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Inclusion of Preschoolers With Intellectual Disabilities in Organized Social Activities

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Abstract

Inclusion of young children with intellectual disabilities (ID) in organized social activities has received relatively little attention in the literature to date. Twenty-one parents of children with or at risk for ID were interviewed during their child's transition into school. Information from the first time point (pre-school entry) indicated that respite service use was the only variable that predicted participation in social activities. Family income and parental education level were also positively correlated with their child's participation in social activities. Parents of children who participated in social activities reported being more satisfied with their child's quality of life. Directions for future research are discussed.

Proponents of inclusion have argued that integration of people with intellectual disabilities (ID) is not only ideal, but should be considered the only option. Clearly, for integration to occur, people with ID need opportunities to interact with their typically developing peers. Although there has been considerable research focusing on the integration of adults and adolescents with ID in a number of domains, including recreational and social activities (Abbott & McConkey, 2006; Gardner & Carran, 2005; Myers, Ager, Kerr, & Myles, 1998), research concerning children has focused largely on school and preschool inclusion (Guralnick, Connor, Hammond, Gottmane, & Kinnish, 1996; Meyer, 2001; Odom, Zercher, Li, Marquart, Sandall, & Brown, 2006).

It is reported that, even as preschoolers, children with ID have difficulties forming and maintaining appropriate peer relationships (Guralnick, 1999). While it cannot be guaranteed that exposure to typically developing peers will lead to the formation of friendships, inclusion in social activities is still the goal (Odom, 2000). One would expect that children with ID would benefit the most if opportunities for inclusion in all areas of life could be provided as early as possible. One of the few studies examining variables associated with successful transition for children with ID found that social skills was a key variable in predicting outcome (McIntyre, Blacher, & Baker, 2006). It is felt that inclusion in social activities may be beneficial for the development of social skills, which may facilitate the transition to school. Although inclusion is generally the case in academic settings, it is not clear if inclusion of young children with ID in extracurricular or organized social activities is the norm.

A recent study examining school-aged children and adolescents with ID in Ontario found that the vast majority were participating in organized social activities and were rated as integrated, meaning that their needs were identified and supported in a way that promoted community participation (Solish, Minnes, & Kupferschmidt, 2003). Although the children were supported in these activities, the majority were receiving support from their caregiver alone or their caregiver and a paid worker. While this study found that the children were considered to be integrated in organized social activities, many were not socially integrated, meaning that they did not have many close friends or did not spend much time with close friends. The authors concluded that the distinction between physical integration and social integration is an important one, since it is clear that physical proximity alone does not lead to social interactions with peers.

The present study examined the integration and inclusion of preschool aged children in organized social activities. Demographic information about the number of children participating in activities and the types of activities, as well as information about potential barriers to participation and correlates with social participation will be presented.

Method

Participants

Parents were recruited through information packages sent by nine agencies serving children with ID in South Eastern Ontario on behalf of the research team, as well as through a newspaper article announcing the study. Of the 120 packages sent, twenty-one parents of children with intellectual disabilities (ID) or at risk for ID (i.e., children with developmental delay or deficits in two or more areas of functioning) who were entering school for the first time in September 2006 (20 mothers, 1 father; Mean age = 34.06 years, *SD*=6.77) were included in this study. Their children included 6 girls and 15 boys ranging in age from 43 to 67 months (*M*=55.57 months, *SD*=7.58), with diagnoses such as autism spectrum disorders (57%), Down syndrome (5%), developmental delay (29%), Rett disorder (5%), cerebral palsy (5%) and several other neurodevelopmental disorders (19%).

Procedure

This project was approved by the General Research Ethics Board at Queen's University. Caregivers of children with ID voluntarily participated in three one-hour telephone interviews with the first author as part of a longitudinal study of the transition into school for children with ID. Although the parents were interviewed at three separate times throughout the transition into school, only data from the first time point, (i.e., the summer before school started), will be used in the current analyses.

Measures

Demographic information. Parents provided demographic information pertaining to the child (i.e., date of birth, sex, diagnosis) and the family (i.e., household income, parental education) during the interview.

Scales of Independent Behaviour-Revised Early Development Form (SIB-R EDF; Bruininks, Woodcock, Weatherman, & Hill, 1996). The SIB-R EDF was used to assess adaptive and maladaptive behaviour. The age equivalent adaptive behaviour score and the general maladaptive index, which combines the internalizing, externalizing and asocial domains, were used to measure adaptive and maladaptive behaviour respectively. The SIB-R has been standardized on a normative population which included a sample of children with ID.

Services and supports questionnaire. This measure was developed for use in this study (Clifford, 2007). The questionnaire includes a list of direct services which are often available to young children with ID and their families (e.g., daycare, speech therapy, respite services, parent support groups), and thus has face validity. Parents were asked about current use of the services as well as to rate satisfaction with each service on a 5-point Likert scale ranging from 1 (very unsatisfied) to 5 (very satisfied).

AIMS Interview-Child Version (AIMS; Minnes, Buell, & Solish, 2005). The AIMS Interview is a measure of community integration from an acculturation perspective. Information about whether needs are identified and supported in a way that facilitates community participation is used to identify an individual as assimilated, integrated, marginalized or segregated. (For a more complete explanation of the AIMS Interview see Minnes, Buell, Feldman, McColl, & McCreary, 2002). Research to date indicates that the AIMS Interview, when used with adults with ID, has sound psychometric properties (i.e., discriminant and concurrent validity; Minnes, et al., 2002). Data gathered in pilot studies of children with ID and acquired brain injuries (Alvarez, Minnes & Benn, 2003; Solish et al., 2003) has demonstrated good face and content validity and inter-rater reliability.

Quality of Life for Children With Developmental Disabilities (QOL-C; Renwick et al., 2002). The QOL-C questionnaire, developed for parents of children with ID, was used to provide a measure of overall quality of life. The questionnaire includes 60 statements in three domains: (1) Being (i.e., the person the child is perceived to be), (2) Belonging (i.e., the child's connections to people and places), and (3) Becoming (i.e., how the child's growth and development is nurtured). Following each statement, the parent is asked to answer three questions; 1) "How much does this statement apply to your child's situation right now?"; 2) "How important is this for your child?"; and 3) "How satisfied are you with the way things are?"; by choosing an appropriate response from a 5 point Likert scale from (1) not at all to (5) extremely. Scores of overall satisfaction in each domain (i.e., Being, Belonging and Becoming) were calculated. Due to self-report nature of this questionnaire it was sent to parents by mail for self-administration following the interview.

Results

The twenty-one families included in this study varied in socioeconomic status. Although the majority of participants (42.9%) indicated their annual household income to be less than $25,000, 14.3% indicated their income to be over $95,000, and the other 42.8% ranged between $25,000 and $65,000. In terms of parental education, 90.5% had at least a high school diploma, while 71.4% had a post secondary degree or diploma (college 52.4%; university 9.5%; professional degree 9.5%). The families were using a number of supports and services including daycare/preschool (100%), speech therapy (90.4%), respite services (42.9%) and parent support groups (52.4%). The children were functioning below their chronological age although they did not have many problems with maladaptive behaviour (Table 1, page 14). Generally, the parents reported satisfaction with their child's quality of life in all three domains measured (Table 2).

Table 1. Descriptive Statistics for SIB-R Adaptive and Maladaptive Behaviour

Variable	*Mean*	*SD*
Chronological Age (months)	55.57	7.58
Adaptive Behaviour Age Equivalent (months)	36.19	16.53
General Maladaptive Index	-13.10 [a]	8.24

[a]This score falls within the "Marginally Serious" range.

Table 2. Mean Satisfaction in Quality of Life Domains

Domain	*Mean*	*SD*
The person your child is perceived to be [a]	3.60	0.74
Your child's connections to people and places [b]	3.54	0.46
How your child's growth and development is nurtured [c]	3.68	0.57

Note. Scores reflect parents mean rating of satisfaction within each domain based on a 5-point scale (1 = not at all satisfied to 5 = extremely satisfied).
[a] "Being", [b] "Belonging", [c] "Becoming"

Participation in Social Activities

Information was initially collected to categorize each child in one of the four modes of acculturation. The majority of children with ID were marginalized, or not participating in organized social activities (*n*=13), and so children who did participate in activities were grouped together, regardless of whether participation was rated as integrated, segregated, or assimilated (*n*=8). This grouping did not change the relationship between variables, although it did provide more power since there were fewer groups. The children who did participate in social activities engaged in activities such as swimming, gymnastics, horseback riding, dance/music classes, and a few team sports (e.g., hockey, soccer). Seven of the 13 parents who reported that their child was not participating in organized social activity indicated the main reason to be lack of availability of one-to-one support, while 4 parents stated it was for financial reasons.

Predictors of Participation in Social Activities

The child's level of functioning (i.e., adaptive and maladaptive behaviour) was not correlated with participation in social activities. Adaptive behaviour was negatively correlated with respite service use (r=-.505, p<.01), whereby children who used respite services had lower adaptive behaviour age equivalent scores (M=26.78 months, SD=17.38) than children who did not use respite services (M=43.25, SD=12.25). Household income (r=.448, p<.05) and parental level of education (r=.376, p<.05) were positively correlated with participation in social activities; families with lower income and less education were less likely to have children participating in social activities.

A series of bivariate linear regression models with participation in social activities as the dependent variable and adaptive behaviour, maladaptive behaviour, parental education, household income, and respite service use as independent variables were calculated. The model using household income as a predictor was significant (R^2=.201, F=4.766, p<.05), with families with lower household income less likely to have their child involved in social activities (β=.448, p<.05). Furthermore, the model examining respite service use as a predictor of participation in social activities was also significant (R^2=.232, F=5.726, p<.05) with children having more respite support being less likely to participate in social activities (β=-.481, p<.05). None of the other models were significant.

Outcomes Associated With Participation in Social Activities

One-way ANOVAs were conducted with participation in social activities as the independent variable and satisfaction with Being, Belonging and Becoming as dependent variables. Overall, satisfaction with Being, or the person the child is perceived to be was associated with participation in organized social activities (F=5.88, p<.05), though satisfaction with the child's Belonging, or connections with people and places (F=4.142, p=.058) and Becoming (F=0.07, p=.795) were not.

Among the parents of children who participated in social activities, greater satisfaction with Being (M=4.08, SD=0.56) and Belonging (M=3.80, SD=0.30) were reported compared to parents of children who did not participate in social activities (M=3.32, SD=0.71 and M=3.39, SD=0.48, respectively). There was no significant difference in satisfaction with Becoming between both groups of parents.

Discussion

Given the lack of published research to date on participation in organized social activities for preschoolers with ID, the findings from this study provide important preliminary information. However, due to the small sample size, conclusions based on these preliminary data would be premature. Nevertheless, the finding that the majority of the children in this study were not participating in any social activities outside of home and school is concerning, particularly when the main reasons given for their lack of involvement were lack of financial and one-to-one physical support.

Previous findings indicate that children participating in social activities are often supported by paid workers (Solish, et al., 2003) and that access to respite services increases exposure to social activities (Joyce, Singer, & Isralowitz, 1983). It is somewhat surprising that children in this sample who received respite support, which typically involved a paid worker taking the child out of the home, were less likely to participate in organized social activities. Given that respite use was correlated with adaptive behaviour (r=-.505, p<.01), it may be that adaptive behaviour, while not related to social participation on its own, in combination with respite care does impact likelihood of participating in social activities. The age of the child is also an important variable to consider when examining participation in social activities among those accessing respite services. Previous studies have not focused specifically on the effects of respite services for young children, therefore it cannot be assumed that trends reported among samples of older children (i.e., respite use increasing participation in social activities; Joyce, et al., 1983) hold true for preschool aged children. Further work is needed to explore the impact of adaptive behaviour on social participation among young children.

Recent research in the field of ID has emphasized the importance of including socioeconomic status as a variable in research as it often accounts for poorer well-being or disadvantage (Emerson, Hatton, Llewellyn, Blacher, & Graham, 2006). In this study, household income and parental education were both related to participation in social activities. In general, low levels of involvement in social activities have been found in people with lower income and education levels (Baum, et al., 2000). A Canadian study found that not only were young children of lower socioeconomic status (SES) less involved in formal sports and extracurricular activities in the arts than their peers of higher SES, they also were less involved in group play after school and during recess (Schneider, Richard, Younger, & Freeman, 2000). These authors reported that parents of lower SES have different values and attitudes about their child's involvement in social activities, than their higher SES counterparts. However, they found that lack of participation in children of lower SES does not seem to be simply a matter of attitudes, but also one of feasibility in terms of financial support, time, and parental availability. Lower household income and parental educational attainment may be obstructing access to social activities for all young children, including those with ID.

Finally, similar to results in a study of young adults with ID (Kraemer, McIntyre, & Blacher, 2003), parent reports of their child's quality of life in this study were related to participation in social activities. Many studies have shown the benefits of friends and social support, and although involvement in organized social activities does not guarantee a child will have friends, it may provide opportunities to develop relationships. Researchers have acknowledged the importance of distinguishing between physical integration and social integration, indicating that physical proximity alone does not ensure children with ID will be included in friendships (Cummins & Lau, 2003; Solish et al., 2003). However, if as in this study, the majority of children are not even participating in social activities; physical integration may be a first step.

Further research examining the involvement of children with ID in organized social activities prior to and during transition into school is required in order to fully understand the issues. For example, a study evaluating the transition experiences of children who do and do not participate in organized social activities prior to or during the transition to school may provide some information about the direct effects of involvement in social activities. While beyond the scope of this paper, analysis of the data from the second and third time points of this study may provide information about the impact of early social inclusion on transition success for these children. Currently, efforts are being made to expand this sample, which may lead to replication of the regression analyses using a model combining the independent variables investigated in this study. Furthermore, a control group of typically developing children and their parents will also be added to this sample. A control group will provide an opportunity to determine realistic expectations regarding involvement of preschoolers in social activities based on age, and regarding the needs of families. Furthermore, detailed data collection and analysis are required to determine the true barriers to participation and integration. It will be important to distinguish between actual and perceived lack of support, as well as to determine if professionals may be playing a role in facilitating or impeding participation. With further research examining the role of social activities in preparing children with ID for the transition to school, a better understanding of the benefits of and barriers to social participation of these children may be obtained. Continued research on this topic should provide recommendations related to involvement in social activities for these children and their families.

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