=6), Hudson (n=10), Hunterdon (n=4), Mercer (n=5), Middlesex (n=12), Monmouth (n=17), Morris (n=10), Ocean (n=13), Passaic (n=7), Salem (n=4), Somerset (n=17), Sussex (n=4), Union (n=12), and Warren (n=3).

The demographic profile of the responding schools and districts closely approximated the demographics of New Jersey in general. Below, *Table 1* provides a side-by-side comparison of the demographic variables from the dataset, compared with the demographic variables for New Jersey at large. Data for New Jersey at large is from the Department of Education.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Survey data</th>
<th>DOE data</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N=207</td>
<td>N=324</td>
</tr>
<tr>
<td><strong>District size</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Small</td>
<td>137 (67.1%)</td>
<td>191 (58.9%)</td>
</tr>
<tr>
<td>Moderate</td>
<td>35 (16.9%)</td>
<td>73 (22.5%)</td>
</tr>
<tr>
<td>Large</td>
<td>25 (12.1%)</td>
<td>53 (16.4%)</td>
</tr>
<tr>
<td>Very Large</td>
<td>5 (2.4%)</td>
<td>7 (2.2%)</td>
</tr>
<tr>
<td><strong>District Type</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Public</td>
<td>153 (73.91%)</td>
<td>695 (79.7%)</td>
</tr>
<tr>
<td>Non-public (including charter)</td>
<td>53 (25.6%)</td>
<td>177 (20.3%)</td>
</tr>
<tr>
<td><strong>Location</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urban</td>
<td>40 (19.3%)</td>
<td></td>
</tr>
<tr>
<td>Suburban</td>
<td>136 (65.7%)</td>
<td></td>
</tr>
<tr>
<td>Rural</td>
<td>21 (10.1%)</td>
<td></td>
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<tr>
<td><strong>Free Lunch</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-10%</td>
<td>56 (27.1%)</td>
<td>81 (25.0%)</td>
</tr>
<tr>
<td>11-25%</td>
<td>40 (19.3%)</td>
<td>76 (23.5%)</td>
</tr>
<tr>
<td>26-50%</td>
<td>37 (17.9%)</td>
<td>82 (25.3%)</td>
</tr>
<tr>
<td>51-75%</td>
<td>24 (11.6%)</td>
<td>48 (14.8%)</td>
</tr>
<tr>
<td>More than 75%</td>
<td>35 (16.9%)</td>
<td>37 (11.4%)</td>
</tr>
<tr>
<td><strong>Transition Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under 14</td>
<td>50 (24.2%)</td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>124 (59.9%)</td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>11 (5.3%)</td>
<td></td>
</tr>
<tr>
<td>16 and over</td>
<td>20 (9.7%)</td>
<td></td>
</tr>
</tbody>
</table>

*Table 1: Comparison Variables: Frequencies of descriptive variables in the overall survey and frequencies from DOE data for New Jersey school districts in 2013-2014, where available. Both total number of responses for each group and valid percentages were calculated. Please note that because of missing variables, total counts do not equal 207 for most variables, and percentages do not sum to 100.*
**Transition**

As can be seen from Table 1, 84.1% of the districts (n = 174) report compliance, reporting that the school or district typically begins transition-related instructional activities by age 14, with most (n = 124) doing so at age 14. Of the 31 districts that typically begin transition-related activities at age 15 and 16 and over, 3 were regional or receiving schools. Since students may be older when entering the school or district, it is not clear whether the student would have received transition-related instruction at their prior K-6 or K-8 school/district. It is also unclear from the data whether the remaining 28 districts that may not be in compliance were regional or receiving schools because this information was not available.

As stated above, those districts that identified from the dataset as not having a high school were dropped from the dataset. However, because of concerns regarding the age at which students commonly begin transition-related instruction, this subset of responses were considered, with 12 schools/districts beginning such instruction when the students were under 14, and 11 schools/districts beginning instruction by age 14. While it may be the case that some students are not receiving transition-related instructional activities until after the age of 14, the extent of this practice is unclear.

**Transition Team**

Parents were nearly always invited to participate in transition activities (96.1%) and usually attended (84.5%). Students with disabilities were usually invited to participate in the transition team as well (92.3%), and frequently attended (81.6%). While siblings are very rarely invited or attend, other family members were sometimes invited (12.1%) and attended about half the time that they were invited (6.3%).

No statistically significant differences exist with regards to invitation of, or attendance at, the meetings by the individual or family members in terms of district size, location, or percentage of students receiving free or reduced lunch. Public districts were more likely than non-public districts to invite the individual student (p = .02), though whether the student actually attended or not was not statistically significantly different.

Differences did exist across demographic categories, however, in whether other social services professionals attended the school or district’s transition team. As would be expected, larger schools were significantly more likely to invite general teachers ($X^2 = 21.63, p = .00$), and have the general teacher attend ($p = .00$). Larger schools were also significantly more likely to invite and have attend a guidance counselor ($p = .00$), school psychologist ($p = .00$), transition specialist ($p = .03$), and vocational rehabilitation representative ($p = .04$). Again, public school districts were significantly more likely to invite general teachers ($p = .00$) and have the general teacher attend ($p = .00$). The public schools were also significantly more likely to invite and have attend a guidance counselor ($p = .00$) and school psychologist ($p = .00$) and vocational rehabilitation representative was marginally significant, the attendance of the vocational rehabilitation representative reached significance ($p = .06$). These demographic differences were attenuated for differences in socio-economic status (as indicated by percentage of students receiving

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Barriers

Barriers to Successful Transition for Students

School size was not associated with barriers for successful transition for students, except for the lack of community acceptance. Smaller districts were significantly more likely to find community acceptance to be a greater barrier ($p = .02$).

On the other hand, type of district was associated with difficulties in the lack of specific curriculum used for transition ($p = .05$), student scheduling ($p = .00$), and student’s medical fragility ($p = .02$). Specifically, non-public institutions found these difficulties to be a greater barrier. Again, lack of community acceptance was identified as a barrier to successful transition ($p = .01$).

Location of the district (rural, suburban, urban) was associated with multiple barriers: family participation ($p = .01$), lack of community based instruction ($p = .02$), and lack of positive behavioral supports ($p = .00$). The latter two were more likely to be identified as barriers by urban districts, while the first was more likely to be identified as a barrier by suburban districts.

SES was also associated with multiple barriers: family participation ($p = .00$), lack of community based instruction ($p = .02$), and lack of positive behavioral supports ($p = .00$). While barriers associated with family participation showed a curvilinear relationship with SES, perceiving the lack of community based instruction and lack of positive behavioral supports as a barrier increased with increases in poverty.

Barriers to Family Participation in the Transition Process

Larger schools were significantly more likely to report that language was a common barrier to family participation ($p = .01$), with no other barriers reaching statistical significance. Type of school was also not associated with any differences in perception of barriers to family participation.

Location, however, was statistically significantly associated with multiple barriers to family participation: lack of communication ($p = .01$), childcare resources ($p = .02$), literacy ($p = .00$), language ($p = .00$), and culture ($p = .00$), as well as parental knowledge of their rights, responsibilities and options showing marginal significance ($p = .05$). Urban districts found the above barriers to be of greater hindrance compared to suburban and rural districts.

Even more so than location, SES was statistically significantly associated with greater number of barriers to family participation, such that all of the barriers listed in the questionnaire were significantly associated with SES: Difficulties with scheduling ($p = .00$),
lack of communication ($p = .00$), transportation ($p = .00$), childcare resources ($p = .00$), literacy ($p = .00$), language ($p = .00$), culture ($p = .00$), as well as parental knowledge of their rights, responsibilities and options ($p = .01$). For every barrier, greater poverty was associated with greater barriers to family participation.

**Information Seeking and Distribution**

In the distribution of information, most districts distributed print material (95.2%) and mostly utilized in-person distribution of information (82.6%). Top means of electronic distribution were web-based materials (80.7%) and email (76.3%). Fewer than half of the schools and districts noted using the remaining modes of distribution: social media, text messages, automated calls, webinars, provider fairs, or support groups.

Smaller districts were more likely to give information in person compared to large districts ($p = .02$), while non-public districts were more likely to use web-based dissemination of materials ($p = .00$). SES predicted the use of web-based information distribution ($p = .02$) and the use of email ($p = .00$), with the poorest districts less likely to use web-based and email-based dissemination of information. Location, however, made no difference.

**Community Interactions**

In addition to the distribution of information, many districts engaged in referring and/or connecting students to various supports and social services available in the community. Among the services that students and families were most frequently referred to, and connected with, were various governmental programs, such as the Division of Vocational Rehabilitation Services (87% referred; 70% connected), Division of Developmental Disabilities (82.6%; 57.5%), and Division of Children and Families (77.8% referred; 56.0% connected). Referrals about post-secondary education was also common, with 77.3% schools and/or districts reporting that they engaged in referring families, and 14% reporting that families were connected to such educational services.

Other government agencies included Social Security Administration (72.0% referred; 42.5% connected) and Medicaid (62.8% referred; 35.7% connected). Other referrals included: Disability service providers (71.5% referred; 50.7% connected), family support providers (69.6% referred; 43% connected), general community supports (e.g., YMCA) (65% referred; 39% connected), and volunteer opportunities (64.3% referred; 43.0% connected).

Likelihood of referrals to various supports and social services available within the larger society varied by demographic characteristics. In providing referrals, larger schools were more likely to provide referrals for post-secondary education ($p = .01$), Centers for Independent Living ($p = .01$), and Medicaid ($p = .01$). For socioeconomic status, while the poorest schools were less likely to make referrals for Division of Developmental Disabilities ($p = .01$) and Medicaid ($p = .03$), this should be considered in the context of high poverty schools being less likely to provide referrals or connections for supports and services overall compared to more affluent schools/districts.
While referrals to various supports and social services were common, other types of community interaction were more rare. Community-Based Instruction (CBI) was rare, with 62.8% of schools reporting that less than 25% of students participate in school- or district-provided CBI. In addition, while 76.3% of the schools and districts reported the availability of public transportation within their community, only 36.7% of the schools and districts “frequently” or “always” taught students with disabilities to use public transportation. Larger schools were more likely to teach students to use public transportation ($p = .04$). Similarly, urban schools reported greater likelihood of the availability of public transportation ($p = .01$), as well as the greater likelihood of teaching students to use public transportation ($p = .04$). Last, while higher poverty was associated with greater likelihood of access to public transportation, the high poverty districts did not differ from other districts in the teaching of access to public transportation, again, perhaps an indication of lack of resources.

**Self-Advocacy**
Teaching of self-advocacy did not vary by demographic variables, with 81.2% of schools teaching self-advocacy. Of the schools that taught self-advocacy, about half “frequently” or “always” provided self-advocacy opportunities outside of the IEP process (52.1%), while only a slightly greater percentage “frequently” or “always” included self-advocacy as an IEP goal or objective (59.3%).

**Post-Transition**
In addition to the mandatory follow-up post-school outcomes study, it was found that some schools conducted other post-graduation surveys or interviews with past students to learn about post-graduation outcomes. Almost one-third of the non-elementary schools conducted such post-graduate studies, with 68 of the schools replying “Yes.” Public schools were significantly associated with a tendency to conduct such studies ($p = .00$). None of the other demographic variables (location, SES, size) reached significance.

**Regional Focus Groups**
As part of this research project, The Boggs Center on Developmental Disabilities conducted a series of 5 regional “Exploring Transition Focus Groups” in Northern, Central, and Southern New Jersey locations. Participants were recruited through Centers for Independent Living (CILs) and the Statewide Parent Advocacy Network (SPAN).

A total of 27 recent graduates with developmental disabilities and 8 of their parents participated, providing feedback through a facilitated discussion focusing on their preparation for adult life, services and supports received to help them prepare, their lives today, and any services and supports currently received (see Appendix B for focus group questions). The young adults who participated in the regional focus groups graduated between 2008 and 2015, with an average age of 23 years. More than half (59.3%) of focus group participants were male and 40.7% (11) were female. Of the 27 recent graduates, the majority (51.9%) identified as Caucasian/white; 14.8% identified as African American/Black; 14.8% identified as More than One Race, and 3.7% identified as Asian.
One participant identified as “American,” one as “Spanish,” and one did not respond. Demographic information was not collected for parents participating in the focus groups.

Focus group notes were recorded by Boggs Center staff, with common responses summarized based on themes and described below.

**Preparation for Adult Life**
Overall, many of the focus group participants began preparing for adult life well into their high school careers. Though a small number of respondents began this planning in 8th or 9th grade, the majority did not start planning for their adult lives until their junior and senior high school years. Additionally, some did not start preparing for adult life until after they had already graduated from high school.

The most commonly cited resource in preparing for adult life was job sampling, either through the school district or through New Jersey's Division of Vocational Rehabilitation Services (DVRS). Despite being the most widely utilized service in planning for adult life, the job preparation and sampling provided through districts and DVRS was not viewed as particularly helpful. Common complaints included the limited role of DVRS during school years, lack of individualization of job sampling experiences, and lack of connection to further education, vocational resources, and lasting jobs after graduation.

Across the board, recent graduates felt they could have benefitted from more guidance, career counseling, and focus on independent living skills. Preparation for adult life was no better for those with mild disabilities, as many felt they were not provided with transferable life skills (finding and applying for work, paying bills, budgeting) or a clear sense of possible careers.

By and large, the most helpful support in preparing for adult life reported by recent graduates with developmental disabilities was that received from family. To a lesser extent, recent graduates described support received from close connection to particular teachers, guidance counselors, or other school personnel.

**Life After Transition**
The majority of recent graduates with developmental disabilities in the focus groups were working or looking for work. For those currently employed, the most common jobs were part-time positions in food service and retail positions. Some recent graduates with mild disabilities worked in trade and general labor positions, including as electricians and movers. Those looking for work were mainly searching for retail positions. To a lesser extent, recent graduates were volunteering or attending day or vocational training programs. Few recent graduates were attending post-secondary education programs.

The most common services received were those available through the Division of Vocational Rehabilitation Services, and included job training, job coaching, and assistance with post-secondary education or training. Reactions regarding the helpfulness of services available through DVRS were mixed. Though some focus group participants felt that DVRS had successfully helped them find and maintain employment, there were several
complaints about the services received. Lack of communication and coordination, poor matching of jobs to interests and availability, limited career counseling and support for job searching and interviewing were frequent complaints about services received through DVRS. Participants also utilized benefit programs including Social Security Disability Income.

Additionally, many focus group participants relied on natural supports such as family and colleagues at work. A small portion of focus group participants received Support Coordination and other services through the Division of Developmental Disabilities (DDD), and some received services through the Personal Preference Program with the Division of Disability Services. Outside therapies and services, such as mental health services and counseling, independent living skills training, nutrition and personal training, and music therapy were utilized by some participants.

**Phone Interviews**
In addition to the focus groups described above, in-depth, structured interviews were conducted with 62 individuals with developmental disabilities and/or their family members. A full list of phone interview questions can be found in Appendix C.

Fourteen of the 62 interviews were conducted with individuals with disabilities and 48 were conducted primarily with parents or siblings of individuals with disabilities. The average age of the individuals who participated in the interviews – or about whom the interview questions were answered – was 23.6 years, and ages ranged from 18-28; thirty-nine (62.9%) of the individuals were male and 23 (37.1%) were female. Interview subjects were primarily Caucasian/white (83.6%); 8.2% were Hispanic; 5% were Asian; and 3.3% were African American/Black.

**Self-Advocacy**
When asked if the school district taught about self-advocacy, 66% of respondents said “yes,” 23% said “no” and 12% said that they “did not know” or “did not remember.” However, many of those who ultimately responded “yes” had difficulty answering this question because they were unsure how to define self-advocacy. When asked if they still advocate for themselves by telling people what they want, 68% of respondents said “yes” and 31% said “no.” Many of those who said “no” were family members of individuals who are non-verbal or who don’t communicate their desires and needs. Overwhelmingly, the feedback received from individuals and families expressed the lack of clarity around what is meant by “self-advocacy,” and what the purpose of teaching about “self-advocacy” is meant to empower people to do.

**Support Services**
Interview respondents were asked whether they received services from a number of state and community agencies, including DDD, DDS, DVRS, community organizations for individuals with disabilities, community organizations for individuals with or without disabilities, etc. If respondents indicated that they received services from a specific agency or organization, they were asked what services that organization provides. One clear pattern that emerged from the responses to these questions is that people are often unsure
or unaware of what organization/agency is providing what service. This was particularly true for DDS and the PPP program. Also significant is that none of the 62 interview respondents had utilized the services of a one-stop career center.

51% of interview respondents said that services from these agencies started immediately upon graduation from high school; 44% said that services did not begin immediately upon graduation; 5% could not remember whether services began right away. Among those individuals for whom services did not begin immediately, 26% waited more than 6 months for services to begin and 18% waited more than 12 months for services to begin. 68% (30 individuals) of those whose services did not begin immediately indicated that waiting for services made things harder.

Delays in receiving services made things harder for both the individuals and their families emotionally and financially. When describing the hardships that accompanied service delays, parents elaborated:

- “He didn’t have enough structure, a schedule, employment, he does better when he has focus, dignity in work, a way of passing the day.”
- “She had been working in high school and then she was home for years, caused major depression in [her], it was not an easy transition.”
- “I was in a panic over this.”
- “Financially it was a challenge finding and training staff.”

When asked how they learn about services, such as state agencies, that can be of help, interview respondents listed a combination of personal connection and service professionals. Responses included (but were not limited to):

- Personal research
- Connections with the family/friends
- Word of mouth in community and social activities
- Networking
- School transition teams
- Case managers
- Support Coordinator
- Webinars
- Conferences
- SPAN

When asked what the best way to learn about services would be, the most common response was a consolidated internet page that listed all services individuals and families would need to access from which agencies. Many people elaborated that this would be easier than getting passed around from person to person when they call a specific agency with a particular question. Other responses included open houses, booklets of services provided by different agencies and when to apply for each, conferences, other families, school, support coordinators, etc. (See Appendix B, question 26 for a full list).
Participants were asked about the difficulties they experienced in accessing services from state agencies. These difficulties are categorized below:

- **Transportation concerns**: lack of transportation
- **System navigation concerns**: navigating the housing process; difficulty navigating websites and technological glitches; process of applying for services was a “full-time job;” unsure of where to begin the process; lengthy process. As one parent described, “When you’ve done everything you can to avoid a crisis, they still happen because the system is so confused.”
- **Service quality and availability concerns**: availability of suitable programs; housing and services aimed at higher functioning individuals; staff turnover; no services for deaf and blind individuals. For example, one parent shared, “You can't find what’s available and when you find what’s available it may not apply to your child.”
- **Communication concerns**: not receiving a reply from an agency; not receiving the information needed from the support agency; limited time to ask questions; no singular place to call and ask a question.
- **Budgetary concerns**: lack of funds; size of budget.

Most significantly, 68% of interview respondents said that they are not receiving all the services they need. The quotes below illustrate both the type of services that individuals need, but are not receiving, and how parents compensate for the lack of services.

- “He’s not receiving services he is entitled to receive, I’m taking care of meeting his needs (job coaching, social and recreational programs, money).”
- “Sussex County is extremely limited, I need physical therapy for her, no one even does orthotics here, no place to repair wheelchair.”
- “She needs behavior modification and a respite program giving mom a break.”
- “It’s a huge problem, really frustrating getting transportation, need AccessLink but it’s not available for us.”

**Housing**

89% (55 individuals) of interview respondents lived with their family members, 1 lived independently, and 10% (6 individuals) lived in another supported housing situation including a condo/apartment with paid staff, group home, college campus, or with a teacher. 86% (51 individuals) of respondents were always satisfied and 14% (8 individuals) were sometimes satisfied with this living situation. The majority of interview respondents (64%; 39 individuals) do not have paid staff who help at home; 36% (22 individuals) do have paid staff who help them at home.

When asked who they might want to live with in the future, 35% (21 individuals) of interview respondents indicated at home with their family; 18% (11 individuals) said they’d like to live independently; 13% (8 individuals) said they’d like to live with friends; and 33% (20 individuals) gave other responses that included with a roommate; anywhere but at home; with a long-term partner; in a group home; in an apartment with self-hired
Interview respondents provided many things that might keep them from living this way in the future, including things like:

- Lack of housing
- Lack of appropriate housing options
- Always a waiting list
- Trust
- Having the skills to take care of oneself
- Having enough money
- Lack of services and transportation
- Medical issues
- Lack of sufficient employment with good income and benefits

**How Recent Graduates Spend Their Day**

Respondents were asked about where they go during the day. Results suggest that individuals participate in a variety of daytime activities, with some individuals participating in multiple types of activities throughout the week. The majority of respondents either attend a day program (51%) or work (43%), or both, during the day. A smaller percentage of respondents, 19%, engage in volunteer activities. Participation in community activities was reported by 11% of respondents. Only seven individuals (11%) indicated that they attend college. An additional 4 people (6% of respondents) said they participate in other activities, specifically multiple day programs or internships.

**Day Programs**

The individuals or parents of individuals who attend a day program were asked to explain what they like about the program. Responses included things like the variety of activities; a focus on teaching daily living skills and independence through these activities; the safe and clean environment where there are interactive staff members; familiar faces; opportunities for developing friendships and socializing with friends; and the routine and structure they provide.

In addition, interview participants were asked to describe what they would like to change about their day program. Responses included:

- Greater focus on work, particularly on career planning and providing paid jobs to day program attendees, as opposed to volunteer opportunities;
- More variety in activities, for individuals who are at different functioning levels and for those who have been at a specific day program for an extended period of time
- More day programs that are in close proximity to the individual’s home
- Reports on the individual’s behavior at the day program
- Extended days to allow for parents to have full-time employment
- Calendar of events provided to individuals and family members
- Physical therapy services available to individuals
- Larger space at day program
- Improved quality of staff members
Work
Approximately half of the interview respondents (46%) are currently working. Of those working, 86% (24 individuals) work part-time and 14% (4 individuals) work full-time. When asked how long they had been working, 50% of respondents reported working for over 3 years, 35% for 1-3 years, 12% for 7-11 months, and 4% for 0-6 months.

When asked how they get to work, the overwhelming majority of individuals (79%) responded “other” and specifically identified their parents, paid drivers or support staff, and Access Link as their primary mode of transportation to and from work. Two interview respondents (7%) drove themselves to work, three (10%) walked, and one individual used public transportation (local bus or train). An additional finding of significance is that 95% of interview respondents did not use Social Security work incentives to pay for transportation to work and many of those 55 individuals did not know about Social Security Work Incentives at all.

Individuals or parents of individuals who are working were asked how they found their current job. Forty four percent of respondents (14 individuals) became aware of their job through their school; 16% (5 individuals) found the job on their own through personal contacts or individual job searching; and 9% indicated that DVRS counselors were instrumental in helping them find their job. A large percentage (31%) of respondents learned about employment opportunities from a variety of “other” sources including special education counselors, job coaches, family businesses, friends, the SAIL program, and Revolution NJ.

Study participants were asked if they had friends at work and 73% (19 individuals) reported they do have friends at work. It is important to note, however, that many interview respondents qualified this response by saying that individuals do not necessarily spend time with co-workers outside of work.

Those who do not work
About half (53%) of study participants are not working. When asked why they are not working, common responses included lack of opportunities, particularly opportunities that are appropriate to the individual's capacity and functioning level; the individual's lack of focus and attention; personal medical issues; lack of supervision; and limited access to reliable transportation.

Interestingly, 50% of those who are not working do not want to work. Motivation and lack of desire to work are cited as reasons that individuals are not working. The other half of those who are not working, but who have a desire to work face barriers such as lack of opportunity or need for supports, that are keeping them from gaining employment.

Interview respondents were asked what is keeping them from working. Common responses are listed below:
- Lack of personal motivation: “I always envisioned he would work but he isn’t motivated, not interested in working”
• Lack of cognitive ability and attention span
• Anxiety and fear of working with strangers
• Lack of reliable transportation
• Difficulty in finding an employment opportunity

**Post-Secondary Education**
The majority of interview respondents did not attend any post-secondary education (71%, 44 individuals). A small number of respondents did attend some type of school after graduating from high school (29%, 18 individuals) including a 4-year college (11%), a community college (72%), a vocational school (11%), or another type of schooling such as the Helen Keller National Center (6%). Overall, those individuals who participated in any type of post-secondary education heard about their programs through word of mouth from family, friends, and school transition coordinators. A majority of the 18 individuals who attended post-secondary education stated that they have friends they interact with at school (79%), but some said that they did not have friends at school (21%). Those individuals who did not attend post-secondary education listed the following reasons for their not attending:
  • Lack of financial support, which includes that paying for school would take up the majority of a person’s budget
  • Lack of knowledge about programs/opportunities
  • Lack of transportation
  • Lack of inclusive environment

**Health Care**
When an individual turned 18 or 21, 70% of interview respondents reported changing to an adult health care provider; 30% did not. Thirty-nine percent of interview respondents stated that they found it hard to find a doctor. Reasons included:
  • Doctor was not accepting of insurance, particularly Medicaid
  • Location of doctor’s office
  • Waiting list to see doctor
  • Gender-specific doctor
  • Not accepting and/or knowledgeable of individuals with disabilities

**Transportation**
The most often cited form of transportation interviewee respondents rely on to navigate the community is their parents, family, and/or friends (51%). Some respondents (12%) use Access Link and 22% of respondents use other means of transportation such as transportation provided by a day program, medical transportation, and personally hired drivers. Very few interview respondents use public transportation (5%), drive themselves (3%), walk (7%), or ride a bike (2%) most often to navigate their community. Twenty-seven percent (17) of interview respondents took drivers’ education while in high school, and 5 of those individuals (8% of interview respondents overall) have a driver’s license. Although 65% of interview respondents stated that public transportation available within their community, only 19% of those individuals utilize the service.
The reasons for not using public transportation included:
- Lack of support on the bus
- Lack of proper social skills
- Concerns about safety
- Only travels within the county
- Set up process is too long
- Distance from home to bus stop

*Technology*
92% (57 individuals) of interview respondents used technology such as cell phones and computers in their daily life, and all but 1 of the 57 people who answered this question find technology to be sometimes or always helpful.

<table>
<thead>
<tr>
<th>Type of Technology</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cellular phone</td>
<td>44</td>
<td>77.2</td>
</tr>
<tr>
<td>Tablet</td>
<td>31</td>
<td>54.4</td>
</tr>
<tr>
<td>Laptop/computer</td>
<td>44</td>
<td>77.2</td>
</tr>
<tr>
<td>Specific software</td>
<td>1</td>
<td>1.8</td>
</tr>
<tr>
<td>Other**</td>
<td>19</td>
<td>33.3</td>
</tr>
</tbody>
</table>

Table 2: Technology usage among study participants
* Participants were asked to report on all forms of technology that is used, therefore total responses do not add to 57.
** Other forms of technology include: devices for listening to music, watching television and movies, and video games, as well as one device used by a blind and deaf individual to communicate.

When asked what they used technology for, almost all interview respondents indicated entertainment and/or social communication, such as keeping in touch with friends. No one indicated using technology as an assistive communicative device. We did not directly ask about assistive communicative technology in the survey but would suggest asking more specifically about this use of technology in future research of this type.

**Discussion**

*Recurring Themes & Connections*
A number of common themes emerged through review and comparison of data from all sources. Across the board, focus group participants and phone interview respondents would have liked more education around transferrable life skills to help people live more independently, a greater focus on job skills and career planning, and better connection to resources and services before and after graduation. Though an overwhelming majority of school districts reported teaching about self-advocacy (81.2%), many young adults with
disabilities and family members participating in phone interviews had difficulty responding to this question as they were unsure what was meant by “self-advocacy.”

No clear path to finding or utilizing services emerged from findings. Many school districts reported referring students and families to agencies and organizations offering services for adults with disabilities, including the Division of Vocational Rehabilitation Services (87%), Division of Developmental Disabilities (82.6%), and disability service providers (71.5%); however, 44% of phone interview respondents indicated that services did not begin immediately upon graduation. Over two-thirds (68%) of those who did not begin receiving services immediately following graduation explained that waiting for services made things harder. Importantly, 68% of phone interview respondents said they are not receiving all of the services they need.

Services were not seen as adequately meeting the needs of those they are meant to support, nor were they individualized to focus on the specific needs of individuals accessing them. Among those receiving services, focus group participants commonly cited lack of responsiveness to individual needs and interests, especially around seeking employment. In phone interviews, individuals attending day programs and their family members similarly felt that more variety in activities was needed based on different levels of functioning and length of time spent in the program. Additionally, lack of transportation was a pervasive barrier to achievement of nearly all post-school outcome success.

**Study Limitations**
The *Exploring Transition in New Jersey* study offers findings to better understand the transition experience, including barriers to and successes in achieving commonly identified post-school outcomes among young adults with developmental disabilities in the state. The study utilized a variety of methods, including school district surveys, regional focus groups, and phone interviews to gather information about transition from young adults with developmental disabilities, their families, and those who support them. Cumulatively, the study reached 304 respondents, comprised of 207 school districts, and 41 individuals with developmental disabilities and 56 family members participating in regional focus groups and phone interviews.

Despite distributing information about study participation broadly, this study was unable to capture the experiences of those considered the hardest to reach. Though purposeful attempts were made to disseminate information about study participation to organizations serving diverse populations, the individuals with developmental disabilities and families participating in focus group and phone interview activities did not reflect the diversity within the state. In addition, focus group and phone interview participants self-selected to participate rather than being selected through random sample. Due to this self-selection, there may be unknown differences among those who chose to participate and those who did not. Importantly, the focus group and interview format provided little opportunity to hear from those unable to communicate on their own, and results are therefore not representative of those with the most significant disabilities.
**Recommendations**

The findings presented in this report provide an overview of the research results gathered through the project’s several research activities, including school district surveys, regional focus groups, and phone interviews. This data shows that while there are successes, continued effort must take place to ensure successful transitions for youth with developmental disabilities. The following recommendations are suggestions for guiding future efforts to strengthen transition to adulthood based upon what was learned from young adults with developmental disabilities, their families, and school district personnel, as well as best practices in transition from state-based and national literature.

- Expand awareness and education around self-determination and self-advocacy to create a shared understanding and purpose of these skills for young adults with developmental disabilities, their families, and the professionals who support them.
- Cultivate a sense of shared responsibility for transition through interagency collaboration to ensure more effective coordination and earlier connection to paid services and other supports.
- Enhance capacity across service systems to provide individualized supports and services that are person-centered and developed to meet the needs of each individual.
- Instill expectations of employment from a young age among students with developmental disabilities, including those with the most significant disabilities, their families, and the professionals who support them, and expand the use of supports to increase success in competitive employment.
- Strengthen education that provides young adults with developmental disabilities with the skills that can help them to live as independently as possible.
- Increase information and education for families about service systems, options for supports, benefits, and work incentive programs.
- Increase and expand availability of transportation with the understanding that lack of transportation is a major barrier to independence and achievement of all post-school outcomes.
- Increase availability of service providers and qualified direct support professionals and enhance access to services and supports in all domains of life.
References


APPENDIX A: SCHOOL DISTRICT SURVEY
SURVEY: EXPLORING TRANSITION IN NEW JERSEY

Introduction:
As Special Education Coordinator for your school district, charter school, or private school, your participation is requested in this survey about the experience of transition from high school to adult life. This survey will be used in research being conducted by The Boggs Center for Developmental Disabilities and funded by the New Jersey Council on Developmental Disabilities with the goal of developing a more reliable infrastructure of services and supports for people with intellectual and developmental disabilities who are aging out of the school system.

Definitions:
The NJ Department of Education defines Transition as a formal process of long-range cooperative planning that will assist students with disabilities to successfully move from school into the adult world. High quality transition planning and services will enable students with disabilities to pursue their desired postsecondary goals.

The National Institutes of Health (NIH) defines Intellectual Disability as "a group of disorders characterized by a limited mental capacity and difficulty with adaptive behaviors such as managing money, schedules and routines, or social interactions. Intellectual disability originates before the age of 18."

NIH defines Developmental Disability as "a severe, long term disability that can affect cognitive ability, physical functioning, or both. These disabilities appear before age 22 and likely life-long. The term ‘developmental disability’ encompasses intellectual disability but also includes physical disability."

Instructions for Completion:
- Please answer the questions for the educational system you represent, whether a school district or single school. If there is a more appropriate person within your system, with greater knowledge about the transition process, please feel free to forward them to complete and return.
- When you have completed the survey, please return in the enclosed self-addressed stamped envelope.
- Please return your response by [date].

This survey should take about 10 minutes to complete.

Your completion will serve as consent to participate in the research, and your responses will be completely anonymous.

Thank you in advance for your participation.
About Your District/School

1. What is the size of your school district or school? Check only one:
   - Small school district: fewer than 2,560 students total
   - Moderate school district: 2,561 – 4,240 students total
   - Large school district: 5,240 – 13,161 students total
   - Very large school district: more than 13,161 students total

2. What type of school district do you represent? Check all that apply:
   - Public school district
   - Regional school district
   - County vocational school
   - Special services district
   - Private special education school
   - Charter school
   - Receiving school
   - Other (please specify): ________________________________

3. Which of the following best describes the location of your school/school district? Please check one:
   - Urban
   - Suburban
   - Rural

4. What percentage of students within your school/school district received free or reduced lunch last year? Please check one
   - 0-10%
   - 11-25%
   - 26-50%
   - 51-75%
   - More than 75%
5. What county is your school/school district in? Please check one:
   - □ Atlantic
   - □ Bergen
   - □ Burlington
   - □ Camden
   - □ Cape May
   - □ Cumberland
   - □ Essex
   - □ Gloucester
   - □ Hudson
   - □ Hunterdon
   - □ Mercer
   - □ Middlesex
   - □ Monmouth
   - □ Morris
   - □ Ocean
   - □ Passaic
   - □ Salem
   - □ Somerset
   - □ Sussex
   - □ Union
   - □ Warren

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Transition

1. At what age do students *commonly* begin transition-related instructional activities within your school/within your district?
   - □ Under 14
   - □ 14
   - □ 15
   - □ 16+

2. In general, who participates in your school’s/district’s transition team? Check all that apply:

<table>
<thead>
<tr>
<th>Participant</th>
<th>Invited</th>
<th>Attends</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent(s)/guardian(s)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sibling(s)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other family members</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other caregivers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Special education teacher(s)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>General education teacher(s)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Guidance counselor(s)</td>
<td></td>
<td></td>
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<tr>
<td>School psychologist(s)</td>
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<td></td>
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<tr>
<td>Social worker(s)</td>
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<tr>
<td>Transition specialist(s)</td>
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<td></td>
</tr>
<tr>
<td>Department head(s)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vocational rehabilitation representative(s)</td>
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<td></td>
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<tr>
<td>Employment representative(s)</td>
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<td></td>
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<tr>
<td>Juvenile justice representative(s)</td>
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<tr>
<td>Other youth services representative(s) (please specify)</td>
<td></td>
<td></td>
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<tr>
<td>Other adult services representative(s) (please specify):</td>
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<tr>
<td>Other (please specify):</td>
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</tr>
<tr>
<td>Other (please specify):</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Approved by the Rutgers IRB

Page 4 of 10
3. Please indicate below the ways in **students commonly** participate in your school’s/district’s transition process. Check all that apply:

<table>
<thead>
<tr>
<th>Type of participation</th>
<th>Student</th>
<th>Family</th>
</tr>
</thead>
<tbody>
<tr>
<td>Invited to IEP meeting</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attends IEP meeting</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Leads IEP meeting</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Provides input for IEP</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Completes assessments</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (please specify):</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (please specify):</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

4. Please indicate below the ways in which **families commonly** participate in your school’s/district’s transition process. Check all that apply:

<table>
<thead>
<tr>
<th>Type of participation</th>
<th>Student</th>
<th>Family</th>
</tr>
</thead>
<tbody>
<tr>
<td>Invited to IEP meeting</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attends IEP meeting</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Leads IEP meeting</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Provides input for IEP</td>
<td></td>
<td></td>
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<tr>
<td>Completes assessments</td>
<td></td>
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<tr>
<td>Other (please specify):</td>
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<tr>
<td>Other (please specify):</td>
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</tr>
</tbody>
</table>
5. There are many potential barriers to successful transition to adult life for *students* with disabilities. In the table below, note if the barriers to transition listed below pose a major barrier, a moderate barrier, a minor barrier, or are not a barrier for *students*. Please add any barriers you perceive that are not listed below and mark its severity.

<table>
<thead>
<tr>
<th>Barrier</th>
<th>Major Barrier</th>
<th>Moderate Barrier</th>
<th>Minor Barrier</th>
<th>Not a Barrier</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficulty of involvement of other state agencies</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Priority focus on academics</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difficulties meeting instructional needs of students</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No specific curriculum used for transition</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Student scheduling</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family participation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No community-based instruction</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Differing expectations across individual, family, and school</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No Positive Behavioral Supports</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of community acceptance</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Student medical fragility</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Limited school/public transportation resources</td>
<td></td>
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<tr>
<td>Other (please specify):</td>
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<tr>
<td>Other (please specify):</td>
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</tbody>
</table>
6. Below is a list of common barriers that prevent families from participating in the transition process. Please use the table below to note the barriers you see in your school/district, and note for each if its impact is a major barrier, a moderate barrier, a minor barrier, or not a barrier. Please add any barriers you perceive that are not listed below and mark its severity.

<table>
<thead>
<tr>
<th>Barrier</th>
<th>Major Barrier</th>
<th>Moderate Barrier</th>
<th>Minor Barrier</th>
<th>Not a Barrier</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scheduling meetings</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of communication</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transportation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child care resources</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Literacy barriers</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Language barriers</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cultural barriers</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parental knowledge of rights, responsibilities, and/or options</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Other (please specify):</td>
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<tr>
<td>Other (please specify):</td>
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</tr>
</tbody>
</table>

7. What best practices has your school/district found to prepare families and encourage their participation in the transition process?

_____________________________________________________________________
_____________________________________________________________________

8. Beyond the mandatory follow-up post-school outcomes study, does your school/district conduct other post-graduation surveys or interviews with past students to learn about post-education outcomes?

   □ Yes
   □ No

8a) If yes, what does your school/district do and how is this information used?

_____________________________________________________________________
_____________________________________________________________________

APPROVED
OCT 21 2014
Approved by the Rutgers IRB

EXPIRES
OCT 20 2015
Approved by the Rutgers IRB
9. How frequently do families seek information about each of the following topics as their children transition out of school, and how often do you provide this information?

<table>
<thead>
<tr>
<th>Topic</th>
<th>Frequency Expressed</th>
<th>Do you provide this information?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical Care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Continuing Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transportation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adult Services and Supports</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maintaining Relationships</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family Networking/Peer Support Opportunities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical Fitness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nutrition and Diet</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recreation</td>
<td></td>
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<tr>
<td>Housing</td>
<td></td>
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<tr>
<td>Mental Health</td>
<td></td>
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<tr>
<td>Guardianship</td>
<td></td>
<td></td>
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<tr>
<td>Other (please specify):</td>
<td></td>
<td></td>
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<tr>
<td>Other (please specify):</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

10. How does your school/district distribute information to families? Check all that apply:

- Print Material
- Web-based Material
- Social Media
- Email
- Text Messages
- Automated calls
- In Person Presentations
- Webinars
- Provider Fairs
- Family networking/peer support groups
- Other (please specify):
11. Which of these supports and services has your school/district referred and/or connected students to? Check all that apply:

<table>
<thead>
<tr>
<th>Services</th>
<th>Referred</th>
<th>Connected</th>
</tr>
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<td>Employment services through Division of Vocational Rehabilitation Services</td>
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<tr>
<td>General Community Supports (YMCA, art classes, etc.)</td>
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<td>Disability Service Providers</td>
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<td>Volunteer opportunities</td>
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<td>Post-Secondary Education</td>
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<td>Family Support Providers (respite, camps, etc.)</td>
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<td>Advocacy organizations (please specify)</td>
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<td>Division of Developmental Disabilities Support coordination/Case Management (please specify)</td>
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<td>Division of Children and Families</td>
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<td>Social Security Administration</td>
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<td>Centers for Independent Living</td>
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<td>Medicaid</td>
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<td>Other (please specify):</td>
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<td>Other (please specify):</td>
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12. When students have paid Structural Learning Experiences in high school as part of their education, how often do they continue as paid employees after graduation? Please circle one:

- Always
- Frequently
- Rarely
- Never

13. Community-Based Instruction (CBI) is sustained and repeated instruction that takes place in the community rather than in the school building. What percentage of students with disabilities participate in school- or district-provided CBI?
   - □ Less than 25%
   - □ 25-50%
   - □ 51-75%
   - □ More than 75%

14. What are some examples of CBI that your school/district provides (please list)?
15. Does your school/district teach self-advocacy?
   □ Yes
   □ No

15a) If yes, how?

16. How often does your school/district provide self-advocacy opportunities outside of the IEP process (e.g., Dare to Dream conference, school self-advocacy clubs)? Please circle one:

   | Always | Frequently | Rarely | Never |

17. How often is self-advocacy included as part of the student’s IEP goals/objectives? Please circle one:

   | Always | Frequently | Rarely | Never |

18. Is public transportation available in your community?
   □ Yes
   □ No

19. How often do you teach students with disabilities to use public transportation? Please circle one:

   | Always | Frequently | Rarely | Never |

Please return your completed survey in the enclosed self-addressed stamped envelope by [date].
Thank you for your participation.
APPENDIX B: FOCUS GROUP QUESTIONS

Discussion Questions

High School:

1. When did you start preparing for adult life (age, grade)? What do you remember most about that process?
2. What kinds of services/supports did you receive to help you prepare? What was most helpful? What was least helpful?

Today:

3. Tell me about your life today. Are you working? Are you going to school? What do you do in your free time?
4. What services/supports are you receiving now? How much do they help, and what would help more?
5. What was the biggest change after high school? What stayed the same?
6. What is best about life after high school? What is hardest?

Wrap-Up

Is there anything else you would like to share today?

Closing

Thank you so much for your participation in this group today! The information you provided will be extremely helpful as we try to learn what’s working well and where we can improve the transition process for people in New Jersey.
APPENDIX C: PHONE INTERVIEW QUESTIONS

First I’m going to ask you about your school and your district. Remember, if you don’t know the answer or don’t feel comfortable answering, it’s not a problem. Just let me know and we can move on.

15. How old are you? ____________

16. What is your gender? _________

17. What is your ethnicity? _________

18. What high school did you graduate from?
   School Name: ____________________________________
   Town: __________________________________________

Great. Now I’m going to ask you some questions about the things your high school did to help you prepare for life after graduation. Remember, if you don’t know the answer or don’t feel comfortable answering, it’s not a problem. Just let me know and we can move on.

19. Did your school/district teach self-advocacy--for example, how to tell people what you want? [Circle one]
   Yes  No  I don’t know/I don’t remember

20. Do you still self-advocate by telling people what you want?
   Yes  No  I don’t know/I don’t remember
Now I’m going to ask you some questions about different areas of your life today, starting with the services you receive. Remember, if you don’t know the answer or don’t feel comfortable answering, it’s not a problem. Just let me know and we can move on.

Services:

21. I’m going to read a list of state agencies and other agencies and organizations to learn if you’ve met with them. Have you met with:

   Division of Developmental Disabilities (DDD) at the Department of Human Services
   Yes  No  I don’t know/I don’t remember
   If Yes: what services do they provide?

   Division of Vocational Rehabilitation Services (DVRS) at the Department of Labor
   Yes  No  I don’t know/I don’t remember
   If Yes: what services do they provide?

   Commission for the Blind and Visually Impaired (CBVI) at the Department of Human Services
   Yes  No  I don’t know/I don’t remember
   If Yes: what services do they provide?

   Division of the Deaf and Hard of Hearing (DDHH) at the Department of Human Services
   Yes  No  I don’t know/I don’t remember
   If Yes: what services do they provide?
Division of Disability Services (DDS) at the Department of Human Services

Yes  No  I don’t know/I don’t remember

If Yes: what services do they provide?

One Stop Career Centers at the Department of Labor

Yes  No  I don’t know/I don’t remember

If Yes: what services do they provide?

Disability organizations

Yes  No  I don’t know/I don’t remember

If Yes: what services do they provide?

Community organizations that aren’t for people with disabilities

Yes  No  I don’t know/I don’t remember

If Yes: what services do they provide?

Social Security

Yes  No  I don’t know/I don’t remember

A Center for Independent Living

Yes  No  I don’t know/I don’t remember

Anything we missed?

Yes  No  I don’t know/I don’t remember

If Yes: Which ones, and what services do they provide?
22. When you graduated from high school, did your services from the agencies mentioned above start immediately?

   Yes  (Go to Q25)  No  I don’t know/I don’t remember

   Can you tell me more about that?

23. In general, how long did it take for them to start?

24. Did that make things harder for your/your family?

   Yes  No  I don’t know/I don’t remember

   Can you tell me more about that? *(Prompt to learn what hardships this caused for individual and family)*

25. How do you learn about services that can help you, such as state agencies (prompt, if needed: like DDD)?

26. What would be the best way to learn about services that can help you?

27. How satisfied are you with the services you receive? *[Read choices.]*

   Always satisfied  Sometimes satisfied  Never satisfied

   Why do you say that?

28. How respectful are the services you receive of your culture, religion, and beliefs? *[Read choices.]*

   Always respectful  Sometimes respectful  Never respectful

   Why do you say that?

29. What are some of the difficulties you have run into in getting services from state agencies?

   Why do you say that?
30. Are you receiving the services you need?

Yes        No

Please describe:

31. Is there anything else you’d like to tell me about the services you receive?

Now I’m going to ask you some questions about where you live. Remember, if you don’t know the answer or don’t feel comfortable answering, it’s not a problem. Just let me know and we can move on.

Living Arrangements:

32. Who do you live with? (Do not read prompts)

Family Member(s)   Independently   With friends

Other (specify) ____________________________________________

33. How long have you lived there?

34. Do you want to stay there for a long time?

Yes        No        I don’t know

35. Who might you want to live with in the future? (Do not read prompts)

Home   Independently   With friends

Other (specify) ____________________________________________

36. What might keep you from doing that?

37. Do you have paid staff that help you at home?

Yes (Go to Q)        No (Go to Q)

38. How satisfied are you with the work they do? [Read choices.]

Always satisfied   Sometimes satisfied   Never satisfied

Why do you say that?
39. How satisfied are you with your living situation? [Read choices.]

- Always satisfied
- Sometimes satisfied
- Never satisfied

Why do you say that? ______________________________________________________

40. Is there anything else you’d like to tell me about your living situation?

Now I’m going to ask you some questions about what you do during the day, including day programs, jobs and working. Remember, if you don’t know the answer or don’t feel comfortable answering, it’s not a problem. Just let me know and we can move on.

Work:

41. Where do you go during the day? [Check all that apply. For anything other than day program, go to Q]
   - Day program (Go to Q42)
   - Work
   - Volunteer
   - Community activities
   - College
   - Other (please describe):

42. What do you do there?

43. What do you like about your day program?

44. What would you like to change about your day program?

45. Are you satisfied with the staff that work at your day program?
   Why do you say that?

46. Does your day program help you to participate in community activities?
   - Yes (Go to Q47)
   - No (Go to Q66)
   - I don’t know/I don’t remember (Go to Q)

47. If yes, like what?

48. Do you go with a group of people?
   - Yes (Go to Q49)
   - No (Go to Q66)

49. Who do you go with? (Go to Q66)
50. Are you working now?

Yes (Go to Q54) No (Go to Q51)

51. If no, why not?

52. Do you want to work?

Yes No

53. What is keeping you from working? (Go to Q66)

54. If yes, where?

55. Is that a part-time or a full-time job?

Part-time Full-time

56. How long have you been working there?

57. How do you get there? (Do not read prompts, circle all that apply)

Public transportation Ride share Drive myself Walk Bike

Other:

58. How did you find out about this job? (Do not read prompts, circle all that apply)

School On my own Someone I knew outside of school DVRS Counselor

I don’t know/remember

Other:

59. Is your job aware of your disability?

Yes No I don’t know

60. Who spoke with people at your job about any special needs you might have?
61. Do you receive any accommodations at work that other employees don’t get, such as for job tasks?
   Yes               No

62. Do you have a job coach who teaches you job skills at your workplace?
   Yes               No

63. If yes, how satisfied are you with this person? [Read choices.]
   Always satisfied       Sometimes satisfied       Never satisfied
   Why do you say that?

64. How satisfied are you with this job? [Read choices.]
   Always satisfied       Sometimes satisfied       Never satisfied
   Why do you say that?

65. Do you have friends at work?
   Yes               No

66. What job would you like to have one day?

67. What might keep you from doing that?

68. Is there anything else you’d like to tell me about working?

Now I’m going to ask you some questions about education since graduation. Remember, if you don’t know the answer or don’t feel comfortable answering, it’s not a problem. Just let me know and we can move on.

Post-Secondary Education:

69. Did you go to any kind of school after you graduated from high school?
   Yes (Go to Q70)       No (Go to Q79)

70. What kind of school? (Read prompts)
   4-year college       Community college       Vocational school
   Something else (please specify):
71. Do/did you take more than one class per semester?
   Yes          No

72. What are/were you going to school for?

73. How did you find out about your program?

74. Is/was your school aware of your disability?
   Yes          No

75. Are/were you receiving services or supports at school that other students don’t get? (If necessary, give examples: like extra tutoring or extra time on tests.)
   Yes          No

76. Do you have friends at school?
   Yes          No

77. What do/did you plan to do when you graduate?

78. How satisfied are you with school? [Read choices.] (Go to Q82)
   Always satisfied          Sometimes satisfied          Never satisfied
   Why do you say that?

79. Do you plan to go to school in the future?
   Yes          No

80. What kind of school would you like to attend?

81. What makes it difficult to attend school now?

82. What are your goals further into the future?

83. Is there anything else you’d like to tell me about your experiences with school after high school?
   Yes          No
Now I’m going to ask you some questions about healthcare since graduation. Remember, if you don’t know the answer or don’t feel comfortable answering, it’s not a problem. Just let me know and we can move on.

Healthcare

84. Do you think of yourself as healthy or not healthy?
   Healthy           Not healthy           I don’t know/I’m not sure

85. What are some things you do to keep yourself healthy?

86. Do you have any health concerns?
   Yes                        No                        I don’t know/I’m not sure

87. What do you do if you don’t feel well?
88. Do you have a doctor or doctors you see on a regular basis, like for an annual physical?
   Yes (Go to Q89)            No (Go to Q92)

89. Does anyone go to your appointments with you?
   Yes                         No

90. Who goes with you to your appointments?

91. What do they do when they go to the doctor with you? (Go to Q93)

92. Why not?

93. Do you see a dentist on a regular basis?
   Yes (Go to Q95)            No (Go to Q94)

94. Why not?

95. Did you change doctors when you turned 18 or 21?
96. Is it ever hard to find a doctor to go to see?

Yes  No (Go to Q98)

97. Why?

98. Is there anything else you’d like to tell me about your experiences with healthcare after graduation?

Now I’m going to ask you some questions about relationships and free time. Remember, if you don’t know the answer or don’t feel comfortable answering, it’s not a problem. Just let me know and we can move on.

Relationships and Community Living:

99. What do you do for fun?

100. Who do you do those things with?

101. Where do you go?

102. What is your favorite thing to do in your free time?

103. Are you a member of any community groups, such as religious organizations, clubs, sports teams, or volunteer organizations?

Yes (Go to Q104)  No (Go to Q106)

104. Are these groups just for people with disabilities, or do they include people with and without disabilities?

Just for people with disabilities  Include people with and without disabilities
105. How did you find out about these groups and activities? *(Do not read prompts, circle all that apply)*

- [ ] Friends
- [ ] Family
- [ ] Service provider
- [ ] Social media
- [ ] Newspaper/local publication
- [ ] Radio
- [ ] Signs around town
- [ ] CIL
- [ ] Other: _____________________________________
- [ ] I don’t know/I don’t remember

106. Do you attend any religious services, such as those at a church, temple, mosque, or other house of worship?

- [ ] Yes
- [ ] No

107. Do you have a boyfriend/girlfriend/significant other?

- [ ] Yes *(Go to Q109)*
- [ ] No *(Go to Q108)*

108. Do you want a boyfriend/girlfriend/significant other?

- [ ] Yes
- [ ] No

109. Have you had any kind of class in sexual health?

- [ ] Yes
- [ ] No

110. How satisfied are you with how you spend your free time? [Read choices.]

- Always satisfied
- Sometimes satisfied
- Never satisfied

Why do you say that?

111. What keeps you from doing more fun stuff?

112. Is there anything else you’d like to tell me about this part of your life?
Now I’m going to ask you some questions about transportation. Remember, if you don’t know the answer or don’t feel comfortable answering, it’s not a problem. Just let me know and we can move on.

Transportation:

113. In general, how do you get around in your community?

114. Is public transportation available in your community?
   Yes  No  I don’t know

115. Do you use public transportation?
   Yes (Go to Q117)  No

116. Why not?

117. Did you take Drivers Ed?
   Yes  No

118. Do you have a driver’s license?
   Yes (Go to Q120)  No

119. What is preventing you from having a driver’s license?

120. What makes it hard to get around?

121. Do you use Social Security work incentives to help pay for transportation?
   Yes  No

122. Is there anything else you’d like to tell me about your experiences with transportation?
Now I’m going to ask you some questions about how you use technology. Remember, if you don’t know the answer or don’t feel comfortable answering, it’s not a problem. Just let me know and we can move on.

Technology:

123. Do you use technology, such as cell phones or computers, in your day to day life?

   Yes   No (Go to Q130)

124. What technology do you use in your day to day life? (Do not read prompts, circle all that apply)

   ■ Cell phone
   ■ Tablet
   ■ Laptop/computer
   ■ Specific software
   ■ Other: ___________________
   ■ I don’t know/I don’t remember

125. How helpful is technology to you? [Read choices.]

   Always helpful   Sometimes helpful   Never helpful

126. Why do you say that?

127. What do you use it for?

128. What is the most helpful technology you use today?

129. Why do you say that?

130. What is your biggest problem with using technology?

131. Is there anything else you’d like me to know about how you use technology?
Now I’m going to ask you some questions about voting in elections. Remember, if you don’t know the answer or don’t feel comfortable answering, it’s not a problem. Just let me know and we can move on.

Voting in Elections:

132. Are you registered to vote?
   Yes (Go to Q134) No

133. What is preventing you from registering to vote? (Go to Q135)

134. Have you ever voted in an election? (Note: we do not want to ask or know who they voted for.)
   Yes No

135. What makes it hard to vote?

136. Is there anything else you’d like to tell me about your experiences with voting?

Wrap Up:
Those are all the questions I have; thank you so much for talking with me today!

137. Is there anything else we should have asked you?

   When complete, go to wrap up script on page 1.