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Normative or Heavy Clouds? Early Indicators of Nonverbal Learning Disability Based on Mothers’ Reports

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Normative or Heavy Clouds? Early Indicators of Nonverbal Learning Disability Based on Mothers’ Reports

Abstract
Background: Children with Nonverbal Learning Disabilities (NVLD) are verbally competent and particularly weak in nonverbal, visuospatial, and social abilities. Most of the literature about NVLD discusses the all-around functioning and diagnosis process during school years. In this qualitative study, the perceptions of mothers of children with NVLD were explored in the context of their children's daily functioning characteristics during their first 3 years. The aim was to identify early indicators and warning signs of NVLD during the developmental process.

Method: Five mothers participated in two in-depth, semi-structured retrospective interviews.

Results: Two main themes were identified: (a) “Everything was so normal,” which revealed normal development in the first year, and (b) “The era of heavy clouds,” which revealed warning signs at the age of 2 to 3 years. Developmental profile similarities and unique individual characteristics were identified and highlighted, and the effects on daily occupations and social interactions during early childhood were revealed. The findings support the need for in-depth evaluation and early identification in the crucial developmental preschool years.

Conclusions: A deeper understanding of the nature and uniqueness of a significant learning disability like NVLD and its vast impact on a child’s functioning and participation limitations may assist health care practitioners to adapt and provide suitable interventions.

Comments
The authors report no conflicts of interest to disclose.

Keywords
developmental continuum, nonverbal learning disability, qualitative research, warning signs

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This applied research is available in The Open Journal of Occupational Therapy: https://scholarworks.wmich.edu/ojot/vol6/iss2/3
Nonverbal Learning Disabilities (NVLD) has been described as a subtype of learning disabilities (Pennington, 2009). Data on the prevalence of NVLD is lacking, yet it is estimated that 5% to 10% of clinical populations present with NVLD (Davis & Broitman, 2011). Children in this subgroup are verbally competent and have the expected basic language and reading skills for their age range. However, they are particularly weak in nonverbal, visuospatial, and social abilities, which results in severe adaptive and learning difficulties (Mammarella & Cornoldi, 2014; Pennington, 2009).

Diagnosing NVLD is problematic and challenging because there is a lack of worldwide consensus regarding the diagnosis criteria (Mammarella & Cornoldi, 2014; Yalof, 2006). NVLD is not recognized or included in any formal diagnostic manual or guideline (Broitman & Davis, 2013; Fine, Semrud-Clikeman, Bledsoe, & Musielak, 2013). The limited awareness of NVLD means that these children are frequently misdiagnosed in their younger years (Tanguay, 2001) or are often diagnosed only late in childhood, when they encounter difficulties in their academic achievements at school (Mammarella & Cornoldi, 2014). In some cases, these children may not be diagnosed at all or may receive numerous mistaken diagnoses, such as a general diagnosis of learning disabilities (LD), LD not otherwise specified, dyscalculia, social-emotional disorder, or Asperger’s syndrome, all of which have similarities to certain symptoms of NVLD (Ghaziuddin, 2010; Yalof, 2006). The diagnosis complexity and the lack of understanding of the cause of the atypical behavior results in much suffering for these children and their families (Hagai, 2005). Identifying NVLD as early as possible is critical given that the absence of an accurate diagnosis could create unrealistic demands and expectations of the child and lead to negative emotional cycles and implementation of inefficient intervention programs (Little, 1999; Thompson, 1997).

Because of the diagnosis complexity (Fine, 2013; Hagai, 2005), identification of early warning signs may assist in early diagnoses of these children and help direct early, suitable, and promoting interventions. Much of the knowledge concerning the diagnosis and development of children with NVLD derives solely from clinical impressions (Fine, 2013). Most literature related to the developmental characteristics of NVLD focuses on school-aged children and adolescence (Palombo, 2006; Petti, Voelker, Shore, & Hayman-Abello, 2003; Rourke, 1995) and devotes less attention to infancy and early childhood (Palombo, 2006; Thompson, 1997). Research describes difficulties in visual-spatial, academic, and social skills. These difficulties are usually identified in the context of problems that occur in school or by comparison with typical peers (Fine et al., 2013). Yet, Davis and Broitman (2011) acknowledged that our understanding of the early signs of NVLD is limited and that further clinical research is required.

Early signs in the first 2 years of childhood have been described in the literature predominantly in the motor developmental domain, including difficulties in gross and fine motor skills, balance development, and lack of coordination (Johnson, 1987; Rourke, 1995; Thompson, 1997). Davis and Broitman (2011) described advanced cognitive development during the preschool years, apart from difficulty in making sense of experiences involving nonverbal skills. In addition, these children tend to overfocus on particular tasks and verbally label everything (Johnson, 1987; Rourke, 1995). They also have a unique memorization and verbatim ability (Thompson, 1997), an “adult-like” speech, and an early acquisition of reading skills. However, difficulties in interpersonal communication are evident, and they prefer socializing with one friend rather than with a group. Despite the children’s high-level verbal abilities, social communication difficulties can cause confusion among their parents (Davis & Broitman, 2011; Thompson, 1997). Hence, these children’s strengths during their first 3 years of development are mainly described in the cognitive and language domains. However, their weaknesses are...
concealed in the motor and spatial developmental domains and the sensory and emotional domains. Toward the later part of their first 3 years, the interpersonal and socialization difficulties begin to manifest.

According to the family-centered conceptual approach, parents are considered experts about their children and their needs (Rosenbaum, King, Law, King, & Evans, 1998). They are a meaningful factor in their children’s development and, aside from clinicians, may be a valuable source of information for promoting diagnosis in the early years. Park (2012) describes engaging in conversation with adults who spend the most time with the child to be the most common method to discover concerns about children. Also, obtaining information from parents is important to gain a profound understanding of children’s difficulties and how these difficulties affect the daily functioning of children and their families (Rosenbaum et al., 1998).

Moreover, use of the mothers’ own words can assist in authentically describing experiences (Degotardi, Torr, & Cross, 2008). However, existing literature about parents of children with NVLD focuses mainly on the parents’ emotional stress (Antshel & Guy-Ronald, 2006; Little, 2002) and their concerns with and pleasure in raising a child with these difficulties (Little & Clark, 2006). Information about daily function characteristics of children with NVLD is scarce, although it may possibly contain valuable evidence and represent the early signs of their diagnosis. Qualitative study, including in-depth interviews, has been suggested as a possible approach to obtain a profound picture of the uniqueness of NVLD. Interviews can supply a deep understanding of a parent’s personal experience of raising a child with NVLD (Dillaway et al., 2006; Fontana & Frey, 2000).

Despite the apparent contribution of a mother’s memories of early-year experiences of her child’s daily life across the developmental timeline, no such research focused on early warning signs concerning the daily function characteristics has been found. Thus, the purpose of this qualitative study was to explore, retrospectively, the developmental milestones and warning signs of children with NVLD via their mothers’ perspectives related to their children’s daily functioning characteristics during their first 3 years.

Method

Qualitative methods are a natural choice for understanding the complexity of occupation (Corcoran, 2005). In this study, a qualitative-phenomenological research design was implemented. Phenomenological research is a qualitative strategy in which the researcher identifies the essence of human experiences about phenomenon as described by participants in a study (Creswell, 2013). Mothers were chosen to be interviewed for this study, as they represent the most knowledgeable informants (Corcoran, 2005). Because of the complexity of locating children with NVLD, we invested effort in finding this hard-to-reach sample of mothers who can restore the memory of their children’s developmental events. According to this purposeful sample method, each informant illustratively represents the explored phenomenon and each participant was analyzed as a unique case (Mason, 2002). Phenomenological research is based on a limited number of informants, ranging from five and up, that best represent the population and who are considered “information rich.” Depth is traded for representativeness without claiming to generalize the conclusions of the entire population (Creswell, 2007; Patton, 2002). In the current study, five interviewees provided sufficiently rich information. Approval for the study was obtained from the institutional ethics committee.

Participants

Five mothers of children aged 6 to 15 years diagnosed with NVLD by a developmental neurologist or a clinical psychologist participated in the study. Five potential mothers were initially contacted by the second author via other health professionals (doctors, occupational
therapists, psychologists, etc.). The primary inclusion criteria for the mothers ensured a high verbal expressive level required to phrase memories, perceptions, and experiences in addition to the ability to endure a thorough and in-depth interview. The subject and purpose of the study were described to the mothers and they were asked to participate. All five of the mothers we approached agreed to participate. Signed consent was obtained and confidentiality and the possibility to withdraw from the study at any stage were assured. All of the mothers were fluent in the Hebrew language with a minimum of 12 years of education that ensured a high verbal expressive level required to phrase memories, perceptions, and experiences in addition to the ability to endure a thorough and in-depth interview. All of the mothers were aged 35 to 48 years, were Israeli born, and lived in the northern region of the country.

Table 1 summarizes the mothers’ demographic characteristics. All names were changed to prevent identification. Their children’s characteristics are presented in Table 2. The children were all boys aged 5 to 13 years.

Table 1  
**Mothers’ Demographic Characteristics**

<table>
<thead>
<tr>
<th>Mother of Birth Year</th>
<th>Education</th>
<th>Occupation</th>
<th>Marital status + number of children</th>
<th>Residence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ophir 1973</td>
<td>Master’s degree</td>
<td>Housewife</td>
<td>Married +2</td>
<td>City</td>
</tr>
<tr>
<td>Adi 1960</td>
<td>Bachelor’s degree</td>
<td>Allied health profession</td>
<td>Married +3</td>
<td>Moshav (cooperative community)</td>
</tr>
<tr>
<td>Itai 1970</td>
<td>Master’s degree</td>
<td>Lawyer</td>
<td>Married +3</td>
<td>Community settlement</td>
</tr>
<tr>
<td>Tom 1967</td>
<td>Bachelor’s degree</td>
<td>Allied health profession</td>
<td>Married +3</td>
<td>Community settlement</td>
</tr>
<tr>
<td>Idan 1965</td>
<td>Bachelor’s degree</td>
<td>Allied health profession</td>
<td>Married +3</td>
<td>Community settlement</td>
</tr>
</tbody>
</table>

Table 2  
**Children’s Demographic Characteristics**

<table>
<thead>
<tr>
<th>Child’s Name</th>
<th>Birth year</th>
<th>Birth order</th>
<th>School framework</th>
<th>Age of DX</th>
<th>Professional DX</th>
<th>Therapies</th>
<th>Additional DX</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ophir</td>
<td>1999</td>
<td>1st</td>
<td>Elementary (accompanied by teaching aid)</td>
<td>5</td>
<td>Neurologist</td>
<td>Occupational therapy Speech therapy Emotional therapy</td>
<td>ADHD with medication since 5 yrs old</td>
</tr>
<tr>
<td>Adi</td>
<td>1998</td>
<td>2nd</td>
<td>Elementary (assistance from special ed. teacher)</td>
<td>8</td>
<td>Neurologist</td>
<td>Occupational therapy Emotional therapy</td>
<td>ADHD with medication since 7 yrs old</td>
</tr>
<tr>
<td>Itai</td>
<td>2001</td>
<td>1st</td>
<td>Elementary (assistance from special ed. teacher)</td>
<td>9</td>
<td>Clinical psychologist</td>
<td>Occupational therapy</td>
<td></td>
</tr>
<tr>
<td>Tom</td>
<td>1996</td>
<td>1st</td>
<td>Elementary</td>
<td>9</td>
<td>Clinical psychologist</td>
<td>Occupational therapy Emotional therapy</td>
<td></td>
</tr>
<tr>
<td>Idan</td>
<td>1992</td>
<td>1st</td>
<td>Private Middle school</td>
<td>13</td>
<td>Clinical psychologist</td>
<td>Occupational therapy Emotional therapy</td>
<td>ADHD with medication since 7 yrs old</td>
</tr>
</tbody>
</table>

*Note. DX = diagnosis.*
Procedure

The mothers were contacted via doctors, occupational therapists, and psychologists. Written informed consent was obtained from all of the mothers included in the study. Each mother completed a demographic questionnaire containing questions about herself and about her child.

The second author conducted two in-depth interviews in Hebrew with each mother in the participant’s natural home environment (Corcoran, 2005). The 1.5 to 2 hr interviews were semi-structured and directed by an interview guide that enabled comparison between the interviews (Laliberte-Rudman & Moll, 2001; Spradley, 1979). During the first interview, open-ended questions were used to generate the mother’s memories of her child’s daily life experiences. The interview guide, which was originally written in Hebrew and translated into English for publication (see Appendix), embarked with general questions about the child’s development and gradually progressed to focus on infancy (first year) and early childhood (second and third year) characteristics. Strengths and weaknesses were emphasized and the way in which they manifested in activities of daily living, such as self-care, play, and social life, and in learning in various environments, such as the home and pre-school. The second interview, which took place 2 to 4 weeks after the first, included more detailed questions, the completion of missing information, clarification, and elucidation of discussions using questions directly related to subjects and events initially mentioned. The interviews were audio-recorded and transcribed verbatim.

Analysis

The entire analysis process was conducted in Hebrew to maintain the meaning of the original interviews. The transcripts included in this paper were translated at the final stage. Data were organized into major themes and sub-themes using an inductive content analysis procedure (Patton, 2002; Shkedi, 2003). The initial analysis included longitudinal classification of content appearing in all interviews, followed by segmentation according to expressed meanings in psychological and phenomenological concepts (main categories) and finally formation of main themes. Coding was performed by an integrative and recurring process, where each interview was coded according to the previous analysis as a base for identification of new categories or exclusion of previous categories. Finally, the sub-categories were combined into main themes. As three of the children were diagnosed with ADHD, only themes common to all five mothers are presented. To avoid bias and ensure reliability, we performed triangulation of data from the interviews allowing clarifications and deepening of issues. Triangulation is the comparison of information obtained by a number of sources that is related to the same data in order to allow the researcher to view the phenomenon from different angles (Corcoran, 2005). In this study, triangulation was performed by (a) comparison between the interviews; (b) comparison of data to available literature; and (c) comparison of data with a reflective journal written by the second author that included the researcher’s experiences, thoughts, and feelings during the research process (Roller & Lavrakas, 2015).

In addition, four experienced pediatric occupational therapists performed an expert audit of the various stages of data analysis. Finally, a thick description using quotations of the mothers’ narratives reinforced the credibility of the data analysis. A thick description specifies many details and conceptual structures and meanings, as opposed to a thin description, which is a factual account without any interpretation (Geertz, 1973). In addition, peer debriefing was incorporated to enhance the accuracy of the analysis (Creswell, 2013). Two experienced pediatric occupational therapists reviewed the analysis process, the main results, and the interpretations.

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Results

Analysis of the interviews and observations identified two themes related to the developmental continuum of the child with NVLD: (a) Infancy: “Everything was so normal,” revealed the mothers’ perceptions and experiences of their children’s development and interaction in the first year of life and (b) Early childhood, 2 to 3 years: “The era of the heavy clouds” revealed the mothers’ first experiences of milestones and of warning signs. This manifested in developmental gaps and was particularly noticeable around the child’s introduction to the external social world.

Infancy: “Everything was so Normal”

All five mothers described their babies as vital and communicative and as having made good infant-mother and infant-environment connection during their first year of infancy. The infant-mother interaction was described positively, filled with warmth and love, communication, bonding games, and mutual enjoyment. Comments such as “good relationship,” “excellent connection,” and “I never got tired of him,” expressed this bonding experience. Three of the mothers described their sons’ strengths as being happy and joyful babies. Phrases such as “smiley and loved” and “sociable and happy,” expressed the babies’ vitality and the mothers’ sense of felt contentment. Daily life during infancy was described by three of the mothers as “comfortable and flowing.” Itai’s mother’s description was the most powerful among the five mothers. She described a comfortable, flowing, flexible, and even ideal upbringing of her son: “He could have been taken anywhere. We travelled all over the world with him, happily. He was just adorable . . . he slept regularly, regular diaper changes, feeding habits, satisfied, happy, no crying.”

All five of the mothers reported normative sensory motor development, although four of them argued that this normal development was bound with certain limitations. Ophir’s mother discussed how her son disliked lying on his stomach. Itai’s mother spoke about his delayed crawling and walking and that he was hypotonic. Tom’s mother reported typical sensorimotor development at 1 year of age, apart from him not waving goodbye and clapping hands. Idan’s mother noticed slow development.

All five of the mothers were satisfied with their child’s language development and described the environment exploration as normative during infancy. Idan’s mother used the word “normative,” Ophir’s mother described it as “expected from a baby,” and Adi’s mother experienced her child as “interested and inquisitive.” The remaining two mothers described their sons’ exploration of their environment as normative but different. For example, Itai’s mother said he explored with his eyes more than with his hands.

In summary, during the first year of life, none of the children aroused their mothers’ concerns. Each mother described her baby as communicative, able to form a relationship with his environment, and as having typical speech development. And they expressed the enjoyment of raising their child.

Early Childhood, 2 to 3 years: “The Era of the Heavy Clouds”

Contrary to the mothers’ impressions during the first year of life, all five of them reported warning signs regarding their children around the age of 2 to 3 years that began to flash on two separate levels.

The first level was the actual development process characterized by a gap between observed delayed gross and fine motor skills and good cognitive development related to verbal and auditory functions. All of the mothers mentioned an emerging gap between planning and executing motor activities, which resulted in frustration and avoidance of play performance. These difficulties began to show signs in gross motor skills, threading beads, building blocks, and games and drawing. Ophir’s mother spoke about how her son hated going to the playground, and Idan’s mother stated:
“He didn’t enjoy ball games and motor challenges.” Itai’s mother shared how the gaps in her son’s play behavior expressed the difference between her son and his peers: “The extremity, seeing children really sitting down and doing something and he didn’t touch anything. He wasn’t interested in building with blocks or joining a puzzle.”

Of interest is that all but one of the mothers did not identify decreased imaginary play as a warning sign at the time. Ophir’s mother described how his imaginary play concerned her because he showed no interest in playing imaginary games in his early years and only began to show an interest at around the age of 5. Idan’s mother described how this developmental process level expressed the gap, stating that the one domain developed surprisingly well while another domain was of concern:

There was a huge difference between his exceptional verbal development and his playing skills…it was of concern. I saw a problem with playing skills, I saw difficulty with blocks and circles, he would just lift the lid and put the blocks inside the box and close it, on the other hand, his verbal domain flowed extraordinarily. I mean…it really surprised us.

These differences caused confusion and concern as expressed by Idan’s mother, who named the early childhood years “the era of the heavy clouds” when she could not understand whether her son was a “genius-retard or a retard-genius.”

Difficulty in playing was emphasized in comparison to the higher verbal ability and the gap between the domains. Indeed, all of the mothers commended their children’s love of songs, stories, and music, and their children’s highly developed cognitive abilities. They all referred to the auditory and verbal aspect including “remembering words of songs,” as described by Ophir’s mother, and “making up new words for songs and really nice phrases,” as described by Adi’s mother. Although both mothers reported a language delay and sentence formation only at the age of 2 to 3 years, each still perceived this area as one of her child’s strengths.

The second level was the children’s encounters, especially when outside of the home environment, with other children and during non-routine situations, which began around the age of 2 to 3 years when the children began attending daycare. Identified warning signs at this stage were evident when participation with peers and in age-related complex activities begin to develop. Most of the mothers described difficulty adjusting to the framework with peers. Three of the mothers described a general lack of participation in daycare activities and displayed avoidance. Ophir’s mother said that her son used to “walk around” and “not really do anything.” Tom’s mother described how her son did not participate in activities and “most of the time lay down on the mattress.”

The three mothers described almost no participation in daycare activities, which caused a clear functional gap between their children and their peers. Ophir’s mother, together with two other mothers, described her child’s difficulty during this period in life when going to social events and activities, such as extracurricular activities, daycare events, birthday parties, and family events:

Birthday parties were a nightmare…and daycare events. I would return home crying because he didn’t participate, he sat on my lap, close to me and didn’t move … a shopping mall for a child like this at that age, it is a punishment! It’s like an amusement park…he doesn’t know where to look first. Firstly, he runs, runs away from us, gets lost, when we call him back and pull his arm, then he lies down on the floor…then we quickly pick him up in our arms and straight home. Do you understand? A nightmare!

Ophir’s mother’s words are evidence of the significant difficulty in going out to crowded events, such as birthday parties, that combine the need to process sensory and spatial information and to understand the social situation with the desire to participate. The difficulties described during
encounters with children outside of the home setting created a similar situation among most of the children, who preferred the home environment to going to the mall, participating in events, and spending time with friends. Most of the mothers described home as the optimal environment. Idan’s mother used the expression “My home is my castle.”

Ophir and Adi’s mothers spoke about having very few playdates in the afternoons during the early years. When they did occur, their children preferred to have other children over to their own homes. In addition, two mothers, Idan’s and Itai’s, began noticing first signs of social difficulties. They noticed that their children did not know how to respond when another child would grab their toys or hit them and that they used to refrain from playing in a group.

Along with these complex encounters in the daycare environment, warning signs began appearing during non-routine situations and social events. Two of the mothers described varied levels of difficulties during schedule changes. Tom’s mother spoke about the need for preparation before any change in the daily routine. Moreover, Ophir’s mother described how changes in routine required major and deep preparation, and that daily life flow was impossible.

Although each mother drew a unique picture of her son’s development, the descriptions created a similar characteristic developmental profile of the children in this study. No significant concern occurred among the mothers during infancy. However, between infancy and the age of three, warning signs began to appear when the gap between motor and verbal performance became evident during the children’s encounters outside of the home environment.

**Discussion**

The purpose of this study was to broaden the existing knowledge of NVLD through the retrospective memories and perceptions of mothers concerning the developmental continuum of their children during infancy and their first 3 years as seen specifically in their children’s daily functional events. The results present a typical similar developmental profile characteristic of the five participating children from their first year of infancy to their third year of childhood.

The results shed new light on a period rarely mentioned in the NVLD literature. The unique glance into the mothers’ memories portrays the first year experienced as normal; all of the mothers experienced a reciprocal and enjoyable relationship with their babies. The children’s motor development was accompanied by slight reservations alongside the normal verbal development that was even earlier than expected. The results revealed in the interviews are supported by the available NVLD literature that describes normal or advanced verbal development in the first years and on-time acquisition of first motor milestones (Rourke, 1995; Thompson, 1997).

The following 2 years, however, were characterized as a period when all of the mothers remembered the appearance of warning signs in the developmental functional domain and more so during encounters outside of the home environment. In addition to describing a lack of an ability to play, the mothers described the children’s good verbal development and stated their confusion facing the gaps between strengths and weaknesses in their children’s development. The available NVLD literature supports these memories. Thompson (1997) and Rourke (1995) claimed that gaps between motor function and verbal development begin to appear at this age when children begin building games and puzzles and when they encounter more complex motor functioning that requires bilateral coordination. Yet, the literature does not mention the specific age when these problems begin to appear, and it does not provide information concerning the full span of influence on children’s participation in various occupations and environments. These mothers’ memories highlight the early position on the children’s developmental timeline.

The appearance of social difficulties around preschool age (Palombo, 2006) and in social perception (Fine et al., 2013) has also been described. However, the results of this study raise two
novel aspects not yet discussed. First, the ages of 2 to 3 years as the timeline in which difficulties began to surface and arouse the mothers’ concerns. Second, the wide scope of the children’s non-participation in environments outside of the home.

These results raise the question of why these significantly lower participation characteristics were evident to the mothers compared to other children specifically between the ages of 2 to 3 years. Despite the literature not directly discussing NVLD at this age, this stage is associated with many significant developmental achievements. At this age, the child develops independent investigation of the environment that is driven by natural curiosity, forms independent ideas and initiation, and develops a sense of self-efficiency characterized by multiple experiences and the feeling of control (Bandura, 1986; Erikson, 1963; Sroufe et al., 1996). Also, social relationships with peers develop significantly. Social encounters and friendships with peers increase and include cooperation, mutual help and competitiveness, and aggression and disputes (Sohlberg; 2007; Sroufe et al., 1996). The mothers noted that their children already had difficulties at this stage and tended to avoid a wide range of gross and fine motor games. This may possibly have compromised their ability to gain independent investigation of their environment. Furthermore, this avoidance may possibly negatively affect these children’s future social well-being. Loneliness, fewer social contacts, and psychological distress can occur when children withdraw from social games involving motor activities (Missiuna et al., 2014; Poulsen Ziviani, Cuskelley, & Smith, 2007). Mothers also described difficulty obtaining developmental milestones via environment investigation and joining peer groups that resulted in an almost complete lack of participation, particularly in the preschool and social environments.

Participation is defined as involvement in life situations with positive effects on health and well-being. Participation in daily activities is an integral part of child development, and a child’s participation in typical preschool activities affects health, self-esteem, and social adaptation (Bouffard, Watkinson, Thompson, Causgrove-Dunn, & Romanow, 1996; Mandich, Polatajko, & Rodger, 2003; Smyth & Anderson, 2000; WHO, 2001). Moreover, social participation is defined as one of the meaningful and valued life occupations that bring purpose to life (AOTA, 2014).

The results of this study do not clearly explain the reasons that caused inadequate participation at such a young age. It is unclear as to whether the reasons lie in the motor difficulties; in the organizational deficits; or in a lack of visuospatial abilities, social skills, or a combination of all aspects. This finding, revealed by the mothers’ recollections of their children’s daily functioning, provides a new dimension to the meaning of the children’s difficulties at a young age and the need for early identification.

In addition to reporting their children’s limited preschool participation, three of the mothers reported a lack of participation in social encounters, such as birthday parties and going to new places. These findings are supported by literature describing the difficulties of children with NVLD at trying unfamiliar situations, such as new games, places, and people (Harnadek & Rourke, 1994). The literature attempts to explain the reasons based on the children’s difficulty in processing emotional experiences, learning from past experiences, and projecting them to the future, as well as their difficulty in organizing episodic knowledge, declarative knowledge, or procedural knowledge (Lamberts & Shanks, 1997; Voeller, 1986).

**Limitations and Future Research**

This study has some limitations, and caution is required in generalizing the results to the entire NVLD population. This study investigated only the mothers’ retrospective perceptions about their sons in a wide age range. Furthermore, three of the children in the study were diagnosed with ADHD. This diagnosis may hinder isolation of the child’s difficulties caused specifically by NVLD. Nevertheless, comorbidity between NVLD and ADHD has been found (Palombo, 2006) and this
additional diagnosis characterizes the children with NVLD. An additional limitation is the lack of agreement concerning the diagnoses of NVLD. The participating children were diagnosed by professionals considered experts in the field. Yet, there is no knowledge of the measures and criteria used for the diagnosis that might explain the lack of agreement concerning the diagnoses. It is presumed that the measures were not uniform. Nonetheless, it is important to note that this is a general limitation that characterizes the complexity of a NVLD diagnosis at this stage of knowledge development in the field and is not specific to this study alone. This is a primary study in occupational therapy concerning NVLD and additional research is recommended to further ground the results. Future research should include a larger sample that represents both girls and boys of different ages. Beyond larger samples, future research should incorporate quantitative and qualitative research methods to convey the experiences and to deepen the understanding not only of the behavior observed but also of the perceived reasons for the behavior.

**Conclusion**

The results of this study show that the NVLD characteristics of the children in this study began impacting their social participation in preschool activities during non-routine events starting at 2 to 3 years of age. These findings support the considerable need for in-depth evaluation and early identification of deficient participation in the preschool years and the accompanying anguish that may occur during these crucial and significant years in establishing independence, social competence, and self-esteem (Sroufe et al., 1996).

**Implications for Occupational Therapy Practice and Research**

This study is a stepping stone in the investigation of NVLD and shows how NVLD shapes all daily occupations during early childhood. The disorder significantly impacts social and learning daily functioning. Therefore, this study reinforces the need to develop awareness among parents, educators, and therapists about the nature and uniqueness of NVLD and the vast affect it has on a child’s daily functioning in early childhood and its possible implications on functioning in later years. The scope of occupational therapy includes all skills that contribute to daily functioning, such as executive functioning skills, organizational and sensorimotor abilities, and social skills (AOTA, 2014). The social skills enable social participation that support engagement in social situations with peers, friends, family, and the community beginning in childhood and continuing throughout the lifespan (AOTA, 2014).

Therefore, occupational therapy intervention can significantly assist in providing care for these children. Because of the multifaceted benefits of occupational therapy intervention, achievement of client-centered intervention goals aimed to promote participation (AOTA, 2014) may help children with such a significant learning disability as NVLD to integrate well into everyday life and social activities, thereby improving their quality of life.

Suggested highlights for assessment and intervention include:

- Thorough assessment of the child’s strengths and challenges.
- Individual and group therapy performed in various environments.
- Focus on a range of client-centered occupations while building on the child’s strengths.
- Communication with parents and other caregivers and team members.
- Provide parents with tools and strategies to improve daily functioning and quality of life in the early years and later.

**References**


Little, L., & Clark, R. R. (2006). Wonders and worries of parenting a child with Asperger syndrome...


Appendix

Interview guide

First interview:

General
- Tell me about your child (including pregnancy and birth history)
- Main characteristics of your child
- When did you begin to recognize a problem?
- When was your child diagnosed with NVLD, and by whom?

Specific questions asked during the first and/or second interview, following the responses to the general questions:

Infancy
- How was your child as an infant? (sleeping habits, eating, transitions, modulation, attitude toward people, attitude toward objects)
- What was your daily life like? (Flexibility, wake-sleep, food, transitions, routines)
- How did you experience your relationship with him as a baby?
- How did he connect with other people? Family members? Friends? What characterized the people he connected with?
- How did he play? (investigative play with objects, interactive play with an adult and with a child or sibling)
- What were his favorite things? And what did he dislike most?
- What were his strengths and weaknesses as a baby?
- What environment enabled him to function optimally or minimally?
- Looking back, did you see warning signs during infancy? If so, what were they?

Childhood
- Describe how your child integrated into preschool (what was difficult/easy, social integration, academic integration)
- Describe your daily schedule and routine when your child began going to preschool.
- What characterized your child’s play and leisure time?
- What characterized your child’s play (at home, with a parent, with a friend at home or preschool)?
- What made you worry most at that time? Did you see red flags?
- What satisfied and gave a good feeling to your child?
- What were the things your child liked/disliked most?
- What were your child’s strengths and weaknesses as a toddler/child?
- What environment enabled your child the best/worst functioning?

School
- How was beginning first grade?
- How does your child manage at school today (academically and socially)?
- What characterized your child’s leisure time?
- What environment enables your child the best/worst functioning?
- What characterized your child’s play (what does your child play with, with whom)?
- How does the professional help you received over the years reflect today?
- What worries you most today?
- What are your concerns about the future?
- If a mother of a child recently diagnosed with NVLD asked you to describe what it means to be a mother of a child like that, what would you say?
- Looking back, are there things you would do differently? What would you tell parents? Therapists? Educators?