Facilitating Family Occupations: Family Member Perceptions of a Specialized Environment for Children With Mental Retardation

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KEY WORDS
• child, institutionalized
• environment
• family relations
• human activities
• mental retardation

OBJECTIVE. We studied the experience of family occupations in the Snoezelen context (i.e., a highly specialized therapeutic room for family gatherings) and analyzed how it facilitated occupations for parents of children with severe and profound mental retardation living in residential facilities.

METHOD. In-depth interviews and participatory observations were held with 10 families of children with mental retardation living in a long-term residential facility for children with mental retardation in Haifa, Israel.

RESULTS. Two main themes emerged: The Snoezelen environment was experienced as another world, where parents sensed detachment from external reality and a transition to relaxation and intimacy. The intimacy of the Snoezelen world fostered the experience of being together as a family, where all family members shared fun activities and strengthened their relationship.

CONCLUSIONS. A sense of intimacy and relaxation, provided by the Snoezelen environment, is important in facilitating family occupations for this population. Interventions in occupational therapy must be designed that take these requirements into consideration.


In the population of children with severe and profound mental retardation, little is known about how their institutionalization affects family occupations. Because daily life experiences generally form the basis of family occupations, children living in residential care facilities may experience limited participation in such occupations. The research described in this article focuses on the creation of an enabling context for family occupations in this population.

Family occupations are defined as culturally meaningful chunks of activities engaged in together by the entire family (Segal, 1999). These activities promote family health and well-being (Feise, 2007); endow family integrity (Schultz & Winifred, 2002); and act positively on family satisfaction, interaction, and stability (Orthner & Mancini, 1990). Virtually all published literature on family occupations refers to families raising their children, with or without disabilities, within the natural home environment (e.g., Dunst, Hamby, Trivette, Raab, & Bruder, 2002; Fiese, 2007; Segal, 1999). Little is known about families who place their children with disabilities in institutions. Living separately, these children and their families have little opportunity to participate in joint family occupations. For them, family visits and events held at the residential facility constitute the main, if not the only, opportunities for family occupations and contacts.

In a long-term residential facility for children with mental retardation in Haifa, Israel, a unique attempt was made to conduct family occupations within the tranquil...
context of the Snoezelen room (Nasser, Cahana, Landel, Kessel, & Merrick, 2004). Snoezelen refers to specially equipped rooms in which the nature, quantity, arrangement, and intensity of stimulation is controlled (Shapiro & Bacher, 2002) in an environment designed to stimulate the senses by means of light, sound, touch, smell, and taste (Lindsay et al., 1997). The Snoezelen environment is intended to enhance relaxation, enjoyment, and social interaction (DeBunsen, 1994; Shapiro & Bacher, 2002).

Since the start of this effort at the end of 2000, approximately 40 different families (including parents and siblings) have participated in more than 500 sessions of family occupations held in the Snoezelen room. Each family is invited to spend 1 hr of fun activity with their child in this therapeutic environment. Usually an occupational therapist, and sometimes a social worker, joins in and tries to encourage interaction between family members and the child with disability (Nasser et al., 2004). In the current study, we sought to discover and understand the meaning of family occupations in the Snoezelen environment for parents and other family members.

Background Literature

Family Occupations of Children With Mental Retardation Living in Residential Facilities

Family members participate in family occupations, such as family celebrations, traditions, dinners, or leisure activities (Segal, 1999). Such occupations are said to provide families with space and time to be together (Sachs & Jarus, 2004; Segal, 1999); promote family health (Fiese, 2007); create emotional connections (Fiese, 2006); enable the formation of family beliefs and values; and impart to the family a sense of stability, identity, and relationship (Segal, 2004; Schuck & Bucy, 1997).

Parents who raise their children with disabilities at home make adaptations to meet their children’s special needs (Dunst et al., 2002; Weisner, Matheson, Coots, & Bernheimer, 2005), yet evidence suggests that these families are similar to others in their efforts and in the purposes of their family occupations. As in most families, the purposes of family occupations in families with children who have special needs include being together, sharing, and providing learning opportunities for children (Segal, 1999).

Despite the importance and contribution of family occupations for the family as a whole and for each of its members, little is known about this phenomenon with regard to children with mental retardation who live in institutions. Because family occupations generally occur in the natural setting of the home, the absence of children with mental retardation from family daily life limits their participation in such occupations. Family occupations may then mainly occur during family visits with the child, when the family takes the child home, or when the child participates in family events held in the given residential facility.

Studies on the engagement of families in such activities have yielded equivocal findings. Until the late 1980s, such studies showed that parents maintained little contact with their children with mental retardation living in institutions (Blacher, Baker, & Feinfield, 1999). More recent studies have shown that families maintained higher levels of involvement even years after the placement of their children (e.g., Baker & Blacher, 2002; Blacher, 1994; Schwartz, 2005; Selzer, Krauss, Hong, & Orsmond, 2001). These contrasting findings represent a change in attitudes to institutionalization and disclose the role of the institution in affecting parents’ involvement in their children’s lives. Although these studies may accurately record important details about the degree of family involvement, they fail to capture the complexity inherent in this phenomenon and leave essential issues to be addressed, such as the experience and role of family members during family occupations; the contribution of such occupations to the family unit, family members, and family relations; and the ways in which contextual elements enable or disable family occupations and contacts.

Such issues are highly relevant for the population of children with severe and profound mental retardation living in institutions. Despite the trend of deinstitutionalization and the decrease in the number of children placed in institutions (Breedlove et al., 2005; Lakin & Stancliffe, 2007), this population is still at increased risk for out-of-home placement (Llewellyn, McConnell, Thompson, & Whybrow, 2005; McIntyre, Blacher, & Backer, 2002) because of low functioning level, complex medical and behavioral conditions, and the need for numerous services (Hanneman & Blacher, 1998; Llewellyn et al., 2005; Rosen, 1986). In Israel, as in other countries, children with severe and profound mental retardation constitute a significant proportion of institutions’ population. Data from the Department of Mental Retardation of the Israel Ministry of Social Affairs show that 60% of children with mental retardation living in institutions (ages 0–19) are diagnosed with severe and profound mental retardation (Merrick, 2007). Moreover, compared with children with higher functioning, this population demonstrates low levels of family involvement (Schwartz & Tsumi, 2003).

Snoezelen Environment

Providing sensory stimulation through the Snoezelen environment is one of the intervention approaches available for this population (O’Neal & Velde, 2006). The dearth of
intervention resources for improving the emotional and relational conditions of people with severe and profound developmental disabilities, together with the widely held notion that Snoezelen is a pleasurable, friendly, and highly humane approach, resulted in its fairly rapid acceptance and use for treatment (Lancioni, Cuvo, & O’Reilly, 2002). Today in Israel, this method is used in more than 25 residential care centers and 3 community settings for people with mental retardation (Nasser et al., 2004).

Despite its popularity, the effectiveness of the Snoezelen as a treatment intervention approach for children with disabilities is ambiguous. Findings of most studies indicate positive effects mainly on behavioral and emotional social skills (e.g., DeBunse, 1994; Kaplan, Clopton, Kaplan, Messebauer, & McPherson, 2006; Lancioni, Singh, O’Reilly, Oliva, & Basili, 2005; Lavie, Shapiro, & Julius, 2005; Shapiro, Parush, Green, & Roth, 1997). Several studies, however, reported lack of influence (e.g., Lancioni et al., 2002; McKee, Harris, Rice, & Silk, 2007), and others reported the appearance of unfavorable behaviors such as inconvenience and overexcitement of participants (e.g., Hogg, Cavet, Loretto, & Smidde, 2001; Lancioni et al., 2002). These findings emphasized the need for more studies investigating the effectiveness of the Snoezelen in diverse populations and new areas. The current research highlights its potential use with an innovative approach: a context encouraging family occupations. In addition, this research provides firsthand information from people without disabilities (the parents) about the effect of the Snoezelen. Such information can deepen our understanding of this environment and its effect on our clients.

The research questions were as follows:
1. How do parents experience family occupations, held in the Snoezelen context, with their children with disabilities?
2. How do parents perceive the experience of other family members participating in family occupations held in the Snoezelen?
3. What is the meaning of these occupations for parents, and how do the occupations affect family relations?

Method

A naturalistic qualitative method based on a phenomenological approach was used. Qualitative inquiry is most suitable for studying human occupations, especially when little is known about a phenomenon and when the study is based on the need for understanding complex interactions (Creswell, 1998), such as those in families of children with disabilities, when the nature of such interactions is unique for each family and the child lives out of home (Blacher, 1994). We received approval from the institution’s review board and ethics committee at the University of Haifa.

Participants

Ten families were selected for the study through directed sampling. All families had children with severe or profound mental retardation living in a long-term residential facility for children with mental retardation in Haifa, Israel. Participants were selected according to the following criteria:

- The family had one child or more with the diagnosis of severe or profound mental retardation.
- The family had no other children with disabilities living in other institutions.
- The family had participated in at least 10 monthly consecutive family occupations held in the Snoezelen.

Potential participants (11 families) were identified by an occupational therapist (Kareem Nasser) and a social worker, who both worked in the institution and participated in family occupations held in the Snoezelen. Nasser contacted the families and introduced the study. Ten families agreed to participate and provided informed consent.

Sociodemographic Characteristics of Participants

The sample included six Jewish and four Arab families. Nine of the families were two-parent families, and one was a single-parent family. Because the father in the latter family had no contact with his child with disability, only the mother participated in the study. Five families lived in the city and suburbs of Haifa, three lived in cities in central Israel, and two lived in the North (Galilee). All parents except one mother, who had immigrated to Israel from Argentina before she married, were born in Israel. Parents’ ages ranged from 31 to 53. Most families had one child with profound mental retardation; the children were totally dependent in all occupational areas. One family had a child (Calanit, a pseudonym) who had severe mental retardation but could walk and eat independently, and one family had two children with profound mental retardation. All children lived in the institution, and their ages ranged from 4 to 17 (see Table 1 for families’ characteristics).

Description of the Institution and Snoezelen Room

The institution where the study took place was a public, nonprofit long-term residential facility located in the center of Haifa. At the time of the study, the facility housed 60 young residents, ages 2 months to 21 years, all of whom were Arabs and Jews from different parts of Israel. All had severe or profound levels of mental retardation, were wheelchair bound, and required nursing treatment.
Table 1. Families’ Characteristics

<table>
<thead>
<tr>
<th>Family</th>
<th>Child’s Pseudonym</th>
<th>Gender</th>
<th>Age (Years)</th>
<th>Years of Institutionalization</th>
<th>No. of Siblings</th>
<th>Father’s Age</th>
<th>Mother’s Age</th>
<th>Area of Living</th>
<th>Ethnicity</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Gadi</td>
<td>Male</td>
<td>17</td>
<td>16</td>
<td>2</td>
<td>45</td>
<td>45</td>
<td>Urban</td>
<td>Jewish</td>
</tr>
<tr>
<td>2</td>
<td>Calanit</td>
<td>Female</td>
<td>14</td>
<td>11</td>
<td>3</td>
<td>40</td>
<td>45</td>
<td>Urban</td>
<td>Jewish</td>
</tr>
<tr>
<td>3</td>
<td>Or</td>
<td>Female</td>
<td>13</td>
<td>12</td>
<td>4</td>
<td>52</td>
<td>42</td>
<td>Suburb</td>
<td>Jewish</td>
</tr>
<tr>
<td>4</td>
<td>Erez</td>
<td>Male</td>
<td>12</td>
<td>5</td>
<td>—</td>
<td>39</td>
<td>36</td>
<td>Suburb</td>
<td>Jewish</td>
</tr>
<tr>
<td>5</td>
<td>Batia</td>
<td>Female</td>
<td>10</td>
<td>9</td>
<td>2</td>
<td>45</td>
<td>38</td>
<td>Urban</td>
<td>Jewish</td>
</tr>
<tr>
<td>6</td>
<td>Rima</td>
<td>Female</td>
<td>10</td>
<td>9</td>
<td>2</td>
<td>35</td>
<td>33</td>
<td>Village</td>
<td>Arab</td>
</tr>
<tr>
<td>7</td>
<td>Gilad</td>
<td>Male</td>
<td>9</td>
<td>3</td>
<td>2</td>
<td>39</td>
<td>36</td>
<td>Suburb</td>
<td>Jewish</td>
</tr>
<tr>
<td>8</td>
<td>Said</td>
<td>Male</td>
<td>8</td>
<td>3</td>
<td>2</td>
<td>34</td>
<td>33</td>
<td>Suburb</td>
<td>Arab</td>
</tr>
<tr>
<td>9</td>
<td>Hilmi</td>
<td>Male</td>
<td>7</td>
<td>3</td>
<td>2</td>
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<td>30</td>
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<td>Arab</td>
</tr>
<tr>
<td>10</td>
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<td>Female</td>
<td>4</td>
<td>3</td>
<td>1</td>
<td>34</td>
<td>30</td>
<td>Village</td>
<td>Arab</td>
</tr>
</tbody>
</table>

Note. — = no siblings.

The building complex had three floors, including a living area and a special education school that served the institution’s residents. The Snoezelen room was located on the first floor, close to the living area and other activity and therapy rooms. The Snoezelen room contained diverse equipment such as a bubble tube, solar projector, leaf chair, and aroma fan. The room’s floor was covered with white mattresses. All residents entered the Snoezelen room for individual therapy sessions or group leisure activities, guided by staff skilled in working with children with disabilities. The family occupation sessions were most often conducted with one family and one therapist.

Data Collection

Semistructured, in-depth interviews and participant observations were used for data collection. After parent agreement was obtained, one interview and two observations took place with each family. The interview, which lasted approximately 90 min, was held with both parents present and followed an interview guide. The interview began with open-ended questions, starting with the Grand Tour (Spradley, 1979) or general questions (e.g., “What does family occupation mean to you?” “Can you describe family occupations you usually conduct?”) and gradually narrowed to specific family occupations taking place in the Snoezelen. The questions were meant to elicit a description of specific activities, perceptions, feelings, and experiences of family members in the Snoezelen (e.g., “Can you describe a typical family gathering in the Snoezelen?” “How do you feel during the family occupation?” “How do you feel after the family occupation?”). The interview guide was refined after pilot testing with three families and was continuously modified during the study. Dalia Sachs conducted all interviews, which were held in the informants’ first language (i.e., Arabic with Arabs and Hebrew with Jews). Interviews were audiotaped and transcribed for further analysis. Observations were videotaped and transcribed. Field notes were recorded by Kareem Nasser to decrease bias, because he had prolonged engagement in the studied phenomenon (he worked at the institution and was continually involved in family occupations within the Snoezelen). Field notes consisted of our perceptions, feelings, and thoughts during the data collection process.

Data Analysis

Data analysis was ongoing, beginning with transcription of the interviews, which allowed us to reexperience them at a deeper level. Each transcript was read multiple times by both of us to absorb the essence of the entire interview. Using line-by-line analysis, we each coded data from two interviews, analyzing the meaning and experience of family occupations inside and outside of the Snoezelen. We compared, discussed, and reviewed codes and then grouped them into 30 higher-order concepts, such as “feelings of parents during family occupations in the Snoezelen,” “the role of the therapist,” and “difficulties conducting family occupations in other contexts.” In the following step, we analyzed the other eight interviews in an integrative cyclic process in which each emerging theme was identified and coded on the basis of the previous one, which then served as the basis for identifying new categories or deleting previous ones (Creswell, 1998). During this step, we constantly discussed emerging themes and continually refined interpretations to clarify the ultimate presentation of findings. Similarities and differences among the informants constituted the basis for identifying the main two study themes. The observations were analyzed and coded according to codes identified in the interviews. Analyses of the observations enabled triangulation of the data, enriched the descriptions given by the parents, and thus deepened the understanding of the parents’ experience.
Data Trustworthiness
Several steps were taken to ensure trustworthiness of the data. Triangulation was accomplished by comparison of data from interviews, observations, and field notes. Confirmability and audit of the research process was established by maintaining accurate documentation and retention of audiotapes, transcription of interviews, and filming of observations. Peer debriefing was conducted by Dalia Sachs, who accompanied all stages of the study.

The findings were discussed with three professionals: an occupational therapist and social worker who had both worked for 5 years with families in the Snoezelen and an occupational therapist specializing in Snoezelen use with children with developmental disabilities. In addition, the prolonged engagement of Kareem Nasser in the family occupations held in the Snoezelen enabled both a deeper understanding of the phenomenon and the establishment of informant trust (Lincoln & Guba, 1985). To trace possible biases that may have resulted from his long acquaintance with the institution and parents, several measures were taken, including field note recordings, triangulation, and constant accompaniment by Dalia Sachs.

Results
Two main themes were identified from the data: the Snoezelen as “another world” and “being together as a family.” The first theme referred to parents’ experience of family occupations taking place in the Snoezelen, and the second reflected the main purpose of these occupations.

Snoezelen as “Another World”
When entering the Snoezelen, all families except one expressed a feeling of detachment from the reality outside of the room and a transition into another world of relaxation, tranquility, and intimacy. Being in that unique and distinctive reality fostered family togetherness. Manal’s father said, “You enter the room [Snoezelen], and you feel you are in another world, no inside, no outside, no noise, no nothing.” Gilad’s father added, “It is as if you are in a play or in a film, detached from the outside world.” The other parents similarly described a contrast between the reality created inside the Snoezelen and that outside it; entering it was experienced as stepping into a different, illusory, and relaxed world, like being in a play or movie.

Parents raised two major issues regarding the experience of detachment, one related to the environment of the living areas in the institution and the other related to their children’s disability. For seven families, entering the Snoezelen made it possible to break away from the atmosphere of the main living area and move to a different one where they could be together with their children. Visiting the institution was difficult for the parents. There, they entered a world of many children with severe disabilities, which exacerbated their sorrow and their pain. The living areas were noisy and did not allow intimate visits with their child. Entering the Snoezelen environment allowed an experience of intimacy and freedom.

There are children here who make me shrink. How can this be? . . . It’s just painful to me. So in order to cut off that pain, I take [Calanit] and go to the park or to all kinds of places, only in order not to be here and also to be more with her. At least we have this room [the Snoezelen] that lets us be together. It’s the most intimate room here [in the institution]. (Calanit’s father)

A mother added that the Snoezelen gave her a quiet, intimate environment:

For me, the Snoezelen is a kind of being alone with them [her children with disabilities], some kind of detachment from the bustling residential room, from the noise of other children, the caregivers and the loud music. (Mother of Erez and Oren)

The second issue of detachment from the everyday world was related to the way parents viewed their children with disabilities. For some parents, especially mothers, being in the Snoezelen gave them a different perspective on their children and freed them from seeing the children as “disabled.” Eight mothers and four fathers described a shift in focus from their children’s disability to their innate capabilities.

Beside his bed I stand before a 15-year-old child, who is like an infant of 1 week, unable to turn over, or to calm himself, and who is becoming more deformed by the year, and this makes me very worried. In the Snoezelen I can forget that he is 15. Maybe this is it. I can forget all labels of age and things like that. (Gilad’s mother)

[In the Snoezelen] her skin looks soft and not suffering. It looks as if she feels good; I can smell her. When she’s in the wheelchair outside the room, you look at the position of the head, the hands, and you see details, you see the situation. Now when you are in the [Snoezelen] room you don’t look at these things. I mean that I cling to her and I don’t examine her, I’m with her. I try to get close to her and not in front of her. And when she reacts to the lights then it is fun. Sometimes there’s a little conversation between us; she’s like humming. I talk to her and she answers “hhmmm hhmm.” It’s fun. (Batia’s mother)

Amazingly, the physical and sensory features of the Snoezelen created a space of intimacy, with physical and

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Moreover, most parents stress that during regular family gatherings and outings, their families or go on family excursions and events. Children living in institutions are usually not present in daily family occupation in the Snoezelen; at that time the mother was pregnant. She expressed stress and inconvenience, and the father experienced lack of intimacy and freeness.

When entering the room, I feel I’m in another world, detached from the world outside, like I’m dreaming. The atmosphere, the music, the lights, everything. [Later she added.] I don’t know why I feel stressed there. I’m not that kind of a person that feels stressed when being in closed places. I just don’t feel comfortable there, maybe it’s because Rima can’t jump and play with her sisters and brothers, maybe that’s the reason [cries]. (Rima’s mother)

Although entering the Snoezelen was experienced as being in a dream, this mother felt tense and focused on her daughter’s disability and difficulty playing with her brothers and sisters. During the interview, Rima’s mother and father noted other aspects of their experience, such as the awkwardness of walking on the mattresses covering the floor, the need to watch out for the expensive instruments, and the presence of the therapists.

The observations made after the mother had given birth yielded a different picture from what the parents said during the interview. The mother looked relaxed, happy, and active in stimulating her child with disability and playing with the other children. Perhaps her experience of stress and inconvenience the previous time inside the Snoezelen had been affected by her pregnancy. Matters were different with the father. He sat to one side (outside the family circle) for most of the activity in the Snoezelen, which he did not enjoy; he was not part of the family occupation and the intimacy that was generated there.

**Being Together as a Family**

For all families, the experience of being together was expressed as the main purpose of the family occupation inside the Snoezelen. Three major components characterized this experience: the participation of the children with disabilities in family togetherness, enjoyment of siblings, and closeness of siblings and their sister or brother with disability.

The whole family being together, including the child with a disability, is rare and not taken for granted by parents. Children living in institutions are usually not present in daily family occupations in their natural home and rarely visit their families or go on family excursions and events. Moreover, most parents stress that during regular family visits to the institution, they find it difficult to assemble all family members. Some of them describe how they usually sit with the child with disability in one place while the siblings play somewhere else. So family occupations held inside the Snoezelen became the main opportunity for a family gathering and for the experience of family unity and wholeness. “The jigsaw puzzle is complete,” said Batia’s mother. Or’s father added, “The family activity [inside the Snoezelen] unites us. It gives us all the feeling that there is another person that belongs to the family.” Calanit’s father elaborated,

It [the activity inside the Snoezelen] gives us something very important, to be together as a family, for half an hour, a complete family with all the children, where they share the same playthings. [Later he added.] When we come here [to the Snoezelen] we feel that the family is complete, the whole person-power is there, all the four children.

For these and all other parents, the participation of the child living in the institution was the essence of family occupations inside the Snoezelen. Moreover, for some parents it was a prerequisite for carrying out this activity. On the occasions when the child with disability could not participate in the activity (because of sickness or because he or she was asleep), they refused to enter the Snoezelen and engage in the activities. Moreover, children with disability were usually the focus of family activity held inside the Snoezelen. Observations revealed that during the activity time, most parents (especially mothers) and some siblings (especially daughters) surrounded the child with disability; moved him or her from place to place; and tried to stimulate, comfort, and make him or her happy.

In the Snoezelen, we always work with Said. We usually massage him with aromatic oil, play him nice music, and me and his sister expose him to things. [Later she added.] When we keep exposing him to stimulations it reminds him that he has senses and that he feels. (Said’s mother)

It is interesting that mothers emphasized more than fathers the need for stimulating and being close to the child. Mothers were often observed, sometimes together with daughters, massaging the children with disability, exposing them to visual and tactile stimulation, rocking them on the hammock, taking them to their bosom, hugging, and talking to them. Most fathers were less physically close to their child with disability; only two fathers were observed having prolonged physical contact with their child. Other fathers got closer to their children only when encouraged to by the therapist.

Enjoyment of siblings is another important component of the “being together” experience inside the Snoezelen. All families (except the one consisting of only two children, both with disability) described how the siblings looked forward excitedly to the activity in the Snoezelen, enjoyed it, felt
disappointed when it ended, and continued to ask to return. Gadi’s mother described her two daughters’ feelings: “They feel they’re coming to the most precious time in the world. They wait for it.” Rima’s mother added, “Before coming to the Snoezelen, they [Rima’s siblings] always plan what they will do there.” Observations showed that siblings mostly engaged in activities that were fun for them, like swinging, jumping, and rolling. For example, Said’s and Hilmi’s brothers and Or’s and Gadi’s sisters chortled after rolling on the physioball. Or’s brother and sister, Batia’s sister, and Gilad’s brother laughed and shouted while swinging fast on the hammock. It appears that for the siblings being in the Snoezelen meant having fun.

Being together in such a joyful atmosphere encouraged closeness between children living in the institution and their siblings. During the activity, the siblings, especially the sisters, tried to draw near to their brother or sister with disability and exhibit a caring attitude to him or her. Hilmi’s younger brother took the initiative and placed a cushion under Hilmi’s legs so that he could sit comfortably. Calanit’s younger sister held her safely so she would not fall off the leaf chair, and Rima’s older sister spent most of the activity time with her. She held Calanit on the leaf chair, showed her the lighting balls, and kissed her.

The degree of closeness differed from one family to another and among siblings in the same family. In some families, the relationship was close and warm. In others, the children did not demonstrate closeness to their brother or sister with disability. Nevertheless, many of the parents talked about the family occupations in the Snoezelen as an opportunity to develop or maintain the relationship between the children with a future perspective, when the responsibility for the child with disability might fall on the well-functioning sibling.

Discussion

This is a pioneering study investigating family occupations in populations of children with severe and profound mental retardation living in institutions. Its findings highlight the importance of these occupations for such a population and the crucial impact of the context as enabling or restricting occupations (Dickie, Cutchin, & Humphry, 2006; Dunn, Brown, & McGuigan, 1994). Lack of intimacy and the scarcity of possibilities for suitable and joyful activities in the institution hinder family members’ ability to be together. By contrast, the intimate, relaxing, detached, and joyful context of the Snoezelen room encourages families to come together and reaffirms its members’ relations.

Our findings indicate that families of children with disabilities who live in institutions are similar to those who raise their children with disabilities at home, with regard to the meaning and purposes of family occupations. Similar to parents in those families who conduct family occupations for the purpose of being together and sharing and affording learning opportunities (Segal, 1999), parents of children with disabilities living in institutions conduct family occupations inside the Snoezelen for the purpose of being together as family and affording learning opportunities for their children by stimulating those with disabilities and encouraging siblings to interact with and take care of them. Family occupations in the Snoezelen thereby provide the family with a sense of identity and a means of socialization and enable transmission of family beliefs and values (Schuck & Bucy, 1997; Segal, 2004), such as taking care of each other and maintaining family unity.

Unlike families who raise their children with disabilities at home, families of children with mental retardation living in institutions lack the home environment and intensity of everyday life that provide the basis of family occupations. The children’s absence from family everyday life and the nonintimate context of the institution limit opportunities for the construction of meaningful family occupations. Thus, we can grasp the importance of the children’s participation in family occupations held in the Snoezelen for the parents, where the child with disability becomes the focus of activity. This circumstance may shed light on findings regarding the dearth of parents’ visits to their children with disabilities who live in institutions (Baker & Blacher, 1993; Blacher et al., 1999).

It is interesting that intimacy, as a major characteristic of family occupations, was not mentioned in other studies. Presumably the reason is that in those studies, family occupations were investigated only in families of children living in their natural homes, where intimacy is taken for granted and permanent. The necessity of an intimate context for family occupations becomes more acute after placement, when the intimate home space becomes unavailable. Being in the Snoezelen with all family members present and detached from the institutional context gave most parents a feeling of intimacy.

The unique sensory stimulation engendered in the Snoezelen was experienced as contributing to the creation of an atmosphere of relaxation and detachment from the everyday world. Everyday life for parents of children with disabilities is an extreme personal and social challenge. Acceptance of their child, provision of caring needs, societal attitudes to mental retardation, family pressure, and feelings of frustration and dissatisfaction are only a few of the coping requirements for these parents (Azar & Badr, 2006; McConkey, Truesdale-Kennedy, Chang, Jarrah, & Shukri, 2008). Institutionalization of their children is an additional
critical stage that increases the weight of their existing feelings of personal guilt and shame (Foster, 1987; Krauss, Selzer, & Jacobson, 2005; McDermott, Valentine, Anderson, Gallup, & Thompson, 1997). Dealing with their own feelings, with those around them, and with the doubts and anxiety of their other children may result in much stress in the lives of parents and families; it is amplified by the institutional environment. The Snoezelen becomes a place where they can break away from everyday reality. With its sensory stimulation and isolation from the outside world, the Snoezelen enables parents to feel relaxation and sense that they are in another, better world. The addition of the physical adaptability of the environment to their child with disability, which facilitates his or her better positioning and manipulation, creates a “barrier-free” environment in which the parents can experience a world without restrictions and enjoy interaction with their child, rather than with their “disabled” child.

Yet not all parents experienced relaxation and intimacy in the Snoezelen. Rima’s family, especially her father, experienced stress and lack of intimacy. That finding suggests that the Snoezelen context can also induce stress and inconvenience in those who enter it. Shapiro and Bacher (2002) emphasized that people react differently to the sensory stimulation in the Snoezelen. This finding highlights the importance of adjusting the environment to its participants’ wishes and preferences. Still, both Rima’s parents concurred that being together was the main purpose of family occupations inside the Snoezelen.

The siblings’ experience during family occupations in the Snoezelen is important. Their excitement and enjoyment prioritize this family activity for the parents, especially for the purpose of being together (Segal, 1999). Moreover, strengthening the relationship between siblings and their brothers and sisters living in the institution was the parents’ overt purpose for the present experience of family unity, as well as for the future, when responsibility may have to shift from themselves to their able children.

Limitations and Future Research

This study has limitations, and generalization should be made with caution. The sample was small, and the participants represent families who persistently participated in family occupations in the Snoezelen. The sample probably contains families who have positive experiences in the Snoezelen.

Although the heterogeneity of the participants reflects the general Israeli population, it could blur differences in experiences and perceptions. A homogeneous sample, which is usual in a phenomenological study, could deepen understanding of the particular participants’ experience. Another limitation is that Nasser worked in the institution, joined the family occupations inside the Snoezelen and interviewed parents. Although his prolonged engagement was an advantage, his involvement in conducting the interviews could have influenced parents who may have wanted to please him. Last, although interviewing both parents together allowed the family unit to be emphasized, this may have caused disadvantages—such as one parent assuming control of the conversation.

Additional studies on family occupations within this population are needed. Recommended are larger samples including families who do not participate regularly in the occupations inside the Snoezelen. In addition, it is important to deepen our understanding of the enabling and disabling effect of the Snoezelen and other contexts on family members and relations.

Conclusions

Although most experts prefer the natural home (Johnson & Kastner, 2005), and despite the advancement of deinstitutionalization movements, many children in Israel and in other countries around the world—especially those with severe and profound disabilities—will continue to be placed in institutions. Families who are interested in sustaining high-level, high-quality relationships with their children face enormous difficulties, mainly because of contextual obstructions. The absence of intimate space for families, problems stimulating children with disabilities, difficulty including these children in family activities, and lack of institutionally supported opportunities for such occupations may decrease family involvement and visits and can negatively affect family integrity and togetherness.

Moving from the residential habitation into the Snoezelen was experienced as passing from anxieties and worries to relaxation, from focusing on the children’s disability to the discovery of their capabilities, from lack of intimacy to intimacy, and thus from being apart to being together as family. The enabling context of the Snoezelen can provide professionals with guidance to modify the institutional context in general, beyond the Snoezelen, to enable and encourage family occupations.

Professionals working with such a population must understand that leaving the natural home does not mean leaving the family. It is our obligation as occupational therapists to view families as the main social and cultural context of their children with disabilities living in the institution. Only in that way will therapists succeed in designing effective interventions focused on family needs and encouraging parental involvement.
References


