

**FINAL COMPREHENSIVE REPORT
FAMILY-CENTERED TRANSITION PLANNING FOR STUDENTS WITH
AUTISM SPECTRUM DISORDERS**

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I. Introduction

Post school outcomes for individuals with Autism Spectrum Disorders (ASD) have been disappointing, with many adults attending sheltered workshops, day activity centers, or spending their days at home or in institutional care. There is a lack of validated models of effective transition planning specific to the needs of this population, including the influence of information provided to families and students about adult services, funding streams, and benefits planning on the career planning process; and the accommodations and supports required to individuals with ASD to be active participants in planning and career exploration.

This study examined the effectiveness of a 3-component intervention on the transition readiness of 49 young adults with autism spectrum disorders (ASD) using a randomized controlled trial in New Hampshire and Maine. Intervention components included (a) structured information/training sessions for families related to post-high-school options, support funding, and planning, (b) a series of person-centered planning meetings in each individual's home to develop a vision and plan for the future and form a supportive group who will sustain their involvement beyond the end of high school, and (c) career exploration activities such as job shadows, informational interviews, college visits and work experiences, guided by a career facilitator and a peer mentor.

Quantitative data was collected from students and their families on the following dependent measures: Self-Determination, Vocational Decision-Making, Student Expectations for the Future, and Family Expectations for the Future. A measure of adaptive behavior was used as a covariate. Student Individual Education Plans (IEPs) were content-analyzed for the quality of transition services and planning provided by high schools. Semi-structured interviews analyzed through qualitative methods provided additional information on the perspectives of project participants. Both qualitative and quantitative findings are summarized in this report.

II. Review of the Literature

Employment and postsecondary education outcomes for adults with ASD have been particularly poor, with many adults attending sheltered workshops, day activity centers, or spending their days at home or in institutional care (Garcia-Villamizar, Wehman, & Navarro, 2002; Howlin, 2000; Targett & Wehman, 2009). Even those considered to be high-functioning are more likely to be unemployed than both their typically developing peers and those with less severe social disabilities (Cameto, Levine, & Wagner, 2004; Targett & Wehman, 2009; Tsatsanis, Foley, & Donehower, 2004). For those who do find work, underemployment is common (Hendricks, 2010). Workers with

ASD also switch jobs frequently, are paid less than their co-workers, and tend to view their work experiences in negative terms (Muller, Schuler, Burton, & Yates, 2003).

Only a small minority of those with ASD who could benefit from participation in post-secondary education actually do so (Briel & Getziel, 2009; Howlin, et al, 2004; Jennes-Cousseau et al., 2006). Although many have the academic qualifications to succeed in higher education, concerns about nonacademic issues often limit their post-secondary aspirations (Camarena & Sarigiani, 2009).

The literature suggests that an integrated, comprehensive package of services designed to meet the transition needs of individuals with ASD should be based on effective planning, knowledge of postschool resources, and high expectations.

Effective planning. Many of the poor transition outcomes for individuals with ASD can be attributed to ineffective planning (Presler & Blomquist, 2003; Schall & Wehman, 2009). Traditional planning processes are seldom person and family centered (Schall, 2009; Grigal & Neubert, 2004; deFur, Todd-Allen, & Getzel, 2001). The transition planning process is typically professionally-driven, utilizing formats which distance students and families from active participation (Cooney, 2002). It is important for individuals with ASD and their families to be actively involved in designing individual supports based on their vision and preferences. Transition planning must also address how students with ASD will engage in sufficient career exploration and obtain the necessary experience and skills. Transition-aged youth with ASD often lack the broad range of experiences that provide many adolescents with the background knowledge they need to make informed choices about their future (Frith, 2003) and have a limited understanding of the kinds of jobs held by members of their community (Shall, 2009, Frith, 2003). These youth benefit from community-based experiences that will support their transition to adulthood (Hendricks, Smith, & Wehman, 2009; Schall & Wehman, 2009; Dymond, 2004; Weiner & Zivolich, 2003).

Knowledge of post-school options. Many individuals with ASD and their families need factual information about the complex systems of supports and funding streams that will help them design appropriate individualized supports (Autism Society of America, 2001). Service systems are often overlapping, fragmented and uncoordinated (Waisman Center, 2009). Few families enter the transition process with an understanding of the complex state and federal programs that might be used in supporting the transition to adult life (Schall & Wehman, 2009). Individuals with ASD and their family members may need training and information about possible sources of support if they are to actively participate in the transition process (Briel & Getzel, 2009; Thoma et al., 2001).

High expectations. Parents of youth with ASD often have reduced expectations for their children, regard safety as a more desirable goal than education or employment and express doubts about the likelihood of their children achieving desired adult outcomes (Ivey, 2007). Family members and teachers also maintain low expectations for self-determined behavior (Carter, Owens, Trainor, Sun & Swedeen, 2009) for young adults with disabilities. Low expectations can lead to fewer opportunities for youth with ASD to develop a sense of responsibility appropriate for adults or to achieve career

maturity (Ivey, 2004; Ochs & Roessler, 2001). A strong positive relationship has been found between a high level of expectation of employment on the part of families and teachers and later employment outcomes (Carter, Trainor, Ditchman, Swedeen, Sun & Owens, 2010).

In this project, background literature was used to design a comprehensive intervention model: Family-Centered Transition Planning.

III. Study Design and Methods

This study tested the effectiveness of a 3-component intervention on the transition readiness of young adults with ASD using a randomized controlled trial in New Hampshire and Maine.

Population studied. Individuals between the ages of 16 – 19 at enrollment with a diagnosis on the autism spectrum were eligible for participation. Public high schools in New Hampshire and Maine were contacted and informed of the project. Those indicating a willingness to collaborate identified a contact person who distributed project fact sheets to eligible students and their families. Project staff met with families and students expressing an interest, and informed consent and assent were obtained. A total of 49 students and 49 parents were enrolled.

Sample selection. Following enrollment, students were randomly assigned to participate in year 1 (n = 25 families) or in year 2 (n = 24 families). This delayed-exposure design allowed the year 2 group to serve as a control group in year one, while assuring that all enrolled students and families received the full intervention.

Post-hoc tests showed that students in the two groups were equivalent in age ($M_1 = 17.7$ years, $M_2 = 17.4$ years, $t(47) = .939$, $p = .353$), race ($p = .99$) and gender ($p = .977$). The Adaptive Behavior Assessment Scale II was used to assess level of adaptive behavior across groups at enrollment. The ABAS provides a composite mean scaled score based on an assessment of adaptive skill domains in relation to a standardized sample with a mean of 10 and a standard deviation of 3. Differences in ABAS-II scores across the two groups were not statistically significant ($M_1 = 6.42$, $M_2 = 6.75$, $t(47) = .496$, $p = .63$), indicating that both groups had similar levels of functional impairment at enrollment. Diagnosis on the autism spectrum was confirmed using the Autism Diagnostic Observation Schedule, administered by a trained assessor, and review of school assessment documents.

Instruments used. Self-determination was measured using the ARC Self-Determination Scale. Vocational decision-making was measured using the Vocational Decision-Making Interview. The expectations section of the survey used for the National Longitudinal Transition Study-2 was used to measure student and parent expectations for educational attainment and future independence.

School transition plan quality was measured using the Statement of Transition

Services Review Protocol, a document review protocol and detailed coding manual for answering 35 questions about the presence or absence of items on the student IEP documents. For qualitative interviews, a semi-structured interview guide was followed along with audio-recording and transcription of interviews.

Statistical techniques employed. Group differences in self-determination, vocational decision-making, student and family expectations for the future, and IEP transition plan quality were examined using one-tailed repeated measures t-tests with an alpha of .05.

Qualitative data were analyzed using an open-coding procedure by two independent coders, aided by TAMS Analyzer software.

IV. Detailed Findings

One participant in each group dropped out, both for personal reasons unrelated to the project. Data were collected for the remaining 24 participants in Group 1 and 23 participants in Group 2.

Survey data. In relation to participant survey data, mean scores for the treatment group at enrollment and after one year of FCTP are shown, followed by the results of one-tailed repeated measures t tests:

- Student Expectations: 28.00/32.76 ($t = 2.551, p = .011$)
- Parent Expectations: 25.58/28.79 ($t = 2.323, p = .016$)
- Self-Determination: 59.73/73.93 ($t = 5.583, p = .001$)
- Vocational Decision-Making: 21.58/27.90 ($t = 2.662, p = .006$)

The mean scores for the control group at enrollment and after one year and t test results are as follows:

- Student Expectations: 27.81/30.13 ($t = 1.085, p = 0.115$)
- Parent Expectations: 24.17/23.06 ($t = -.510, p = 0.310$)
- Self-Determination: 62.36/67.07 ($t = 1.646, p = 0.062$)
- Vocational Decision-Making: 22.67/23.87 ($t = 0.638, p = .267$)

Group 1 reported significantly higher student expectations for the future, parent expectations for the future, self-determination, and vocational decision-making ability. The level of improvement in self-determination was extraordinarily high. None of these variables improved significantly for Group 2, although the level of increase in self-determination in Group 2 approached statistical significance.

IEP analysis. In relation to IEP analysis, the transition section of the IEP written previous to project enrollment was scored and compared with the IEP written the following year, or after project participation was underway. IEPs could receive up to 26 points for participation of team members, systematic data collection, a description of projected living arrangements, and type of diploma projected. In addition, 11 transition domains (e.g. employment, post-secondary education, independent living, recreation and leisure) could each receive up to 18 points for quality factors (e.g. specificity of goal,

action steps, timeline and persons responsible) up to a total of 224 points for the ideal transition IEP.

In the FCTP project, the 49 students were from 30 different high schools, 15 in each state. One school referred 4 students, 4 schools referred 3 students, 8 schools referred 2 students, and the remaining 17 schools referred one student each.

For the treatment group, the IEP mean score at enrollment was 30.35, $SD = 13.51$ and the IEP mean score after one year of project participation was 39.53, $SD = 17.28$. This mean difference of 9.18 was statistically significant ($p = .048$). For the control group the IEP mean score at enrollment was 29.74, $SD = 17.87$, and the IEP mean score one year later was 32.94, $SD = 17.28$. This mean difference of 3.20 was not statistically significant ($p = .29$). Thus, the project resulted in significant improvement in transition planning documents. However, scores in the 30's out of a possible 224 points for the ideal transition plan seems disturbingly low, and thus it is fair to conclude that the quality of transition services in student IEPs was poor across all schools in both groups in both states.

Family interviews. A sub-sample of families in group 1 with students expected to remain in high school one additional year were selected for in-depth interviews about their transition experiences in year 2. This allowed an examination of the extent to which Family-Centered Transition Planning resulted in a continuation of transition momentum following conclusion of the intervention. The total number of families in this group was 9, and each family agreed to an interview. Seven interviews were in person, and 2 by telephone. The student participated for all or part of three interviews. Interviews were audio recorded and transcribed.

Interview data were analyzed qualitatively, using an open-coding system by two independent coders, who then met and reconciled their coding systems into a single set of findings. Five findings emerged from this process.

1. Transition information and guidance were well-received by and useful to families. A common theme was the extent to which the day-to-day demands of childrearing and household maintenance tended to take precedence over the need for careful planning for the future, and thus an intervention that kept families on track and parceled out transition tasks into discrete components over time was enormously helpful.

Also helpful was the way the facilitators modeled tenacity and perseverance in working towards goals and following through on plans. The flexibility of the planning process, and the opportunities to meet other families were especially appreciated. Some families also felt that the process was “healing and empowering” for families who had been “traumatized” by the diagnosis of autism for their child. The project’s emphasis on involvement of other supportive people in the planning process also helped families realize that there are other people who could be called upon for support.

Several Group 1 parents reported that the momentum towards meeting transition

objectives had slowed considerably since project services ended. Ideally, these respondents wished that a similar service could be available throughout the entire transition process.

2. The planning process was felt to be growth-enhancing for students. Learning to advocate for oneself and take a more active role in the planning process was a consistent theme for families. One student spoke at his IEP meeting for the first time following planning, and another student made an appointment to see his guidance counselor about dropping a course he disliked; something he would never have done before. Still another student conducted interviews of potential employment service staff within adult service agencies, in order to select the one he liked best.

Families reported that even when students felt uncomfortable or tense because of the planning format or the topic being discussed, the difficulty was very minor, and could even be described as a positive experience. As one parent noted, "Nobody grows up without a little bit of tension."

3. Families became more clearly aware of student strengths and potential. Several parents entered the project feeling, as one parent put it, that they "had trouble imagining" a positive future for their child. Yet by the end of the project several students had their driver's license, one student had driven to the Prom with his date, and a number of students had acquired meaningful job skills or had done well in college classes. One parent was amazed with the cooking skills acquired by her son through a culinary training program, and reported that "When he makes things at home now, everything is all chopped up to be all the same size. It's a work of art." Another parent spoke of being impressed by a poem written by his child:

Father: He has written what I thought was a very interesting poem. What was that called?

Mother: "What I Would Do in 100 Days."

Father: Yes, It was very poignant. It brought tears to my eyes. I mean just to hear his interpretation of his ability, and what he would do, and how he would go about doing it, and what he would get out of it. I thought that was really good. I mean, for lack of a better word, this is a kid who showed insight.

4. Families learned to "think outside the box" in accessing resources. A wide variety of typical resources were accessed for entry into adult life, including friends, relatives, other community members, clubs and teams, and technology such as "i-pads. And formal resources were often used in nontraditional ways. For example, one student arranged for his high school to provide transportation to a local community college during his last year in school so he could gain the experience of trying out a college class, in addition to working on an independent project for high school history credit. Perhaps the most striking example of "out of the box" thinking occurred when one family realized that in order for their son to receive college financial aid he has to be 18 years old, and he would not turn 18 until 6 weeks into the first semester. The family engaged an attorney to obtain court approval for "emancipation" prior to his 18th birthday to allow him to

qualify. Families reported that project services modeled for them and taught them to approach transition obstacles like this in creative ways.

5. Experiences with accessing formal adult services were mixed, with some disappointing experiences with adult services. Families received mixed reception to the requests they made to schools. Many schools were very willing to entertain nontraditional requests if a solid case was made. One school, for example, paid \$1,500 towards the tuition of a summer arts institute for a student interested in pursuing a career in the arts. Other schools were less receptive, particularly when a request involved the expenditure of funds. Several requests for an additional year of school to work on transition goals were denied.

Overall, the experiences of families with adult service organizations tended to be negative. Particularly disappointing was the lack of responsiveness of the vocational rehabilitation system. One family described the experience as “abysmal”, and another reported that “Voc Rehab has never shown up for meetings. They have not done anything.”

V. Discussion and Interpretation of Findings

It is clear that Family-Centered Transition Planning is a highly effective intervention that empowers students and families to take a more active role in the process than is common with traditional transition planning. Quantitative findings showed significant gains in expectations for the future and in vocational decision-making, and very highly significant increases in self-determination for project participants. Project services also resulted in a higher quality of transition plan as recorded on student IEPs.

Qualitative findings support these conclusions and provide additional insight into how the intervention served to (a) increase the creativity with which traditional services were utilized and nontraditional services were accessed, (b) model strategies of perseverance and gradual progress by focusing on one step at a time, (c) connect families to one another and to a wider network of support, and (d) provide opportunities for students to grow and experience adult expectations in small “doses” that fostered growth and assertiveness. The qualitative interview component of the study also showed that post-intervention progress on transition can slow down considerably, suggesting a need for a more ongoing supportive service to families.

Several limitations should be kept in mind in interpreting the results of this study. First, the intensive intervention design and low incidence of the disability to be studied resulted in a fairly low number of subjects per group. However, we found that the intervention is associated with a large effect size, resulting in adequate statistical power for confidence in our conclusions. Second, the intervention was affected by the level of receptivity of individual high school policies and staff and the differential availability of resources across different communities. Our study could not control for these variables. All participating high schools indicated a willingness to work with our project. Nevertheless, variation in variables such as the number and variety of employers,

transportation availability, the quality of adult disability services, and so on was inevitable. It became particularly evident that IEPs are to a large extent administratively-driven documents, only subject to a minor degree of influence by an external project (or, indeed, by the wishes of individual students and families). A final limitation of our study was its brief duration. Because transition occurs over several years, our 24-month study collected post-intervention data before most participants had completed the transition to adult life. Thus, we were able to measure what are in effect proxy variables, such as expectation level, vocational decision-making ability, and self-determination. But we did not directly measure actual employment, post-secondary education, or other outcomes.

This study has a number of clear policy implications in connection with the transition process. First, it is imperative that schools take their transition planning requirements more seriously. We found that even the highest quality transition plans were far from minimally adequate in outlining a positive future and steps towards that future for students with ASD. Within the educational system, the common practice of producing “canned” IEPs based on general templates, and judging their quality solely by administrative and bureaucratic criteria, misses the point of transition planning; and indeed, misses the point of individualized education planning. Current practice should be replaced by a genuine process of listening to each student’s needs and vision for the future, and designing an expansive and detailed plan to reach towards that vision.

Second, we have demonstrated the value of independent facilitation in creating truly person-centered and family-centered plans. We recommend that the responsible parties to the transition process, including high schools, regional vocational rehabilitation offices, and local developmental disability services, as applicable depending on the severity of ASD, pool their resources and invest in the ongoing availability of independent family-centered transition planning facilitation in local communities. The use of blended funding in this way is likely to be extremely cost-effective, because each system benefits from the contributions of the others. And we have seen that the use of this type of planning promises to deliver adult outcomes that result in greater independence from expensive support services and greater level of contribution, including earnings, of individuals with ASD to our communities.

Third, collaboration across organizations involved in transition needs to be given greater emphasis. Adult services at least in the two states in which we have conducted our research do not appear to be responding to the need for transitioning students to become connected to adult supports early in the process. Some experiences, particularly with vocational rehabilitation, were disturbingly poor. These services have an affirmative regulatory obligation to reach out to transitioning youth with disabilities. A re-examination and re-invigoration of the policy framework around interagency collaboration in the transition process appears warranted.

Further research is needed on a larger and more diverse group of students with ASD to assess the degree to which these findings of this study will generalize to other communities, diverse socio-economic groups, and so on. In addition, longitudinal studies are needed to track transition outcomes such as employment and earnings and

participation in post-secondary education over a longer time period.

VI. List of Products

The following products based on the project were produced or are in progress.

Peer-reviewed articles. One article has been published, one is in press, one in review, and three are in preparation, as follows:

Hagner, D. (2010). The role of naturalistic assessment in vocational rehabilitation. *Journal of Rehabilitation*, 76 (1), 28-34.

Hagner, D., Kurtz, A., Cloutier, H., Arakelian, C., Brucker, D. & May, J. (in press). Outcomes of a family-centered transition process for students with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*.

Hagner, D. & Cloutier, H. (in review). "We have never done this before:" Person-directed transition teams and customized employment. *International Journal of Qualitative Studies in Education*.

Hagner, D. & Kurtz, A. (in preparation). The experiences of high school students with ASD and their families with family centered transition planning.

Hagner, D., Kurtz, A., Cloutier, H., & May, J. (in preparation). Person-centered planning with individuals with autism spectrum disorders: Issues and options.

Kurtz, A. & Hagner, D. (in preparation). The impact of family centered transition planning on high school transition IEPs.

Conference presentations. Four national presentations of project findings have been conducted and two more are scheduled, as follows:

After High School, What Comes Next?

Hagner, D., Cloutier, C. & Arakelian, C.

UNH Institute on Disability 7th Annual Summer Autism Institute
Manchester NH
August, 2010

Family-Centered Transition: Preliminary Results

Hagner, D.

Combating Autism Act Initiatives Annual Meeting
Bethesda MD
January, 2011

Family-Centered Transition for Students with Autism Spectrum Disorders

Hagner, D. & Arakelian, C.

Poster Session, Combating Autism Act Initiatives Annual Meeting
Bethesda MD
January, 2011

Family-Centered Transition Planning for Students with Autism Spectrum Disorders
Hagner, D., Kurtz, A. & Cloutier, H.
Council for Exceptional Children, Div. of Career Development and Transition Annual
Conf.
Kansas City MO
October, 2011

Poster Session: Student and family driven transition for youth with Autism Spectrum
Disorders
Kurtz, A.
Assoc. of University Centers of Excellence in Disability Annual Conf.
Arlington VA
November, 2011

Roundtable Session: Supporting Families with Family Members in Transition
Kurtz, A. & Arakelian, C.
Assoc. of University Centers of Excellence in Disability Annual Conf.
Arlington VA
November, 2011.

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