

*A SYSTEMATIC EVALUATION OF PREFERENCES IDENTIFIED
THROUGH PERSON-CENTERED PLANNING FOR
PEOPLE WITH PROFOUND
MULTIPLE DISABILITIES*

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Person-centered planning is becoming a popular means of designing supports for people with disabilities. However, very little research evaluating person-centered planning exists. We evaluated the degree to which items and activities reported to be preferred in person-centered plans represented accurate preferences based on how individuals responded when presented with the items and activities. Person-centered planning meetings were conducted with 4 individuals with profound multiple disabilities to develop preference maps and to identify leisure-related preferences. A sample of the reported preferences in the plans was then systematically assessed by observing each participant's approach and avoidance responses to the items and activities. Of the sampled items and activities reported to be preferred in the plans, 42% represented moderate preferences based on the latter assessment process and 33% represented strong preferences. With 2 participants, several preferences identified in the plans were nonpreferred items and activities based on the preference assessments, and some were frequently avoided. These results suggested that although person-centered plans may identify some accurate preferences for people with profound multiple disabilities, this approach should be used cautiously. Results also suggested that such plans should be supplemented with systematic preference assessments to ensure the accuracy of identified preferences. Future research areas focus on evaluating other aspects of person-centered planning.

DESCRIPTORS: person-centered planning, preference assessments, profound disabilities

An area of rapidly growing popularity in the field of developmental disabilities is person-centered planning. Person-centered planning

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encompasses a variety of approaches for supporting people with disabilities in identifying and experiencing a desired lifestyle. These approaches include, for example, personal futures planning, the McGill action planning system, whole life planning, and essential lifestyle planning (Whitney-Thomas, Shaw, Honey, & Butterworth, 1998). In each of the various models of person-centered planning, there is a central focus on realizing a common set of valued outcomes. These outcomes include participating in

community life, having satisfying social relationships, expressing preferences and making choices, living with dignity, and ongoing development of personal competencies (Kincaid, 1996).

The pervasiveness of person-centered planning's impact is apparent in several ways. In particular, several states recently have required the use of person-centered planning throughout their service delivery systems (e.g., Hagner, Helm, & Butterworth, 1996), person-centered planning has been legally mandated as a result of litigation (Hagner *et al.*), and references to the benefits of person-centered planning are appearing with increasing frequency (Browder, Barbara, & Belfiore, 1997; Holburn, 1997; Mount, 1994). However, despite the growing popularity of person-centered planning, there is a lack of research regarding the efficacy of this approach in determining and providing support (Hagner *et al.*, 1996; Whitney-Thomas *et al.*, 1998), with subsequent calls to investigate the specific effects of person-centered planning (Malette *et al.*, 1992; Roberts, Becker, & Seay, 1997; Whitney-Thomas *et al.*, 1998).

One aspect of person-centered planning that particularly warrants research attention is the use of mapping to identify preferences for individuals with profound multiple disabilities. Mapping is used for several purposes, including soliciting and transcribing opinions of people with disabilities and their support team members regarding the former's perceived likes and dislikes in areas such as leisure, relationships, jobs, and so on (Everson, 1996). Determining preferences is an integral step in all person-centered approaches (Everson & Reid, 1997; Miner & Bates, 1997), and it represents the foundation upon which a person-centered plan is built. It has been recognized, however, that determining preferences of individuals with very severe disabilities can be difficult due to communication challenges (O'Brien, 1987;

Whitney-Thomas *et al.*, 1998). In such cases, the literature recommends that opinions of people who have a close relationship with the individual with disabilities be relied on for identifying preferences (Kincaid, 1996; O'Brien, 1987).

Prior to and during the evolution of person-centered planning models, a considerable amount of behavioral research occurred on assessing preferences among individuals with severe disabilities (see Hughes, Pitkin, & Lorden, *in press*, for a review). One focus of this research has been the identification of reinforcers to use in skill training and related programs (Brown, Gothelf, Guess, & Lehr, 1998). Another focus has been to determine items and activities that an individual prefers, and then to incorporate the items and activities in the individual's daily routine as a means of improving quality of life (Brown *et al.*, 1998; Newton, Ard, & Horner, 1993). This reason for conducting systematic preference assessments, which is the reason of concern here, is closely aligned with the intent of person-centered planning.

One result of this behavioral research is that preferences of individuals with profound disabilities can be reliably determined through observations of approach and avoidance behavior in response to systematically presented stimuli. Research has likewise indicated that when stimuli that have been approached during structured assessments are provided by support staff in the daily routine of persons with profound multiple disabilities, they continue to approach the stimuli (Green, Reid, Perkins, & Gardner, 1991). Research has also supported using stimuli that are frequently approached in preference assessments to improve life enjoyment by increasing happiness indices when those stimuli are provided during the routine day (Green, Gardner, & Reid, 1997; Green & Reid, 1996). Another finding of the behavioral research on preference assessments is

that relying on the opinions of support persons does not represent a consistent means of accurately identifying preferences among people with profound disabilities (Favell & Cannon, 1976; Green et al., 1988; Windsor, Piche, & Locke, 1994).

Currently, the person-centered planning literature and the behavioral research present somewhat conflicting implications for practitioners. Whereas the former recommends personal opinion to identify preferences for individuals whose disabilities preclude clear expression of preferences, the latter suggests such a means is not likely to identify preferences very accurately. However, identifying preferences through person-centered planning incorporates a more comprehensive assessment of personal opinion (cf. Everson, 1996) than typically occurs in the behavioral research on preference assessment (e.g., Green et al., 1988; Windsor et al., 1994).

Despite the increasingly widespread application of person-centered planning, the degree to which a person-centered plan accurately identifies individual preferences has not been evaluated. The purpose of this investigation was to assess the accuracy of a person-centered mapping process to identify specific preferences for individuals with profound multiple disabilities. Reported preferences were evaluated by systematically observing the frequency of approach responses to selected items and events identified in the plans. Relying on individual responses to specific stimuli to evaluate the accuracy of suggested preferences has been reported previously (e.g., Newton et al., 1993), although it did not pertain to preferences derived from person-centered planning for people with profound multiple disabilities.

METHOD

Participants and Setting

Four adults with multiple physical disabilities and profound mental retardation

participated. All participants were nonambulatory, experienced difficulties with upper body movements, and required considerable support to complete self-care routines. The participants lived in a residential facility and attended an adult education program on weekdays.

Lance was 42 years of age and had spastic quadriplegia with multiple contractures. He used one-word utterances in attempts to communicate, although the vocalizations were usually prompted by staff. Keith was 24 years of age and had microcephaly and spastic quadriplegia. He communicated with facial gestures and appeared to comprehend some words when used in the context of familiar activities. Barb was 38 years of age and had microcephaly and spastic quadriplegia. Barb occasionally vocalized one- or two-word utterances and appeared to understand simple sentences in familiar contexts. Sara was 24 years of age and had microcephaly, left hemiplegia with contractures, and a seizure disorder (approximately three seizures per month). She used facial expressions in apparent attempts to communicate. These participants were selected for the study because each had profound multiple disabilities and each lacked communication skills sufficient to describe his or her specific preferences. Also, they attended the same adult education program, although in different classroom components of the program.

Several support staff and friends of the participants also participated. The primary staff participants were 4 certified special education teachers who were each responsible for the educational services for 1 participant, and served as facilitators for the person-centered planning meeting for that consumer. Each teacher had at least 7 years of experience. Additional participants included staff and friends who attended the person-centered meetings (see *Procedure*) and 4 teacher assistants who conducted the preference assessments. The teacher assistants routinely

conducted preference assessments, having been trained by an experimenter. Each assistant was familiar with the participant for whom a preference assessment was conducted, although the individual was not on the assistant's caseload. Preference assessments were conducted in each participant's classroom. Planning meetings took place in a separate lounge area in the education building.

Procedure

The general procedure involved conducting person-centered planning meetings for each participant and systematic preference assessments for a sample of leisure preferences identified in the plans. Preferences related to leisure were targeted because leisure-related preferences typically are an integral part of person-centered plans (e.g., Kincaid, 1996; Miner & Bates, 1997) and are likewise frequently targeted in systematic preference assessments in order to identify preferred items and events to incorporate into the daily routine of people with multiple disabilities (Green & Reid, 1996; Green *et al.*, 1988).

Person-centered planning meetings. Prior to the planning meetings, the 4 teachers attended a half-day training session. The trainer for the session (second author) has extensive experience in person-centered planning (Everson, 1996; Everson & Reid, 1997). The training focused on describing the values of a person-centered philosophy (e.g., planning sessions are directed by the individual, when possible, and his or her friends, and the focus is on an individual's gifts and capacities rather than skill deficits) as well as assessment and planning tools for developing a preferences map. This training included developing a preference map for an individual with severe multiple disabilities who was not a participant in this investigation.

Following the training session, people were invited to attend the person-centered

planning meetings for each of the 4 participants using criteria typically used in person-centered planning (e.g., O'Brien, 1987). Specifically, persons who knew the individual well or were friends of the participant were invited. However, because of the profound nature of the participants' communication impairments, the invitations were developed from staff and friend reports in contrast to the expressed requests of the participants. For Lance, 4 staff members involved in his education program and residential facility attended his meeting along with 1 friend from the community. Keith's meeting involved 5 staff members from his education program and residential facility and 1 friend. Barb's meeting included 4 staff members from the education program and residential facility and 1 community friend. The meeting participants for Sara were 3 staff members from the education program and residential facility and 1 friend. The staff members involved in the meetings represented a variety of different disciplines, based on close relationships with the consumer participants, such as residential direct support personnel, a behavior program specialist, and a student intern.

Attempts were made to hold the planning meetings in a comfortable location, and refreshments were served. During each meeting, the teacher facilitated the development of a leisure preferences map for the participant or focus person using a three-step process (see Mount, 1997, for additional information on the mapping process). First, each participant of the meeting was asked to describe what he or she thought represented the most desired leisure activities and items in response to the question, "What works and what does not work for [focus person]?" Meeting participants were encouraged not to limit their responses to what was currently available, but to consider anything they thought the person really liked. Second, a group graphics process was used in which

colors, pictures, words, and symbols were drawn on a flip chart to record information provided by meeting participants about the focus person's leisure preferences. For example, one color and one symbol were used to indicate something that the focus person liked, and a different color and symbol were used to indicate something that the focus person did not like. In accordance with typical person-centered mapping processes, colors and symbols were used to help meeting participants distinguish and remember preferred versus nonpreferred items and activities and to focus attention on what the client liked and disliked.

The third step in developing the preferences map involved the facilitator asking 11 questions to obtain additional information about the perceived preferences of the focus person. Sample questions included "How do you know when [focus person] is happy?," "What foods, activities, people does [focus person] like?," and "Tell me a story about [focus person] being happy." (A complete list of the questions is available from the authors.) Each response of meeting participants to the initial open-ended questions (Step 1 in developing the preference map) and to the 11 specific questions (Step 3) was recorded on the flip chart unless the preference had already been recorded. If meeting participants disagreed with a reported perception, a separate color and symbol would have been used to indicate the items and activities for which participants disagreed. However, such disagreements did not occur in this investigation. Following each meeting, which lasted approximately 60 min (range, 30 to 90 min), the reported preferences of the focus person were transcribed from the maps on the flip charts into each individual's person-centered plan by the facilitator.

Systematic preference assessments. Preference assessments were conducted using a single-item presentation format and measurement

of approach and avoidance behavior that was designed for individuals with profound disabilities (Pace, Ivancic, Edwards, Iwata, & Page, 1985). This type of preference assessment was well suited to the purpose of this investigation because the assessment has been shown to accurately identify preferred stimuli that, when incorporated into daily activities of people with profound multiple disabilities, are frequently approached (Green, Reid, Perkins, & Gardner, 1991) and are accompanied by indices of happiness (Green et al., 1997; Green & Reid, 1996). The single-item format also was appropriate because the participants did not demonstrate skills to select an item from a group of items (see Parsons, Harper, Jensen, & Reid, 1997).

A variety of stimuli were included in the systematic preference assessments that had been identified with the ongoing procedures of the adult education program. Of concern for this study were those systematically assessed stimuli that were reported to represent preferred items and activities in each participant's person-centered plan. A sample of these stimuli was selected from the plans. These items and activities were selected because they lent themselves to a single-item approach-and-avoidance assessment format. Several preferences identified in the person-centered meetings were not applicable to this format, such as going to a particular restaurant. Also, to ensure that reported preferences in the person-centered plans were accurately represented in the systematic assessment, the sample was conservatively restricted to those items and activities that were specifically described in the plans. Some items and activities were excluded because of lack of specificity (e.g., food was identified as preferred but the plan did not indicate what type of food). Using these criteria, a total sample of 24 items and activities reported to be preferred in the plans was assessed (representing 35% of all items and activities listed in the plans). The sample in-

cluded eight items and activities for Lance (pizza, chocolate milk, stuffed animal, soda, sausage, blowing kisses, doll, hand holding), 10 for Keith (toy truck, soda, magazine, guitar, chocolate milk, special toy, wheelchair dance, special hat, flexible doll, verbal interaction), five for Barb (rock music, coffee with cream and sugar, apples, shopping catalogue, Christmas music), and one for Sara (popcorn).

Approach and avoidance responses were defined and assessed as in previous research (Green, Reid, Canipe, & Gardner, 1991). *Approach* was defined as the participant making an apparent voluntary body movement toward the stimulus, maintaining contact with the stimulus for at least 3 s, exhibiting a positive facial expression, or making a positive vocalization within 5 s of the presentation of the stimulus. *Avoidance* was defined as a negative vocalization, pushing the stimulus away, or making a movement away from the stimulus within 5 s of the presentation of the stimulus. Six assessment sessions with five trials per session were conducted for each item and activity assessed. Approach and avoidance responses were recorded for each trial. Interobserver agreement regarding the occurrence of approach and avoidance was obtained by an experimenter and staff members during 20% of all assessment trials, involving each participant. Occurrence agreement for approach behavior was 100%, whereas for avoidance, occurrence agreement averaged 90% (range, 0% to 100%). Across all interobserver agreement checks, there were no more than two disagreements per participant on avoidance.

Based on previously established criteria (e.g., Fisher *et al.*, 1992; Green *et al.*, 1988; Pace *et al.*, 1985), each assessed stimulus was categorized as highly preferred, moderately preferred, or nonpreferred. The criterion for a highly preferred stimulus was that the stimulus was approached on at least 80% of all assessment trials, and for a moderately

preferred stimulus, the criterion was approached on at least 50% and less than 80% of the trials. Because each participant exhibited preferences using these criteria, a nonpreferred stimulus was defined as being approached on less than 50% of assessment trials.

Evaluation Process

The percentage of approach and avoidance responses was reviewed for each reported preference in the person-centered plans that constituted the sample for which preference assessments were conducted. Each item and activity was then categorized as highly preferred, moderately preferred, or nonpreferred. Staff members who conducted the assessments were not involved in the meetings and were not informed of the preferences that had been identified in the meetings.

RESULTS

Of the 24 sampled items and activities reported to be preferred in the person-centered plans for the 4 participants, eight (33%) were identified as highly preferred on the systematic preference assessments (Figure 1). Ten (42%) were identified as moderately preferred. There was noticeable variability in strengths of preferences based on the systematic preference assessments for the 4 participants. The majority of sampled preferences identified on the plans were found to be highly preferred on the systematic preference assessment for only 1 participant (Barb, who showed a high preference for 80% of the sampled items and activities from her person-centered plan and a moderate preference for 20%). Less than a majority of sampled items and activities from the person-centered plans were strongly preferred on the systematic assessments for Lance (38% high preferences and 38% moderate preferences) and for Keith (10% high and 50% moderate).

For the one item that met the criterion for inclusion in the systematic assessment for Sara, she showed a moderate preference.

For each participant, the percentage of reported preferences derived from the person-centered plans that were systematically assessed to be nonpreferred represented a minority of the total sample (see Figure 1). However, the reported preferences that were assessed to be nonpreferred represented at least one fourth of the sampled preferences for 2 participants (25% for Lance and 40% for Keith). Further analysis indicated that at least one reported preference was avoided during preference assessments for both Lance and Keith. One reported preference for Lance was avoided on 13% of assessment trials, and four reported preferences for Keith were avoided (averaging 40% avoidance during assessments). Two of the reported preferences for Keith were avoided on the majority of assessment trials.

DISCUSSION

The results suggest that caution should be exercised when relying solely on the person-centered mapping process for identifying preferences among people with profound multiple disabilities. Some support for preferences identified on person-centered plans to represent accurate preferences based on participant responses when presented with the items and activities was obtained, but the support had limitations. In regard to support for the person-centered process, 100% of the items and activities in the person-centered plans that were sampled with the preference assessments represented high or moderate preferences based on frequent approach responses to the items and activities by 2 participants. The majority (76% and 60%) of the reported preferences sampled for the other 2 participants were found to represent moderate or high preferences when assessed systematically.

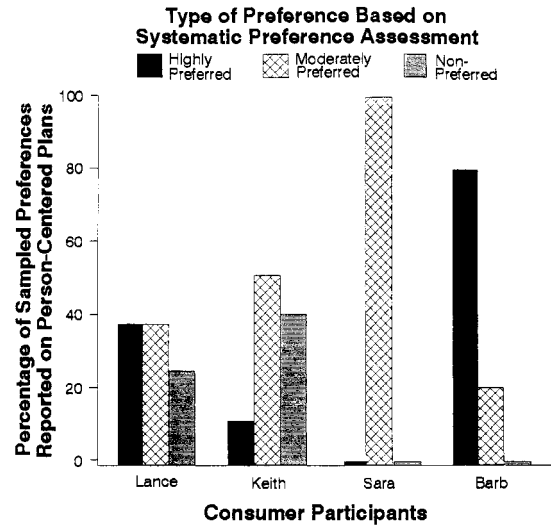


Figure 1. Percentage of sampled items and activities reported on person-centered plans to be preferred that were found to be highly preferred, moderately preferred, and nonpreferred on the systematic preference assessments for each participant.

Several limitations of the accuracy of preferences identified through the mapping process relative to actual participant response to the identified items and activities were apparent. In particular, 25% and 40% of the sampled items and activities reported to be preferred in the plans were found to be nonpreferred on the preference assessment for 2 participants, respectively. More significantly, 20% of the reported preferences for 1 individual were avoided relatively frequently during the assessments, and 10% were avoided on the majority of assessment trials. These results suggest that with some individuals, what is reported to be preferred during person-centered planning meetings will not accurately reflect what an individual will consistently approach when provided the opportunity, and in some cases will represent something the individual will repeatedly avoid.

Another limitation of preferences identified through the mapping process is that mapping resulted in relatively few reported preferences that were found to be highly pre-

ferred when the participants were presented with the items and activities. Across participants, only 33% of the reported preferences were found to be highly preferred. Most of the items that were found to be preferred on the systematic assessments were moderately preferred (42% of items and activities sampled from the plans). Given that a primary purpose of person-centered planning is to improve life enjoyment, it is not clear that most of the items and activities reported to be preferred will promote such a purpose. Specifically, research has shown that only those items and activities approached on at least 80% of assessment trials are likely to be accompanied by indices of happiness among people with profound multiple disabilities (Green *et al.*, 1997; Green & Reid, 1996). Research to date has not indicated that items and activities approached at a moderate level will be accompanied by indices of happiness.

All of the results just noted should be qualified when considering that only a sample (35%) of all items and activities reported to be preferred in the person-centered plans were assessed systematically. It is not known if the other reported preferences would be consistently approached by participants when presented to them. As noted earlier, one reason for restricting the sample of systematically assessed preferences was that several of the preferences reported through person-centered planning were not readily amenable to systematic preference assessment with approach and avoidance responses. Future research should focus on other means of assessing reported preferences among people with profound mental and physical disabilities that are more activity oriented or global than the stimuli typically included in systematic preference assessments (see Fisher, Piazza, Bowman, & Amari, 1996, and Hughes *et al.*, *in press*, for summaries).

To empirically assess a larger number of reported preferences in person-centered

plans, more specificity is needed for the reported preferences. Some preferences identified in the plans lent themselves to quite different interpretations regarding the precise items or activities that were desired. Preference assessments conducted subsequent to the investigation indicated that the general references to various preferences resulted in discrepant results when the items or activities were provided to participants. For example, 1 participant's plan indicated that he liked "anything social." However, when the social activities of holding hands with a staff person and receiving a hug from the same staff person were systematically assessed, the former was approached on 77% of trials (moderate preference) and the latter was approached on 43% (nonpreferred) and was avoided on 27% of the trials. Research should determine if the variable specificity is inherent in the person-centered mapping process, or in the manner in which different facilitators implement the process. In this regard, one difficulty in evaluating person-centered planning processes is a lack of procedural specificity regarding what should occur during the planning. For example, some facilitators require a consensus among meeting participants before recording a perceived preference, whereas others record any preference as long as no other meeting participant disagrees. Before carefully investigating various aspects of person-centered planning, more precise definition of component procedures will be needed.

Another qualification in interpreting the results is that only one component of person-centered planning was evaluated: the use of mapping to identify leisure-related preferences. Other procedural components of person-centered planning, as well as the process as a whole, were not evaluated. Hence, the conclusions noted here should not be extended beyond the component targeted in this investigation. Also, person-centered planning procedures were evaluated only

with people with profound multiple disabilities. It should not be assumed that our findings would generalize to other segments of the population of persons with developmental disabilities.

In light of these findings, several implications for practitioners are apparent. First, the person-centered planning tool of mapping seems to warrant continued investigation as a means of identifying potential preferences among persons with profound disabilities. Second, because the planning process also appears to result in some inaccurate identifications, it is recommended that when mapping is used, the process should be accompanied by systematic preference assessments to ensure the accuracy of what is identified.

When considering these implications, the efficiency of both person-centered planning and systematic preference assessments should be considered. Considerable personnel time is required for person-centered planning in terms of the time needed to train meeting facilitators and the number of people involved in developing the plans during person-centered planning meetings. Systematic preference assessments can also be time consuming. Research should address the amount of time involved in both processes, with a goal of determining the most efficient, yet accurate, means of identifying preferences among people with profound multiple disabilities. In this regard, recent research has demonstrated ways to make preference assessments more efficient (cf. Fisher et al., 1996).

A more practical approach to assessing the accuracy of preferences reported in person-centered plans than occurred in this investigation may be to conduct brief, mini preference assessments (cf. Mason, McGee, Farmer-Dougan, & Risley, 1989) simultaneously while items and activities reported as preferences in the plans are initially incorporated into an individual's routine. The

initial presentation could constitute an evaluation period, with continued presentation dependent on verification that the items and activities are approached and not avoided. Research is needed to evaluate the utility of this type of brief preference assessment for people with profound multiple disabilities.

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STUDY QUESTIONS

1. What are some typical goals of person-centered planning, and what is the role of preference assessments in realizing these goals?
2. What is the apparent discrepancy between methods typically used by person-centered planners and those typically used by behavior analysts to identify preferences for individuals with severe disabilities?

3. Describe the three-step process involved in preference mapping.
4. How were stimuli that had been identified through preference mapping selected for inclusion in the systematic preference assessment, and what proportion of stimuli was included?
5. To what extent did stimuli included in the systematic preference assessment exemplify events or activities that typically serve as the basis for decision making during person-centered planning?
6. Describe the procedures used in the systematic preference assessment, including the dependent measures and the criteria used for categorizing stimuli according to degree of preference.
7. How did the results of the systematic preference assessment compare with those obtained through preference mapping?
8. Given the results of this study and the limitations of preference mapping noted by the authors, how should the opinions of service providers be incorporated into the preference assessment process?

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