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Person-Centered Planning for Transition-Aged Youth with Autism Spectrum Disorders

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Person-centered planning is a process that can allow individuals with disabilities to participate more actively in their transition planning, and more active participation in planning is associated with more positive vocational rehabilitation outcomes. However, youth with Autism Spectrum Disorders (ASD) often face obstacles to participation in person-centered planning, including high levels of anxiety, difficulties with social interaction and communication. This study explores strategies and supports used to help transition-aged youth with ASD participate in person-centered transition planning meetings. Strategies facilitating participation included: (1) individualized preparation for meetings, (2) informal activities to build rapport between the planning facilitator and the youth, (3) flexible meeting designs, (4) distance attendance, and (5) support for alternative means of communication. The findings suggest that person-centered planning can be implemented for transition-aged youth across the autism spectrum as a tool for enhancing participation in transition planning. Implications for the use of this planning process by rehabilitation counselors involved in transition are discussed.

The quality of transition planning from high school to adult life can make a critical difference in the rehabilitation outcomes of youth with disabilities. Characteristics of the planning process associated with positive outcomes for individuals with Autism Spectrum Disorders (ASD) include active involvement of the transitioning youth and family (Benz, Lindstrom, & Yovanoff, 2000), and an emphasis on self-determination and self-advocacy (Cobb & Alwell, 2009; Test, et al., 2009). Unfortunately, these elements are often lacking in transition planning for individuals with ASD (Presler & Blomquist, 2003; Schall & Wehman, 2009), leading to dissatisfaction with the planning process on the part of families (Hetherington, et al., 2010) and contributing to poor post-school outcomes (Cederlund, Hagberg, Billstedt, Gillberg, & Gillberg, 2008; Eaves & Ho, 2008; Shattuck, Narendorf, et al., 2012).

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Person-centered planning has emerged in recent years as an approach that involves consumers and families in the planning process more centrally than traditional planning approaches (DeFur, Todd-Allen, & Getzel, 2001; Grigal & Neubert, 2004; Schall & Wehman, 2009). In person-centered planning, an individual and his or her significant others participate in a series of facilitated group sessions to explore and clarify the individual's capacities, aspirations and supports, and develop community participation goals and plans (Hagner, 2010). The multiple perspectives of the group create a shared vision for the future through a process sometimes called "collective induction" (Michaels & Ferrara, 2005, p. 290). Person-centered planning has been found to be effective in increasing community participation and enhancing social support for individuals with disabilities (Cloutier, Malloy, Hagner, & Cotton, 2006; Holburn, Jacobson, Schwartz, Flory, & Vietze, 2004; Robertson, et al., 2006) and in facilitating access to employment (Hagner, McGahie, & Cloutier, 2001; Menchetti & Garcia, 2003; Wolf-Branigan, Daeschlein, & Cardinal, 2000). A survey of placement practices prevalent in employment services for individuals with developmental

disabilities (Migliore, Butterworth, Nord, Cox, & Gelb, 2012) found that 64% of job placement personnel reported that they had either facilitated or participated in person-centered planning for their consumers.

Some aspects of person-centered planning make this process particularly attractive for use with individuals with ASD. Olney (2000) noted that formal assessment measures may be inappropriate with this population. Multiple and extensive changes in standardized test administration procedures are often required to accommodate for the sensory, emotional, and communication difficulties of this population (Prizant & Wetherby, 2005). These departures from standard procedures may change the meaning of the resulting scores in ways that make it difficult or impossible to interpret the results in relation to test norms (Lee, Reynolds, & Willson, 2003), and thus have a negative impact on vocational planning. Grasso, Jitendra, Browder, and Harp (2004) found that vocational rehabilitation counselors viewed the vocational potential of individuals with developmental disabilities as significantly higher when presented with the results of what they called "ecological assessment" (p. 27) methods, which included person centered planning, than when presented with standardized testing results for the same individuals.

Person-centered planning includes an assessment process which is less formal and more naturalistic (Hagner, 2010), in which topics are covered at the individuals own pace, and information is often presented in visual form, using pictures and diagrams, to make the process accessible to individuals with diverse learning styles (Holburn, et al., 2004; O'Brien, 2002). Alternative ways of presenting information may help individuals with ASD convey and understand information (Fullerton & Coyne, 1999), and presenting information visually may be especially helpful (Hayes, et al., 2010; Preis, 2006).

Person-centered planning may also be useful because it is designed to produce change at both the individual and the systems level (Walker, 2012). Enduring positive adult outcomes for individuals with ASD may require focusing both on the individual and the larger social context (Shattuck, Roux, et al., 2012).

However, there are challenges in implementing person-centered planning with individuals with ASD. Robertson, Emerson, Hatton, Elliott, McIntosh, and Swift (2006) reported that persons with ASD are less likely to participate in person-centered planning than those in other disability groups, and that the plans for those who do participate tend to be of lower quality. Difficulties with social interaction and communication are considered defining characteristics of ASD (Olney, 2000; Standifer, 2009). These difficulties can make it challenging for individuals with ASD to participate actively in group activities, including planning meetings. High levels of social anxiety are also common in individuals with ASD (Bellini, 2006; Standifer, 2009). This may serve as an additional barrier to effective participation in planning meetings. A third challenge is that the autism spectrum encompasses individuals with widely differing levels of adaptive behavior (Standifer, 2009). Adaptive behavior, the ability of an individual to function within everyday environments, is considered a better overall measure of functional impairment for individuals with ASD than diagnostic label or cognitive level (Paul, Miles, Cicchetti, Sparrow, Klin, & Volkmar, 2004). Interventions effective with those who exhibit more adaptive behaviors may not be effective across the entire spectrum (Standifer, 2009). There have been no reports of attempts to utilize or adapt the person-centered planning process specifically for individuals with ASD.

In a transition context, planning is typically initiated by special education staff, who, as part of this process are mandated to make referrals to vocational rehabilitation and other adult services important for a successful transition (Shogren & Plotner, 2012). As Shogren and Plotner (2012) noted, "Best practices in transition planning emphasize family involvement...and coordination with adult service agencies" (p. 17). Thus, in communities with a well-designed transition system, the individual, the family, and vocational and other adult service representatives working together as a transition team collaboratively plan the assessments and other services that will take place during the last years of high school and lay the foundation for a smooth transition from school to adult life. As part of this process, person-centered planning may be considered by the team. The purpose of this study was to provide a descriptive summary and qualitative understanding of participation in person-centered planning for young adults with ASD. The research questions addressed were as follows:

1) To what extent can person-centered planning be utilized for planning transition goals with youth with ASD?

2) What adaptations and accommodations allow youth with ASD to participate fully in the process?

3) Is there a relationship between the level of adaptive behavior of youth with ASD and the use of accommodations?

Method

A mixed method design was employed in this study, consisting of a qualitative analysis of narrative data with an embedded descriptive quantitative analysis to answer the third research question. Participants in this study were recruited based on replies to an announcement of transition assistance distributed to 28 high schools in New Hampshire and Maine as part of a larger project. Special education students with a diagnosis of ASD and over 16 years of age were eligible to participate. School Transition Coordinators distributed the announcements to eligible students and families, and over a three-month period, 47 participants enrolled. A diagnosis of ASD was confirmed by school records and administration of the Autism Diagnostic Observation Schedule. To answer research question 3, the Adaptive Behavior Assessment Scale II (ABAS-II, Harrison & Oakland, 2008) was used to assess level of functional behavior of participating youth. The ABAS-II provides a norm-referenced rating of adaptive skill in the areas of communication, functional academics, self-direction, leisure, social, community use, home living, health and safe-

ty, self-care and work; and it provides a composite adaptive behavior score with a mean of 10 and a standard deviation of 3. Demographic information on the sample including the distribution of ABAS-II scores is provided in Table 1.

Each enrolled youth and family was assisted to identify a group of family, friends, and/or professionals to participate in person-centered planning. Each planning group consisted of the individual and at least one parent or guardian, and additional members such as extended family, friends or neighbors, and school transition staff and rehabilitation counselors working with the individual, depending on availability. Planning group size ranged from 3 to 9, with a mean of 5.2. A summary of planning participants (exclusive of the focal individual and the facilitator) is provided in Table 2.

Between 5 and 8 planning meetings were held per participant, with an average of about 6 meetings per participant. Meetings were held in family homes, unless the family preferred another location. Meetings generally lasted an hour and a half to 2 hours. Typically, a core group of 3-4 individuals attended every meeting, with additional participants attending 1 or 2 meetings each.

Two trained facilitators in each state provided planning facilitation, using a model originally known as the McGill Action Planning System (Vandercook, York, & Forest, 1989), as refined and further described by Cotton (2003) and utilized in previous studies (e.g. Cloutier, Malloy, Hagner, & Cotton, 2006; Hagner, McGahie, & Cloutier, 2001). Areas of focus were determined by the individual and family, with an overall emphasis on providing the foundation for engaging in exploratory activities to develop and embark on a meaningful career path. The topics for a typical 6-meeting sequence were as follows:

1. Introduction and Personal History
2. Career Profile: Skills, Accomplishments and Personal Qualities
3. Career Profile: Preferences and Aspirations
4. Vision For The Future, Resources, and Barriers
5. Transition and Career Goals
6. Career Exploration and Work Experience Action Steps

Facilitators helped the group move from topic to topic, ensured that everyone had an opportunity to contribute, recorded the group's work on flip chart paper, and emailed photographs of the flip chart pages to attendees and other stakeholders after each meeting.

Facilitator training consisted of completing a 3-credit graduate course, Methods, Models and Tools for Person-Centered Planning conducted at the University of New Hampshire. Fidelity to person-centered planning was assessed by means of observations of a sub-sample of six participants' meetings, using an observational checklist called "How Person-centered Was this Planning?" (Hagner, et al., 2012). On this criterion-referenced checklist, a score of 20 serves as a threshold to identify a substantially person-centered planning process. A sub-sample of two meetings in each state were rated by an independent observer, and all four exceeded this threshold, with an average score of 22.4.

Maximizing the participation of the focal individual and proceeding through meeting topics at the person's pace throughout the process are defining characteristics of per-

Table 1

Participant Demographic Variables

Demographic		n
Gender	Male	45
	Female	2
Age	16	7
	17	18
	18	12
	19	10
Functional Behavior*	1.0 - 3.4	5
	3.5 - 6.9	19
	7.0 – 9.4	17
	9.5 – 11.9	6

* ABAS-II score (Mean = 6.51; SD = 2.33).

Table 2

Planning Group Participants

Role	Men	Women	Total	%
Nuclear Family	72	38	110	45
Extended Family	7	36	43	17.5
Friends / Community Members	12	19	31	12.5
School and Rehabilitation Staff	19	42	61	25
TOTAL	110	135	245	100

son-centered planning (Holburn, et al., 2004). Thus, a central focus of each planning team was to ensure that the individual with ASD was at the center of the process and participated fully.

During each planning meeting, planning facilitators noted comments by members of the group, as well as emerging themes, goals and plans, on flip-chart paper. Photographs of flip-chart pages were retained to serve as a record of the group's work. Planning facilitators also recorded any accommodations or adaptations developed by planning groups to allow participants with ASD to participate in planning sessions as part of their written progress notes completed following each meeting.

Meeting flip chart notes and facilitator progress notes were analyzed qualitatively by the first two authors using open-coding (Denzin & Lincoln, 2008). Each author read the full set of data and independently identified each statement indicating an accommodation or adaptation that allowed participants with ASD to participate fully in planning sessions, and grouped statements into coding categories based on content similarity. The researchers then met to compare coding schemes, remove duplication, resolve any discrepancies in wording, and agree on a single list of coding categories.

Results

Evidence of accommodation strategies was found for 29 participants (62%). The use of accommodations did not appear to be restricted to a particular range of adaptive behavior. The distribution of participants who did and did not use accommodations by ABAS-II score is depicted in Figure 1. There was a tendency for those with lower levels of adaptive behavior to use accommodations more frequently, but the difference was not significant ($t = 0.53$, $p = .60$). Accommodations were coded into five categories: (a) individualized preparation meetings, (b) informal rapport-building preparation, (c) flexible meeting designs, (d) distance attendance, and (e) supported participation.

Individualized Preparation Meetings

Planning facilitators met with each youth and family prior to the start of person-centered planning, to discuss topics to be covered and people to be invited, and also to plan for their participation. This procedure is commonly used in person-centered planning to assure that the meetings meet the needs of the individual (Hagner, Helm, & Butterworth, 1996), but was more detailed for participants who wanted the structure of the meeting to be very predictable.

Informal Rapport-Building Preparation

In some cases, participants talked with the facilitator about topics of interest during the initial meeting, and follow-up activities were structured around these interests. For example, one participant and his facilitator prepared "ramen" noodles, then played a videogame. Another planning facilitator accompanied a student to a bookstore to look for books about Disney cartoons. These activities served to build rapport and trust, so that when group meetings began the participant was comfortable with the facilitator.

Flexible Meeting Designs

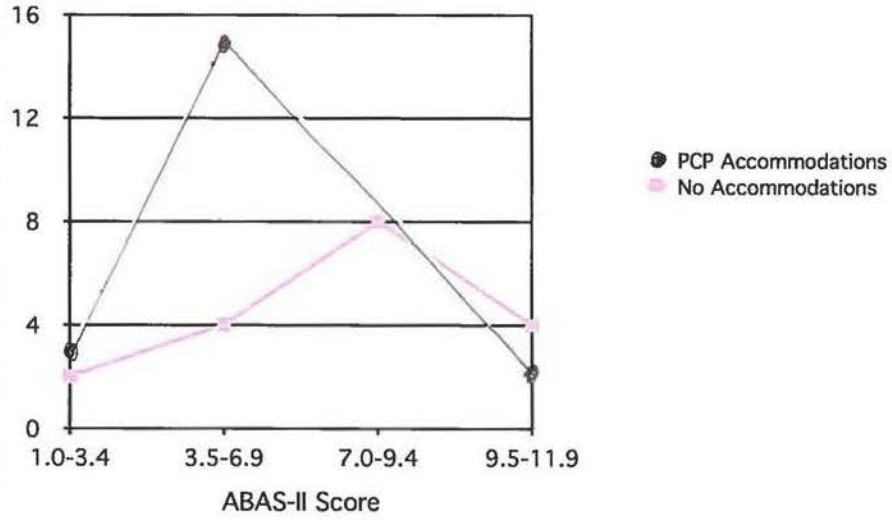
Planning meetings were designed to include opportunities for participants to take breaks as needed or to participate for designated segments. The length of participation varied widely and included: (a) attending most of the meeting but leaving for 5 minutes 2 or 3 times in a 2-hour meeting; (b) attending for the first 30-45 minutes, usually to make a presentation-style statement of goals and thoughts, then subsequent visits to be debriefed on what had occurred; and (c) attending only at the end of a meeting for a 10-15 minute debriefing and to provide a summary perspective on what had been discussed.

Provisions to fill participants in on what took place in their absence typically consisted of summarizing the discussion and flipchart notes recorded in their absence, followed by a question-and-answer session to obtain their perspective.

Distance Attendance

In some cases, youth with ASD did not wish

Figure 1: Number of Participants With and Without Person-Centered Planning Accommodations, by ABAS-II Score



to be directly present in group meetings. For three participants, this involved an unwillingness to sit in a circle in the room where the meeting was being held. These students were able to position themselves at a far enough distance to feel comfortable – the other end of a room outside the meeting circle, in a nearby room, or sitting on a staircase – and still hear what was going on and interject thoughts they wished to share.

Another participant used "Skype" from his bedroom to see and talk with the group. And finally, one participant prepared a "PowerPoint" presentation to be shown at the meeting, outlining his interests and vision for future life beyond high school. He developed the presentation a few days ahead of time with assistance from a young adult with ASD who served on the project team and was available as a peer mentor to participants. The mentor read the slides to the group with the participant sitting next to her, adding clarifications or elaborations when he wished, and answering questions at the end. The participant and mentor then left the meeting, and the group considered how to create a plan to reach his vision.

Supported Participation

Several participants required supports to effectively communicate their thoughts to the planning group. One participant who used an assistive communication device for everyday communication had the device with him in the planning meetings, and the group stopped to check in with him and allow him time to contribute using the device. Another participant whose speech was difficult to understand used what his parents referred to as a "thumbs up / thumbs down system". A member of the group repeated what they heard him say, and he signaled to let them know if they understood correctly.

One participant explained to the facilitator that he felt "out-talked" during the first meeting, because the pace did not leave enough time between comments by others for him to formulate what he wanted to say. This participant asked his tutor from school to sit next to him at subsequent meetings, and he and the tutor composed written notes as the meeting progressed. The tutor announced as each note was completed, and the participant read it out loud to the group.

Another participant also preferred to write rather than speak his comments. The others in the group talked while the facilitator summarized their comments on flip chart paper. The participant then wrote comments on post-it notes, and added these by sticking them on the flip chart to show points he wanted to make.

In one case, simply responding non-judgmentally to a participant's ideas seemed to provide the support needed to increase participation. This individual initially appeared uncomfortable in planning meetings and said very little. At one point the planning facilitator asked him what he liked to do. He responded by saying, "I like to break things." The facilitator then encouraged the planning team to brainstorm jobs where people break things. At this point the individual began participating more actively, recognizing that his comments would be taken seriously and that he had control over the process.

Discussion

Person-centered planning is a technique based on a set of core elements but open to a variety of options and formats to achieve a personalized approach to planning. Within the parameters of such a highly individualized process, characterized more by "the flowering of diverse methods" (O'Brien, 2002, p. 263) than by the application of a prescribed procedure, conceptualizing variations as "accommodations" may be a misnomer. Nevertheless, regardless of the terminology employed, we have noted several variations of this planning process that seem especially well suited to the needs of youth with ASD transitioning to adult life. These variations allowed individuals who experienced difficulties with communication, anxiety, and other social difficulties to participate actively in facilitated group planning sessions. Thus, it appears that person-centered planning can be implemented for youth across the autism spectrum as a tool for enhancing participation in transition planning.

Rehabilitation counselors involved with the transition of youth with ASD to adult life can consider person-centered planning as a valuable tool for helping clarify aspirations and develop plans for adult life with the involvement of a supportive social network. Counselors with graduate training and experience in group facilitation techniques may be ideally suited to serve as person-centered planning facilitators. However, the time commitment involved in facilitating a series of meetings, often scheduled during evenings or on weekends for the convenience of families, renders this an unrealistic expectation for most rehabilitation counseling professionals. More realistically, rehabilitation counselors will refer their clients to an independent individual or agency that specializes in this service, as is the common practice for any other intensive, specialized rehabilitation service. In addition to contracting with independent person-centered planning facilitators, rehabilitation counselors also have an important role to play as a meeting participant, contributing their expertise to specific meetings where vocational goals and strategies are planned, for example. Rehabilitation counselors also receive emailed notes of each meeting, and can remain involved through reviewing these notes and contacting the facilitator between meetings to ask questions or give suggestions as the planning progresses. Such collaborative involvement is an important transition objective for rehabilitation professionals (Plotner, Trach, & Strausser, 2012).

It might be argued that the relatively long-term and time-consuming nature of person-centered planning is difficult to implement in a sustainable way on a large scale. The authors are currently involved in a project that is using two broad strategies to address this issue. First, because transition assistance is an important priority across schools, vocational rehabilitation offices, and, where applicable, state developmental service agencies, the funding for person-centered planning can be shared across more than one agency, resulting

in a modest service cost for each party. And second, independent organizations (i.e. organizations providing no other service that might create a conflict of interest) can be identified which serve as host organizations for (a) identifying a cadre of trained facilitators in a state or other geographical area, (b) creating procedures for matching facilitators to consumers and contracting and billing for services, and (c) ensuring service quality and continued professional development for facilitators. In this project, facilitators work as independent contractors rather than as employees, and most are "moonlighting" for additional income. Although this project is only in its preliminary stages, results have been promising.

This small-scale descriptive summary should be viewed as only a preliminary investigation. Larger-scale studies and more in-depth analyses are recommended to corroborate this finding. In addition, longitudinal studies are required to understand better the relationship between transition planning processes and vocational rehabilitation outcomes.

An important focus for future research should be to examine the effect of varying degrees and styles of planning participation and planning group size on transition outcomes. In addition, future work on increasing youth involvement in transition planning should examine the impact of new digital technologies in facilitating the transition of youth with ASD to adulthood. Several of the participants in this project successfully used electronic devices or digital media such as Skype or PowerPoint as tools to participate more actively in their planning meetings. The use of these and other emerging technologies, consistent with each individual's learning style, holds a great deal of promise for improving transition outcomes for individuals with ASD.

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