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ABSTRACT
        This paper summaries a study on the participation of 10
students (ages 18-21) with developmental disabilities in the transition from
school to work using the Whole Life Planning model. Data included
observations of organizational and planning meetings and structured
interviews with the students, parents, and facilitators. Analysis resulted in
the following findings: students demonstrated four distinct types of
participation (active, controlling, limited, and absent); and student
participation was influenced by the student's personal style, the size of the
meeting, and the level of abstraction in the conversation. Implications and
recommendations are made for ways in which the facilitator can prepare in
advance (such as identifying the student's personal conversational style);
for what the facilitator can do during the first few meetings (such as
concentrating on individualizing the planning approach); for things the
facilitator can do during more abstract planning sessions (such as making
clear connections between the student's relevant starting points and the more
conceptual planning). (Contains 11 references.) (DB)

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Facilitating the Focus Person's Participation in Person Centered Planning

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Introduction

The transition from school to adult life represents a period of enormous change for young people and their families. Adolescents must begin to determine future goals and dreams and struggle with decisions around achieving them. For the adolescent with a disability, this period of transition requires a crucial planning process.

A variety of person centered planning models for transition have been developed that hold promise for strengthening the role of adolescents in preparing for their adult life. Person centered planning maintains an explicit emphasis on empowerment of and primary direction from the individual for whom the planning is being conducted. In order for person centered planning to achieve its mission, the focus person must participate fully in the process. As person centered planning becomes increasingly prevalent in the context of disability-related services, it is important to examine how individuals participate when they are at the center of the process. As a result, the Institute for Community Inclusion conducted research to understand the participation of young people as they transition from school to adult life using Whole Life Planning (Butterworth, Hagner, Heikkinen, Faris, DeMello & McDonough, 1993). Following a review of the major findings of this study, implications for practice are explored that focus on recommendations for increasing student participation.

Methodology

Data for this research were collected using observations and semi-structured interviews. Specifically, 34 observations took place in organizational and planning meetings held in a variety of locations and with a variety of attendees. In addition, 15 interviews took place between the researcher and the students, parents, and facilitators involved in each planning process. Analysis involved coding and organizing data into emerging themes.

Participants

Four communities in Massachusetts participated in the study: Dartmouth, Fitchburg, Milton and Winthrop. These towns have schools which serve a diverse community of students including varying student body sizes, economic levels, and ethnic and cultural backgrounds. In each of the four communities, three students were asked to participate. Due to a small drop-out rate, however, data were collected on ten students who actually participated in the Whole Life Planning processes. These students ranged in age from 18-21 years, had a variety of developmental disabilities (e.g., down syndrome, cerebral palsy, autism), and communicated verbally and non-verbally. The students were from Latino (n=3), White (n=6) and Asian-American (n=1) families.

Findings

Students demonstrated four distinct types of participation: Active, Controlling, Limited, and Absent.

Active participation occurred when the students:
* Engaged in conversation both by responding to questions and adding information on their own.
* Demonstrated comfort with the situation by sitting up attentively, making eye contact with others, smiling, and joking.
* Followed the flow of conversation by responding and initiating discussion.

Controlling participation occurred when the students:
* Expressed personal opinions.
* Voiced dreams that they held for themselves that others did not share.

Limited participation occurred when the students:
* Appeared to not be expressing themselves to the extent that they would have in other circumstances.
* Expressed short, non-committal responses.
* Showed diminished attention to the conversation by becoming more distractible.

Absent participation occurred when the students:
* Repeatedly left the room even for short intervals of time.
* Remained uninvolved in the planning or fell asleep.

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Student participation was influenced by the student's personal style, the size of the meeting, and the level of abstraction in the conversation.

Personal style: definition

The student's personal style was defined as conversational style or preferred patterns of communication not specifically related to individual disabilities. Two distinct groups of students with unique conversational styles were observed. One group could be characterized as gregarious, and the other more withdrawn/low key. Behavioral examples of each group are shown in Table 1.

Table 1
Personal and Conversational Style

Group	Behavioral Examples
Gregarious	Enjoyed storytelling
	Told/laughed at jokes
	Greeted and interacted with others comfortably
	Requested large meetings
Withdrawn/Low Key	Demonstrated shy behaviors
	Hid face in pillows/arms
	Turned face away from others when questioned or approached

Participation increased when:

- Students had gregarious personal styles.
- Students had established conversational styles, regardless of whether they were gregarious or withdrawn .

Participation decreased when:

- Neither students nor facilitators established consistent patterns of communication.
- The facilitator was not able to anticipate when the student would feel the need to leave the meeting due to inconsistent communication patterns.

Size of meeting: definition

Another factor contributing to the level of student participation was the number of individuals present for the gathering. The relationship between student participation and size of meeting seemed dependent on the student's personal style and the meeting purpose.

Participation increased when:

- The size of the meeting was consistent with the student's personal style. For example:

  Students with gregarious personal styles participated more actively in large group meetings that involved many family members and friends.
  Students who were more withdrawn participated more actively in small meetings that typically involved the student, a facilitator, and perhaps a parent or teacher.

- There were smaller organizational (rather than planning) meetings that focused on organizing the process and gathering profile information. These meetings were more student-focused and therefore, more likely to have immediate relevance to the young person.

Level of abstraction: definition

The level of abstraction was defined as the ability of the student to comprehend obscure or complicated information. For example, topical areas and discussion content specifically around planning and visions had a high level of abstraction. Level of abstraction was found to be the strongest predictor of active student participation.

Participation increased when:

- Students felt the topic had immediate relevance to their daily lives.
- Students had a concrete framework or model upon which to build their abstract idea. For example, one participant held tightly to her desire to go to college as she watched two sisters do the same. The student saw her sisters' examples as a concrete expectation of her own post-high school future.

Participation decreased when:

- Discussions turned from organizing the meetings and describing their current life to planning. It is possible that discussion of future events or visions may have been too abstract for students to fully comprehend.

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Table 2 presents additional examples of the relationship between the level of abstraction and student participation.

Table2
The Relationship of Participation and Abstraction

Participation			
High		Low	
Discussions of what students do in their current jobs, classes, and highly preferred activities	Deciding who will attend the upcoming planning meeting	Talking about the purpose of upcoming planning meeting	Brainstorming about the future with meeting participants, especially when suggestions come out of context
Low		High	
Abstraction			

Implications and Recommendations

The intention of person centered planning is to be maximally individualized and build on the dreams and wishes of the focus person. The facilitator can help to insure that the planning process is truly reflective of a unique vision that the focus person actively drives. The following considerations may assist the facilitator in increasing student participation:

To prepare in advance, the facilitator can:

- Identify the student's personal conversational style in order to find a match between style and the planning context. This may take time, but the initial investment will assist in deciding the most appropriate meeting size and structure from the outset.

- Get input from those who know the individual best.

- Facilitate the student's outreach to their network members. This will give the student more control over other participants from the start. Empowerment of the individual is an essential goal and should ultimately increase participation.

- Suggest that the student attend and observe another student's person centered planning process. This will make person centered planning more concrete to students and will help them design a process comfortable to their own styles.

- Ensure that the student makes clear choices about the planning process including who participates, the size of the planning events, and the length of the planning events.

In the first few meetings, the facilitator can:

- Be sure to choose a process that begins with concrete, relevant information that the focus person can engage in. Whole Life Planning, for example, begins with a straightforward listing of activities and experiences the focus person participates in, and what they like and do not like about each activity.

- Concentrate on individualizing the planning approach. For example, consider a longer series of smaller meetings if that matches the student's personal style.

- Experiment with a variety of ways to establish a clear pattern of communication. Examples may include the use of props or personal items that can serve as reminders, prepared comments or scripts, or pictures to support the focus person's participation.

- Take time to evaluate the planning process. Does the meeting size, tone, and conversational flow match the person's type of participation and personal communication style?

During the more abstract planning sessions, the facilitator can:

- Make clear connections between the student's relevant starting points and the more conceptual planning. This can help to avoid losing the focus person in the abstractions of the planning process.

- Insure that the student understands some of the more absract and unrestricted ideas that are generated during creative brainstorming.

- Make sure that the development of goals and plans are what is most important to the student at the time of planning. The goal is to support the individual to control, design, and participate in the process.

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- Identify existing frameworks or models in the student's life on which to base more of the abstract planning concepts so that the student perceives immediate relevance.

Conclusion

Through careful attention to the focus person's preferences in terms of style and structure, meaningful participation by the young adult can be achieved. The facilitator can place the primary emphasis on allowing the focus person to control both the structure and content of the planning process. Open-mindedness and creativity on the part of the facilitator will ultimately allow the person centered planning process to enhance participation from, and be more useful for, its most important member, the individual.

Helpful Resources

Butterworth, J. (Producer) (1994). More Like A Dance: An Introduction to Whole Life Planning. Videotape available from the Institute for Community Inclusion, Children's Hospital, 300 Longwood Avenue, Boston, MA 02115)

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