Occupational Engagement and Adults With Intellectual Disabilities

Wanda J. Mahoney, Elysa Roberts, Kimberly Bryze, Judith A. Parker Kent

People with intellectual disabilities may be predisposed to occupational alienation as a result of an inherent need for ongoing support and limited understanding of how they express choice and engagement in occupation. In response to this risk of occupational injustice, this phenomenological study explored the occupational engagement of adults with intellectual disabilities in a community-based day program. Data were collected through interviews using visual supports and through observation of activity groups using the Volitional Questionnaire. Thematic analysis illustrated how participants demonstrated engagement in occupation through doing activity/initiating action, expressing positive affect, and showing focused attention. Findings can inform how occupational therapy practitioners describe and facilitate occupational engagement in adults with intellectual disabilities.


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Occupational engagement is an essential aspect of occupational therapy practice. The overarching purpose of occupational therapy is “achieving health, well-being, and participation in life through engagement in occupation” (American Occupational Therapy Association [AOTA], 2014, p. S4). Meaning, choice, and motivation are important aspects of occupational engagement (AOTA, 2014). Consequently, when a person is insufficiently involved in choosing meaningful activities, it can lead to experiences of disconnectedness, limited self-expression, or a sense of meaninglessness, which is the injustice of occupational alienation (Townsend & Wilcock, 2004).

People with intellectual disabilities may be predisposed to occupational alienation as a result of an inherent need for ongoing support in at least one major life activity across multiple environments (American Psychiatric Association, 2013). Service providers or family members who offer this support may emphasize engagement in activities with an age-appropriate purpose (Mansell & Beadle-Brown, 2012). However, this focus on age-appropriate purpose may insufficiently address the personal meaning, choice, and motivation essential for true occupational engagement. In this study, occupational engagement was conceptualized as a high level of involvement in meaningful activities (Polatajko et al., 2013). The services that provide safe, purposeful activity for people with intellectual disabilities and other significant cognitive disabilities often inadequately address co-occupation (i.e., mutual engagement in a shared occupation), adapted occupations, and individualized choices (Channon, 2014; Mahoney & Roberts, 2009; Teitelman, Raber, & Watts, 2010). Because these considerations are essential elements for creating opportunities for occupational engagement for these populations, their absence can result in occupational alienation (i.e., when people are required to do occupations they find meaningless; Townsend & Wilcock, 2004).

Previously published results from a larger study of a day program for adults with developmental disabilities (Mahoney & Roberts, 2009) revealed what staff members and clients found meaningful about
program activities. Clients demonstrated what was meaningful to them by being engrossed in an activity; therefore, our study focuses on describing how participants demonstrated this occupational engagement. Our findings can inform the sparse body of knowledge on the lived experiences of people with intellectual disabilities and aid those working with this population to promote engagement in occupation, thereby reducing the risk of occupational alienation.

Method

This qualitative, phenomenological study sought to explore and explain how people with intellectual disabilities demonstrate occupational engagement in a community-based day program.

Participants

Study participants were recruited from a community-based day program for adults with intellectual disabilities in a Midwestern, metropolitan suburb. Staff members recommended clients who were difficult to engage in the program’s activities. Four recommended clients did not participate in the study. Recruitment continued until 10 participants and their guardians, as appropriate, provided written informed consent and assent in accordance with approval from the university institutional review board. Each participant had an intellectual disability to qualify for day program services, and the researchers sought people with significant impairments and the most difficulty engaging in the program activities. None of the participants were receiving occupational therapy services at the time of the study. Table 1 provides additional information about the participants.

Data Collection

Given participants’ limitations in communication, data were collected through interviews using visual supports and through observation using the Volitional Questionnaire (VQ; de las Heras, Geist, Kielhofner, & Li, 2007). Details about the design and use of visual supports to elicit perceptions of activities from participants are reported elsewhere (Mahoney & Roberts, 2009).

The VQ is a standardized observational tool designed to rate 14 behavioral indicators of volition in people who may be unable to provide such information through interview or in a written questionnaire (de las Heras et al., 2007). It uses a rating scale that indicates the amount of environmental support to demonstrate volitional behavior on the following continuum: no opportunity to observe, passive, hesitant, involved, and spontaneous. An environmental characteristics form supplements the rating scale by allowing the rater to note aspects of the activity, physical space, objects used, and social environment that affect volition. The VQ was used in this study to structure observations, ensure consistency across observations, and validate the construct of occupational engagement. Sources of data consisted of transcribed audio recorded interviews, researcher field notes and journals, and VQ rating and supplementary observation forms.

Data were collected from participants through observation during standard activity groups at the day center and interviews. Each participant typically attended up to four 1- to 2-hour-long assigned activity groups with 7–11 other clients and one or two staff members supervising. The activity groups included cooking, arts and crafts, recreation, life skills training, computers, music, listening to books, and sheltered work.

Data collection commenced by observing each participant in a group identified by a staff member as one the participant preferred; the researcher used the VQ to guide the observation. Next, participants were individually interviewed using visual supports of photographs of activity groups and pictures reflecting perceived preferences of each activity as either fun or yucky (Mahoney, 2008). Three additional observations using the VQ were conducted for each participant until data were collected on two preferred and two nonpreferred groups for the purpose of observing a range of occupational engagement.

Table 1. Participant Characteristics

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Gender</th>
<th>Approximate Age, Decade</th>
<th>Communication</th>
<th>Mobility</th>
<th>Living Situation</th>
<th>Work</th>
</tr>
</thead>
<tbody>
<tr>
<td>Megan</td>
<td>F</td>
<td>30s</td>
<td>Facial expressions, gestures</td>
<td>Wheelchair, full physical assistance</td>
<td>Family</td>
<td>None</td>
</tr>
<tr>
<td>Andrea</td>
<td>F</td>
<td>20s</td>
<td>Facial expressions, communication device</td>
<td>Wheelchair, full physical assistance</td>
<td>Supervised residential program</td>
<td>None</td>
</tr>
<tr>
<td>Johnathan</td>
<td>M</td>
<td>20s</td>
<td>Gestures, movements</td>
<td>Independent walking</td>
<td>Family</td>
<td>None</td>
</tr>
<tr>
<td>Theresa</td>
<td>F</td>
<td>50s</td>
<td>Single words, short familiar phrases</td>
<td>Independent walking</td>
<td>Supervised residential program</td>
<td>None</td>
</tr>
<tr>
<td>Timothy</td>
<td>M</td>
<td>40s</td>
<td>Single words, short phrases</td>
<td>Independent walking</td>
<td>Unknown</td>
<td>None</td>
</tr>
<tr>
<td>James</td>
<td>M</td>
<td>40s</td>
<td>Complete sentences, difficult to understand</td>
<td>Independent walking</td>
<td>Unknown</td>
<td>On-site sheltered workshop</td>
</tr>
<tr>
<td>Justin</td>
<td>M</td>
<td>30s</td>
<td>Complete sentences, difficult to understand</td>
<td>Independent walking</td>
<td>Family</td>
<td>On-site sheltered workshop</td>
</tr>
<tr>
<td>Lisa</td>
<td>F</td>
<td>50s</td>
<td>Complete sentences</td>
<td>Independent walking</td>
<td>Supervised residential program</td>
<td>Off-site sheltered workshop</td>
</tr>
<tr>
<td>Charles</td>
<td>M</td>
<td>50s</td>
<td>Short sentences</td>
<td>Independent walking</td>
<td>Supervised residential program</td>
<td>On-site sheltered workshop</td>
</tr>
<tr>
<td>Violet</td>
<td>F</td>
<td>30s</td>
<td>Single words, short phrases</td>
<td>Independent walking</td>
<td>Family</td>
<td>None</td>
</tr>
</tbody>
</table>

Note. F = female; M = male.

*a*Withdrawn after fourth observation. *b*Withdrawn after first observation.
A final interview was conducted with each participant to review preferences for groups and for member checking of initial themes about the meaning of the activities using pictures to represent the initial themes. Two participants withdrew from the study after the first observation, and 1 participant withdrew after all observations but before the final interview, resulting in 8 participants with four observations each.

**Data Analysis**

Data were analyzed thematically using principles described by van Manen (1990). An iterative process of wholistic and selective analyses of data sources was used. This process involved thorough analysis of each observation note to generate the essence of the participants’ experience in an activity group. For example, wholistic analysis of a participant’s engagement in preferred and nonpreferred groups was “engaged in dancing with encouragement and individual invitation” and “sleeping or refusing majority of activity,” respectively. Selective analysis involved highlighting and coding examples from the data to illustrate the participants’ perceived experiences in observed activity groups. The codes and excerpts from the selective analysis were organized into preliminary themes depicting how involvement in meaningful activity (i.e., occupational engagement) was displayed by participants. The researchers developed the themes after repeated readings of the data, discussion, concept mapping, and writing about the codes and preliminary themes.

The researchers analyzed VQ data and observation notes using a wholistic approach to describe the level of occupational engagement (i.e., engaged, less engaged, or not engaged). Subsequent analysis involved comparing VQ ratings and behavioral indicators of volition across occupational engagement levels. If an item had a difference of two or more rating levels between engaged and not engaged (i.e., spontaneous to hesitant or involved to passive), the item was considered to demonstrate the perceived difference in engagement level. The VQ ratings of not observed and passive were considered to be equal because it was often not clear whether the participant did not exhibit the behavior (passive) or whether there was no opportunity to observe it.

Five VQ items emerged as the most distinctive and repeatedly observed indicators of being engaged versus not engaged (i.e., shows that activity is special, indicates goals, stays engaged, pursues activity to completion, and invests additional energy/emotion/attention). Figure 1 illustrates these items and their pattern in relation to the occupational engagement levels generated during the wholistic analysis. The final phase of data analysis involved triangulating the findings from the VQ observations with the themes initially generated from the observation notes, researcher journals, and interviews to formulate the results of this study.

Multiple strategies were used to ensure trustworthiness of the data, analyses, and findings, including triangulation, member checks, modified peer review, reflexive journaling, and detailed audit trails. Mahoney (2008) provided additional details about the study methods, analyses, and efforts to ensure the trustworthiness of the study.

**Results**

Results of the data analysis are reflected in three themes: doing activity/initiating action, expressing positive affect, and showing focused attention. These themes emerged from the data analysis as ways participants demonstrated occupational engagement.

**Doing Activity/Initiating Action**

The theme doing activity/initiating action reflected one way participants demonstrated...
meaningful occupational engagement. Two items on the VQ that represented this theme were “indicates goals” and “pursues activity to completion/accomplishment.” All 8 participants with multiple observations showed a rating difference of two levels or more on the VQ item “pursues activity to completion/accomplishment” when they were engaged versus not engaged in program activities, and 5 participants showed the same difference for the item “indicates goals.” Examples of the theme doing activity/initiating action were indicated when participants reached for desired objects to use during the activity, continued actions, or made choices during the activity, such as

[The staff member] gave the maraca to Theresa and invited her to move beside her to play. Theresa got up and started shaking the maraca. The staff member told her that she could sit beside her, but Theresa remained standing. [After Theresa chose between two songs], the staff member started to play the [chosen] song and [other clients] joined in singing. Theresa shook the maraca and banged it against her opposite hand. She sang along with the song and kept going throughout the song.

Although movement and action were indicative of engagement for many participants, some demonstrated brief periods of engagement by a decrease in self-stimulating movement, as illustrated in the following observation of Johnathan:

Johnathan crossed his opposite leg and took his other shoe off and on. . . He put his open palm against his face. He rocked his torso and rocked the chair. He looked down at the magazine and moved his sleeve up and down. He blew raspberries. . . The staff member started to read a story from a magazine. Johnathan quiet[ed] and [didn’t] move or fidget for a few moments. He started moving around in his chair. Then he was quiet and not fidgeting for a moment.

When participants were not engaged in the program activity, they displayed behaviors suggesting disinterest or dislike such as falling asleep, not interacting with objects, or refusing the activity. In some instances, they engaged in a self-selected activity that the staff members permitted during the group activity:

A staff member asked, "Are you sure you don’t want to do the art project today? It’s a good one.” Timothy did not respond but put the old magazine back, picked up a different magazine, and walked back to his seat.

Expressing Positive Affect

Another important illustration of occupational engagement emerged as the theme expressing positive affect. Behaviors illustrating this theme included smiling, laughing, and expressing satisfaction when engaged in a meaningful activity, such as when “the staff member read a poem about cafeteria food. The staff member was laughing as she read it. Timothy smiled, laughed, and said, ‘Oh! ‘What?’ and ‘Ew’ at different parts of the poem.”

Expressing positive affect aligned with two VQ items. Eight participants demonstrated a difference of at least two rating levels between being engaged and not engaged for the item “shows that an activity is special or significant,” and 6 participants did so for the item “stays engaged.” Although it would appear on the basis of the name of the item "stays engaged" that the item is related to all the themes, the VQ specifically describes this item as “when the individual shows ongoing emotional or affective connection to what is done” (de las Heras et al., 2007, p. 26). Therefore, this item best corresponds to the theme expressing positive affect.

People with limited physical abilities often expressed engagement or disengagement in program activities through their emotional expressions. For example, when Megan was engaged during the music group, “she smiled with the music again, and the staff member said, ‘You laughing at me again over there?’ Megan smiled really big at that point.” In contrast, Megan indicated displeasure when she was not engaged in any activity during a life skills training group:

Megan moves her mouth, makes louder sounds, and seems to be crying. She continues to make louder sounds. The staff member comes to her and asks her if she is comfortable. Megan indicates “no.” The staff member repositions her slightly... and asks if she is better. Megan continues to cry[,] moving her jaw and making crying sounds. The staff member circles around the table spending a few minutes with each [client] talking and getting them to interact with the objects in front of them. [Megan did not have any objects in front of her.] Megan gets louder and has more frequent sounds with her crying.

Showing Focused Attention

The theme showing focused attention reflected occupational engagement when participants focused their attention on the activity or people in the group. The VQ item that corresponded to this theme was “invests additional energy/emotion/attention,” which included rating differences of two or more levels for 7 participants when they were engaged and not engaged. Participants demonstrated this theme through eye contact; focus on the activity to the exclusion of other things; or attentive body language, such as leaning forward, lifting the head up, or turning toward a person.

The following three examples illustrate the connection between the two themes doing activity/initiating action and showing focused attention. In the first, Theresa did not attend to the money activity or initiate actions related to the activity until a staff member initiated interaction:

When the staff member started the money skills, Theresa rubbed her...
face and chewed on her hair. . . . She momentarily looked at the [client] who first got the coins, then put her head back down toward her chest. Theresa had no reaction when the staff member asked coin questions [of the] [client] next to her. Theresa looked up when the staff member came in front of her from across the table, slid a coin in front of her, and asked what it was. Theresa leaned forward, pointed to the coin, and [said] “penny.” The staff member presented another coin, and Theresa said, “quarter.” When told to try again, she said, “dime” . . . . Theresa remained leaning forward during this activity and pointed to each coin presented.

In the second, Timothy sought out closer placement to the staff member and objects for the activity:

Timothy stood up and moved his chair to get closer to the staff member with the flash cards. He tried to squeeze between 2 [clients] in wheelchairs across the table from the staff member. He reached for the table and leaned forward. He named the picture when the staff member asked, “You ready, Timothy?”

In the third, although visual attention to an activity often indicates engagement, in some instances, even while looking around or closing eyes, a person can clearly be engaged in the activity:

While cutting the potato [with hand-over-hand assistance], James alternates between looking up at me or something else in the room and looking at what he is doing. While still helping him cut the potato, the group leader asks another [client] if he’s ready to cut a potato. James says, “No, me.” The group leader finishes helping James cut up the potato.

**Summary**

The examples in this section illustrate patterns in how adults with intellectual disabilities exhibit occupational engagement and demonstrate individual differences that are essential to consider when assessing occupational engagement. With and without staff support, the participants demonstrated choice, involvement, and the meaning they found in engagement in adapted occupations.

**Discussion**

Adults with intellectual disabilities in day programs often require support to access and perform activities (Channon, 2014; Mahoney & Roberts, 2009). They are at risk for occupational alienation if they are not afforded meaningful choices and opportunities for enriching occupational experiences (Townsend & Wilcock, 2004) and if they do not receive the requisite physical and social supports to engage in occupations. Participants in this study expressed high and low occupational engagement in program activities, which illustrates how a person merely being present when activities are occurring is different from a person engaging in occupation. To thwart the risk of occupational alienation, occupational therapy practitioners need to recognize patterns in how specific populations, such as adults with intellectual disabilities, express occupational engagement.

Motivation, choice, and meaning are integral aspects of occupational engagement (AOTA, 2014). Volition encompasses these interconnected aspects because it is a person’s motivation for occupation; how a person feels, thinks, and chooses the activities in which to engage; and how a person ascribes meaning to an activity (de las Heras et al., 2007). The VQ, an observational tool, was useful for assessing and monitoring indicators of occupational engagement, particularly in situations in which participants were unable to verbally express their occupational experiences as meaningful, important, or pleasurable. The participants demonstrated occupational engagement through doing or initiating activity, expressing positive affect, and showing focused attention, which corresponded to five items on the VQ that differentiated participants’ high and low engagement.

Social support from staff members was a major contributor to the participants’ level of occupational engagement in the day program. Staff members facilitated the participants’ occupational engagement by presenting adapted occupations with objects, clear expectations and structure, and environmental supports. Such facilitation was difficult for many staff members in the program, and when staff members did not provide adapted occupations, participants did not exhibit specific behaviors on the VQ. Therefore, it was challenging to determine whether the rating for some items should be no opportunity to observe or passive in the presence of little staff support or co-occupation.

Staff members sometimes permitted participants to engage in self-selected occupations in lieu of or in addition to program activities, which facilitated occupational engagement. However, participants were permitted to do so only when they could independently perform the self-selected activity. Many participants required assistance to access activities, and when the participants experienced occupational engagement in these situations, it was usually through mutual engagement in a shared occupation, or co-occupation, with a staff member (Mahoney & Roberts, 2009). Although staff members and participants usually experienced co-occupation favorably, staff members struggled with engaging with more than one client at a time, which resulted in other clients having to wait a long time for assistance. Because the clients were unable to access any activity while waiting for assistance, this was often an alienating experience.

Regardless of the assistance required by participants, when staff members recognized the participants as occupational beings with individual preferences, gave opportunities for choice making, and honored their choices, participants often engaged in the program activities to a greater extent. However, a client may not find the choices offered by staff members meaningful, which could result in occupational alienation despite the opportunity for choice. The social supports that facilitated occupational engagement in adults with intellectual disabilities are similar to the mediators of action for the occupational engagement of children with autism (Bagatell, 2012) and therapeutic social environments that supported occupational engagement among people with dementia (Teitelman et al., 2010).
The results of this study are not widely generalizable and must be interpreted cautiously because of the small number of participants and attrition. An additional limitation is that this study concentrated on occupational engagement as an optimal experience on the basis of AOTA’s (2014) explanation of the construct. Studying optimal experiences is important to deter potential occupational alienation, although it is essential to recognize occupational engagement as a range of experience, which future studies may seek to explore in more detail. This study represents a novel approach to exploring the perceived experiences of members of a vulnerable population at risk for occupational injustice.

Implications for Occupational Therapy Practice

The findings of this study have the following implications for occupational therapy practice:

- This study can equip occupational therapy practitioners with insights to inform training for day center staff and other caregivers about how to recognize indicators of occupational engagement.
- The study illustrates strategies related to providing social support to promote occupational engagement for people with intellectual disabilities.
- Because occupational engagement is an individual phenomenon, it is important to identify each person’s expressions of meaning, choice, and motivation, and the VQ provides a useful structure for this task.

Conclusion

People with intellectual disabilities may be predisposed to occupational alienation as a result of an inherent need for ongoing support and limited understanding of how they express choice and engagement in occupation. In response to this risk of occupational injustice, this phenomenological study explored the occupational engagement of adults with intellectual disabilities in a community-based day program. Findings can inform how occupational therapy practitioners describe and facilitate occupational engagement in people with intellectual disabilities.

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References


