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Exploring factors that impact activity participation of children and adolescents with severe developmental disabilities.

Authors:

Taheri, A.. Department of Psychology, York University, Toronto, ON, Canada, azint@yorku.ca

Perry, A.. Department of Psychology, York University, North York, ON, Canada

Minnes, P.. Queen's University, Kingston, ON, Canada

Address:

Taheri, A., Department of Psychology, York University, Toronto, ON, Canada, M3J 1P3, azint@yorku.ca

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Abstract:

Background: Despite the benefits of social participation, children and adolescents with developmental disabilities (DD) are often excluded from taking part in social activities. There is a gap in the literature about the factors that contribute to adequate participation of children with severe DD in particular and the barriers to their participation. Taking an ecological perspective, the purpose of this study was to examine child, family and community variables that may impact the activity participation of children and adolescents with severe DD. Methods: A total of 197 parents of children with severe DD (4–19 years) completed a survey, addressing a wide range of child, family and community related variables, as well as a measure of activity participation. Results: Overall, the final model significantly accounted for 30% of the variance in activity participation. Higher adaptive behaviour, greater parental socialisation and placement in an integrated school programme were significant predictors of greater activity participation. Conclusion: Child, family and community factors were all important in understanding the activity participation of children with severe DD, thus supporting the value of an ecological approach. Suggestions for future research and clinical implications are discussed. (PsycINFO Database Record (c) 2018 APA, all rights reserved)

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Exploring factors that impact activity participation of children and adolescents with severe developmental disabilities.

Summary: Background: Despite the benefits of social participation, children and adolescents with developmental disabilities (DD) are often excluded from taking part in social activities. There is a gap in the literature about the factors that contribute to adequate participation of children with severe DD in particular and the barriers to their participation. Taking an ecological perspective, the purpose of this study was to examine child, family and community variables that may impact the activity participation of children and adolescents with severe DD. Methods: A total of 197 parents of children with severe DD (4–19 years) completed a survey, addressing a wide range of child, family and community related variables, as well as a measure of activity participation. Results: Overall, the final model significantly accounted for 30% of the variance in activity participation. Higher adaptive behaviour, greater parental socialisation and placement in an integrated school programme were significant predictors of greater activity participation. Conclusion: Child, family and community factors were all important in understanding the activity participation of children with severe DD, thus supporting the value of an ecological approach. Suggestions for future research and clinical implications are discussed.

It is well known that children and adolescents with developmental disabilities (DD) participate in fewer activities outside of the home and school in comparison to their typically developing peers (e.g. Solish et al. [34]). However, there is a gap in the literature about factors that contribute to adequate participation and reasons for lack of participation. In addition to child characteristics, it is important to consider influences at the family level and in their larger context. Further, there has been less research on children with severe DD in particular (Taheri et al. [35]), where the child factors might be expected to be more influential. The purpose of this study, therefore, is to examine the factors that may impact participation in social, recreational and leisure activities of children and adolescents with severe DD using an ecological approach.

Today, the term 'disability' no longer solely focuses on the characteristics or impairments of individuals (i.e. diagnosis and skill level) but, rather, emphasises the social and environmental factors that contribute to individuals' participation in society (King et al. [13] ; Verdonschot et al. [36]). Additionally, research on quality of life of individuals with DD stresses the importance of developing environments that allow access to places and resources (Schalock et al. [28]). While most research in this area has examined few factors, often those relating only to the child or family, it has not examined the combination of these factors in relation to participation. Therefore, it is important to examine social participation using an ecological perspective (Bronfenbrenner, [3]) and address the relationship amongst community, family and child

variables (similar to King et al. [13]). This framework provides a strengths-based perspective and acknowledges the importance of supportive relationships and environments. With so many potential factors involved at each level, we have provided a brief literature review of child factors, family factors and broader contextual factors that we hypothesise will predict social participation in this population.

Researchers have found differences in predictors of social activity as a function of the child's age and gender (e.g. King et al. [12]). Studies have found that participation decreases for individuals with physical disabilities as age increases (Law et al. [16] ; Maher et al. [22] ; Klaas et al. [14]). In terms of gender, girls with disabilities participate in activities more frequently than boys (Law et al. [16] ; Maher et al. [22] ; Klaas et al. [14]). However, the impact of gender depends on the type of activities, with girls more likely to participate in social and spontaneous activities and boys more likely to participate in physical activities (Bult et al. [5]). It is important for the impact of age and gender to be simultaneously considered in the context of other important child factors, such as functioning level, behavioural problems and diagnosis.

The findings in the literature suggest that adaptive skill level can impact participation for various activities. In a comprehensive review of the literature (Bult et al. [5]), participation of individuals with disabilities was highly linked to gross motor function, manual and cognitive ability, communicative skills, age and gender. Similarly, LaVesser and Berg ([15]) found that, for preschoolers with autism spectrum disorder (ASD), participation was related to children's behaviour and skills (i.e. toilet training, compliance, social skills, following directions, etc.). In another study of children with cerebral palsy, there was a significant association between mobility, self-care and domestic life skills with activity participation (Voorman et al. [37]). Similarly, greater social skills have been linked to participation in various activities for children with or without disabilities (Cowart et al. [7]). Based on these findings, there is a clear link between level of adaptive skills and activity participation.

DD is often accompanied by challenging behaviours (e.g. aggression) and comorbid psychopathologies (i.e. anxiety and depression) (Matson & Shoemaker [23]). Individuals with DD who demonstrate problem behaviours are at greater risk of social exclusion (Bigby [2]). The presence of these behaviours can reduce the number of friendships formed (Solish et al. [33]) and the amount of time spent with peers (Geisthardt et al. [9]). Encouraging social inclusion for people with challenging behaviours may be beneficial in reducing levels of these behaviours (Bigby [2]). However, the relationship between the level of maladaptive behaviours and social participation of those with severe DD is an area that has not been examined. Children and adolescents with more severe DD are likely to have lower adaptive skill levels and higher rates of problem behaviour; thus, they may be especially disadvantaged in terms of social participation.

Children with ASD have impairments in social interaction and these deficits may be present with or without a co-morbid diagnosis of intellectual disability (ID). As a result, it is sensible to assume that the presence of an ASD diagnosis could contribute to children's lack of participation in various activities. In a recent study, it was found that children with both ID and ASD participated in fewer social activities than their typically developing peers (Taheri et al. [35]). In addition, they participated even less often than those with ID only in certain types of activities, including going out to special occasions with friends and taking lessons. Furthermore, LaVesser and Berg ([15]) found that parents of preschoolers with ASD reported reasons relating to the child's characteristics as the main contributors to their children's lack of social participation. The authors report that this is an indication that the child has opportunities to participate but chooses not

to. Therefore, the diagnosis of ASD is an important factor that could exacerbate social exclusion; however, this topic has received surprisingly little empirical attention.

Family demographic factors are known to influence children's social participation. Lower levels of participation for children with disabilities have been linked with lower income, single-parent status, lower parental education level, non-Caucasian ethnicity, lower parental physical functioning and higher levels of parental stress (Sloper et al. [31] ; Law et al. [16] ; Bult et al. [5]). This is of particular concern because it has been suggested that caregivers of children with DD, in comparison to those with typically developing children, have lower socioeconomic status (SES) (e.g. Leonard et al. [17] ; Emerson & Hatton [8]).

The family's participation in social and recreational activities may also be associated with the community participation and independence of children with DD within those families (King et al. [13]). Greater maternal participation in social and recreational activities has been reported to be a predictor of greater participation in social and recreational activities among children with physical and developmental disabilities (King et al. [12]), as well as adolescents and adults with ASD (Orsmond et al. [27]). However, Mactavish and Schleien ([21]) found that patterns of family recreation varied depending on parents' employment status. More research is needed to examine the link between parental social participation and participation in activities for children with severe DD.

Parental mental health difficulties are linked to negative parenting styles, such as being emotionally unavailable or being less responsive to the child's needs (Goodman et al. [10] ; Lovejoy et al. [19]). Furthermore, there is ample evidence linking parental mental health problems to negative child outcomes (Lyons-Ruth et al. [20] ; Smith [32]). For example, children of depressed mothers are known to have greater difficulties in social, behavioural and academic domains (Nolen-Hoeksema et al. [26] ; Lyons-Ruth et al. [20]).

Although a few studies have examined family variables related to social participation, more research is needed in this area. Several factors common in clinical samples, especially in Canada, have not been studied in relation to the social participation of children with severe DD. These include parents' marital status, immigration status, number of children with DD in the family and parental mental health. Together with possible mental health difficulties, these could be considered as possible risk factors that might impact negatively, either individually or cumulatively, on family functioning and children's activity participation.

Broader community factors that may influence children's activity participation include services and supports available and accessible to families. Barriers to participation in activities are often associated with problems gaining access to facilities and programmes (Buttimer & Tierney [6]). For example, lack of transportation can hinder participation in leisure activities (King et al. [13]). Skinner and Slifkin ([30]) found that children with special healthcare needs living in rural areas were less likely to visit a paediatrician and more likely to have unmet healthcare needs. Similarly, it might be expected that children living in more rural and remote locations would have less access to community recreation programmes. Therefore, more research is needed to explore other important community factors (i.e. the size of the community and median income of the area) that may impact access to activities available for those with severe DD. School experiences are an important part of everyday life for children and families, and the quality of this experience may also be an important determinant. Modell et al. ([24]) found that children with moderate to severe DD who attended school in an integrated class participated in significantly more recreational

activities than those in special education classes. It seems reasonable to assume that there are more social opportunities with a class of typically developing peers versus a small number of DD peers. Furthermore, in comparison to dissatisfied parents, parents who were satisfied with their children's educational placement (regardless of whether it was in an integrated or special class) reported more optimal scores on measures of children reaching their potential, being happy and having better quality friendships (Ncube et al. [25]). Therefore, there may be an important but little studied link between educational placements and activity participation.

Guided by the findings in the literature to date, we set out to examine different factors that could impact activity participation, taking an ecological perspective based on an adapted version of Bronfenbrenner's Ecological Model (Bronfenbrenner [3]), which places the individual child at the centre of four systems: microsystem, mesosystem, exosystem, and macrosystem. As modified for this study, at the centre of the model is the child with DD and the variables that relate to the child (i.e. sex, age, level of adaptive skills and maladaptive behaviour and diagnosis of ASD). The second layer includes parental and other family variables (i.e. parental mental health, marital status, number of siblings with DD, immigration status, SES and parental socialisation). The final layer consists of the child's context at school and in the community (i.e. type of school placement and parents' satisfaction with it, the size of the community, and the median income of the neighbourhood) (Figure [NaN]).

Method

The Great Outcomes for Kids Impacted by Severe Developmental Disabilities project (GO4KIDDS) was an Emerging Team grant funded by Canadian Institutes of Health Research (PI: Perry). The objective of the project was to provide a better understanding about the health, well-being and social inclusion of children and youth with severe DD and the experiences of their families. The data used for this study came from the GO4KIDDS Extended Survey completed by parents of children with DD across Canada. Participants were recruited through approximately 500 agencies serving individuals with DD and/or ASD, across the country. The agencies assisted with recruitment by mailing the GO4KIDDS flyers to families, and/or by posting the flyer on their websites, social media sites, or in their waiting rooms.

Participants

A total of 197 parents of children and adolescents (3–19 years) with DD completed the survey. The survey included a number of measures, including standardised measures of skill level and questions regarding level of support needed for daily activities, to ensure that the sample consisted of children with major impairments in various areas of everyday functioning. Fifty-eight per cent of the sample also had an ASD diagnosis. The group with ASD ($M = 55.10$; $SD = 17.51$) did not differ from those without ASD ($M = 51.32$; $SD = 24.90$) in terms of level of adaptive skills ($t = 1.25$, $P = 0.21$). However, the group with ASD ($M = -18.03$; $SD = 12.64$) versus the group without ASD ($M = -11.50$; $SD = 11.48$) had slightly greater maladaptive behaviour ($t = 3.71$, $P < 0.01$). Sample characteristics as reported by the parents are shown in Table [NaN] .

Descriptives for child, family, and community factors and activity participation ($N = 197$)

1 *Note: SIB-R maladaptive index score; larger negative scores indicate more maladaptive behaviour

Measures

Child variables

The survey included questions about the age, sex and diagnosis of the child. Child maladaptive and adaptive behaviour scores were based on the Scales of Independent Behaviour-Revised Short Form (Bruininks et al. [4]). The Scales of Independent Behaviour-Revised Short Form consists of 40 items. Each item was rated from 1 = Never/Rarely to 4 = Does Very Well. In the present study, we used only the first 35 items of the scale. In our sample, the adaptive score had excellent internal consistency ($\alpha = 0.95$). The Problem

Behaviour scale consists of eight behaviours (e.g. hurtful to self, disruptive behaviour), which are rated based on frequency and severity. The General Maladaptive Index score was used which combines all of the problem behaviours. The General Maladaptive Index scores can range from the most severe (–70) to the average range (–10 to +10). This scale also had good internal consistency ($\alpha = 0.89$) in our sample.

Family variables

The survey included a number of questions regarding the caregiver and the family, which made it possible to derive a composite family risk score. First, caregivers were asked about their marital status; if separated, divorced, single or widowed, they obtained a risk score of 1. Second, they were asked about their immigration status; if they had been living in Canada for less than 10 years, they obtained a risk score of 1. Third, they reported on the number of other siblings in the family with disabilities; if they had another child(ren) with DD, they obtained a risk score of 1. Fourth, parental mental health, based on the Kessler 6-Item Psychological Distress Scale (K6; Kessler et al. [11]), was used to screen for serious mental illness; if they were in the clinical range on the Kessler 6, they obtained a risk score of 1. Finally, the scores on all the risk items were added to create a family risk variable, with scores ranging from 0 to 4, with higher scores indicating greater risk. Because of the skewed distribution of these scores, for statistical analysis, scores were then dichotomized. Those with scores 2 or more were classified as 'at risk'. It is important to note that individual 'risk' items might be variable in their influence and not necessarily of equal magnitude.

In addition, the survey included six questions regarding parental socialisation (e.g. how often do you socialise with friends; go out to restaurants; go on vacation, etc.), rated on a 5-point scale ranging from a score of –2 = much less than other people to +2 = much more than other people. These scores were averaged across the six questions for an overall parental socialisation score. This scale had good internal consistency ($\alpha = 0.81$) in our sample.

Family's SES was coded according to the Barratt Simplified Measure of Social Status (Barratt [1]). Scores are based on parental education and occupation. Scores can be calculated for one- or two-parent households, and range from 6 to 66. Inter-rater reliability for Barratt classifications in this sample was reported as excellent, $r = 0.93$.

Community variables

The survey included one question regarding the type of school programme that the child attends (i.e. self-contained special education classroom vs. integrated in regular class) and one question regarding parents' level of satisfaction with the child's education, rated on a 5-point scale from 1 = very dissatisfied to 5 = very satisfied. In addition, one question was included regarding the size of the community (i.e. remote, rural, suburban or urban) in which the family lives. The median income of the neighbourhood was determined based on the family's postal code using Canadian census data.

Activity participation

A modified version of the Activities Questionnaire (Solish et al. [34]) was used to examine activity participation (the same as was used in Taheri et al. [35]). Based on caregiver report, the questionnaire examined the frequency of participation of seven types of activities, each rated on a 5-point Likert scale from 1 = never to 5 = very often. The activities were the following: (1) unstructured play (e.g. friends

coming over); (2) social outings (e.g. going to the mall, to the movies, out for meals); (3) special occasions (e.g. birthday parties); (4) sports team (e.g. hockey, soccer); (5) lessons (e.g. swimming, gymnastics); (6) community activities (e.g. Sunday school, cubs/brownies); and (7) activities for children with special needs (e.g. Special Olympics, special camp programmes). In the current sample, the measure had high internal consistency ($\alpha = 0.80$).

Results

Table [NaN] shows the correlations examining the strength and direction of relationship among all of the variables. Activity participation was significantly correlated with adaptive behaviour ($r = 0.31$) and maladaptive behaviour ($r = 0.22$). It was also negatively correlated with diagnosis of ASD ($r = -0.16$). An independent t-test ($t(187) = 2.19, P < 0.05$) showed there was significantly lower activity participation for those with ASD ($M = 2.26; SD = 1.48$) versus no ASD ($M = 2.72; SD = 1.41$). Activity participation was moderately negatively correlated with parental socialisation ($r = -0.41$). Family risk was also correlated with activity participation ($r = -0.14$). There was significantly lower activity participation ($t(187) = 2.03, p < 0.05$) in families who were in the dichotomized 'at risk' group ($M = 2.28; SD = 1.44$) compared with families not 'at risk' ($M = 2.70; SD = 1.47$). Activity participation was also correlated with the type of school programme ($r = -0.26$). Children in regular classrooms ($M = 2.82; SD = 1.39$) participated in significantly more activities ($t(187) = 3.67, P < 0.01$) than children in special education classes ($M = 2.08; SD = 1.38$).

Intercorrelations of scores on activity participation with child, family and community variables

3 $P < 0.01$

4 Note: Lower scores on maladaptive behaviour (based on the SIB-R General Maladaptive Index score) indicate more severe maladaptive behaviour

Hierarchical regression analysis was used to determine the predictors of activity participation. Table [NaN] shows the descriptive statistics for all the variables used for the multivariate regression analyses to examine predictors of participation. Multi-collinearity was not a concern as no variables were highly correlated, as shown in Table [NaN]. Following the Bronfenbrenner ecological model, variables relating to the child (i.e. diagnosis, age and adaptive and maladaptive behaviour) were entered at step 1. In step 2, the variables relating to the family (i.e. family risk, SES and parental socialisation) were entered. Finally, in step 3, the variables relating to the school and community context (i.e. median income of area, type of school programme and school satisfaction) were entered.

Table [NaN] shows the results of the regression analysis. The results from step 1 indicate that child factors accounted for 21% of the variation in activity participation. ($F_{4,197} = 11.12, P < 0.01$). At step 1, all of the individual child variables were significant. Introducing the family variables at step 2 accounted for another 7% of the variance, and this change was significant ($F_{3,197} = 9.26, P < 0.01$). At this step, all child variables remained significant, except for maladaptive behaviour. Of the family variables, only parental socialisation was significant. Finally, the addition of the school and community context variables at step 3 accounted for only another 2% of the variance, and this change was not significant ($F_{3,197} = 6.85, P = 0.16$), although the variable type of school placement was a significant predictor. At this step, age and diagnosis were no longer significant, but adaptive behaviour and parental socialisation remained significant.

Hierarchical multiple regression analyses predicting activity participation from child, family and community variables

5 $P < 0.05$;

6 $P < 0.01$.

Overall, the final model, with significant coefficients for adaptive behaviour, parental socialisation and type of school programme, significantly accounted for 30% of the variance in activity participation ($F_{10,197} = 8.92$, $P < 0.01$).

Discussion

Guided by the findings in the literature and informed by an ecological perspective, we examined several different factors that we hypothesised would impact activity participation in children with severe DD. Based on hierarchical regression analyses, we determined the predictors of activity participation at each level of the proposed model. At the first level, child factors accounted for 22% of the variance in activity participation. At the second level, family variables accounted for another 7% of the variance. At the third and final level of the model, school and community context variables accounted for another 2% of the variance. Overall, the final model, which combined all of the child, family and community variables, accounted for 30% of the variance in activity participation.

In our final model, adaptive behaviour was the only child variable that significantly predicted activity participation. This finding indicates that higher skill levels predict greater participation in various activities. This is consistent with other evidence in the literature that participation of individuals with disabilities is highly related to their skill level (e.g. Bult et al. [5] ; LaVesser & Berg [15] ; Lopes [18]). Other child factors, such as maladaptive behaviour, sex, age and the presence of an ASD diagnosis, were not predictive of activity participation in the final model, although they were in the initial steps. This result is encouraging since it highlights that particular child characteristics alone, such as maladaptive behaviour or a diagnosis of ASD, are not necessarily predictive of low participation.

Of the family variables, parental socialisation showed the highest zero-order correlation with activity participation ($r = 0.41$) and it significantly predicted participation, even after child variables were

'controlled' at step 1. This is consistent with other studies that have shown family involvement or participation in social and recreational activities is linked to children's participation (King et al. [13] ; Orsmond et al. [27] ; Lopes [18]). However, our measure had an interesting self-perception dimension that differs from other studies, in that it asked families to compare their socialisation to that of other families.

Contrary to our expectations, greater SES did not predict greater activity participation, based on either the Barratt measure (incorporating parent education and occupation) or the neighbourhood income variable. This could reflect a Canadian societal difference or may be a function of our measures. Our created family risk variable was also not related to children's activity participation. This score was an attempt to combine a number of potential risk variables (single marital status, immigration status, having other child(ren) with disabilities and parental mental health problems), each of which occurred in only a small minority of the sample. The combined score was very skewed and was, therefore, dichotomized. As a result, this variable may not have been sensitive enough to demonstrate the logical hypothesised relationship with activity participation.

In terms of school and community context factors, this set of variables did not account for significant variance beyond that accounted for by child and family factors. However, the type of school programme (specifically attending a regular class) significantly predicted activity participation in the final model. This finding accords well with that of Modell et al. ([24]), who also found that children with DD in a regular class took part in more recreational activities than those in special education classes. It is important to contextualise this finding by acknowledging that there may be a number of differences between children and youth in special education versus regular classes that may confound these comparisons. On the other hand, in the present study, several important child characteristics were controlled by virtue of having been entered into the regression at an earlier step. Therefore, these results indicate a clear link between inclusive educational placements and greater activity participation, even for these children with severe DD.

This study has confirmed some previous research findings and has addressed several gaps in the literature, keeping both a theoretical and clinical perspective in mind. These findings have significant implications for how we conceptualise social participation in this population and the factors that impact activity participation. The ecological approach utilised focuses on the strengths of individuals and acknowledges the importance of supportive relationships and environments in creating positive outcomes for the child with severe DD.

Given the benefits of social participation, support and intervention strategies can be aimed at tackling some of the factors that may hinder a child with DD from taking part in such activities. The results indicated that adaptive behaviour was an important predictor of activity participation. Therefore, it is important to encourage schools, parents and intervention programmes to focus on helping children build social, play, communication and independence skills that will thereby enable greater participation in social and recreational activities in school and community settings. There are many evidence-based approaches to teaching these skills (e.g. Wong et al. [38] ; Singh [29]).

Parents' own perceived social participation was a significant predictor of children's participation in activities. This implies that providing better support (e.g. specialised babysitting or respite services) or more opportunities for caregivers to participate in various social activities could have an indirect effect, such that

it improves the activity participation of their children as well. This is a relatively new finding in the literature and an area that needs to be further explored, ideally in longitudinal studies that could untangle the directionality of this finding. Finally, the results regarding the beneficial effects of children's placement with typical peers in regular educational programmes confirm other research findings and lend support to widespread efforts for inclusion with typical peers.

This study had a number of strengths, including a large and diverse sample of parents of children and adolescents with DD. The sample was unique, with many individuals having multiple diagnoses and complex needs. Furthermore, based on standardised measures of children's skills and problem behaviours, we could confirm that our sample consisted of those with severe needs. Although the study has a number of strengths, it is not without limitations. The data were based on caregiver report; therefore, children's participation and predictor variables were based on parental perception. Furthermore, several of the variables were derived for the purpose of the survey (e.g. parental socialisation). These measures were not standardised and psychometric properties are unknown.

Future studies should explore the parameters and predictors of social participation more broadly using stronger measures. In particular, there is a need to develop psychometrically sound methods of assessing the social participation of children and adolescents with DD. In addition, given the findings of this study, a valid measure of the social participation of parents would be helpful. Further research is needed to examine other parental and community factors, such as availability of various activities, accessibility of services (i.e. transportation) and supports needed. It would be ideal to apply other research methodologies to this topic, including systematic behavioural observations of children's participation, and to use multi-method (interviews, surveys) and multi-informant (e.g. teachers, community leaders, coaches, peers) approaches. Finally, time series studies could help untangle the causality and order of effects in the way that child, parent and contextual factors change and influence one another across time.

By addressing these considerations, we can enhance our understanding of social participation in this population. In the meantime, the present study advances our knowledge by taking an ecological approach, studying a more severe and complex group of children, and introducing some novel measures and constructs. Two of the key findings have clear and direct implications for educators, family services and parents. One relates to the importance of parents' own socialisation and the indirect value that may have for their children. The other relates to children's skill level and the need to enhance social, play, communication and independence skills. Efforts in both of these areas would go a long way toward improving the social inclusion and quality of life of children with DD and that of their families.

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Graph: 1 Model of factors impacting activity participation.

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By A. Taheri; A. Perry and P. Minnes

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