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Factors Associated With Participation and Change Over Time in Domestic Life, Peer Relations, and School for Adolescents With and Without Self-Reported Neurodevelopmental Disorders. A Follow-Up Prospective Study

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Even though participation in everyday events is a vital part in the fulfillment of human rights, adolescents with neurodevelopmental disorders (NDD) often face participation restrictions in every-day activities. Few studies have investigated the predictors for participation in different contexts, over time and in relation to the same outcome variables.

Objective: Objective of the current study was therefore to investigate predictors of change in participation operationalized as frequency of attendance and perceived importance in domestic life activities, peer related activities, and school activities as experienced by adolescents with and without self-reported neurodevelopmental disorders.

Method: Associations with participation, both in terms of frequency and perceived importance, in domestic life, peer relations, and the school setting were investigated using six independent variables measuring experience of time and self, sex, age, stress, support from siblings, and atmosphere in family at two-time (with ∼2 years in between). The sample consisted of adolescents with and without self-reported NDD ($n = 916$). Adolescents with self-reported NDD were $n = 154$ and adolescents without self-reported NDD was $n = 762$. Data was collected via self-reported questionnaires administered in schools.

Results: Three key findings are presented. (1) more factors were associated with participation outcomes at time1 for adolescents without NDD than for adolescents with NDD, but this difference in the number of factors decreases with time; (2) few associations were related to time for both adolescents with and without NDD; and (3) patterns of predicting variables were different for adolescents with and without NDD.

Conclusion: The findings indicate that the factors related to participation in and outside school differs between groups, when the impairment or disability is not considered as a predictor for participation. This study supports the need for using a multidimensional developmental and contextual perspective in addressing enhanced participation for adolescents with NDD.

Keywords: ICF-CY, participation, involvement, adolescents, neurodevelopmental disability, self-report

INTRODUCTION

Participation and Participation Restrictions for Adolescents With Neurodevelopmental Disorders

Within the International Classification of Functioning, Disability, and Health (ICF) participation is defined as involvement in a life situation, i.e., functioning in everyday activities (World Health Organization, 2007). Participation is seen as a health-related construct and involvement in life situations probably increase wellbeing as indicated by the relatively strong statistical relation between participation and wellbeing (Arvidsson and Granlund, 2018). Participation has two dimensions: first, the attendance/being there dimension which is a necessary condition for the second dimension, the "being involved while being there"-dimension (Imms et al., 2016). In this study, focusing on participation of adolescents with self-reported NDD, participation is operationalized as frequency of attending activities (representing the "being there" dimension) and the perceived importance of the activity (representing the person's own experience of involvement while being there) (Arvidsson et al., 2012; Imms and Adair, 2017). In the ICF-CY, only the "being there" dimension of participation is possible to rate using the performance qualifier, although a need for a third qualifier for involvement has been suggested by Granlund et al. (2012). Participation in everyday activities in the home, school, leisure activities, and in society is viewed as an important part of a child's development and, in turn, as being related to their future life outcomes and wellbeing (King et al., 2003). Earlier research has demonstrated that mental health, operationalized as either wellbeing or lack of mental problems, is related to social functioning and school achievement (Gustafsson et al., 2010). We know that via participation, children and youths can gain skills and achieve better physical and mental health as well as create social skills essential for the transition into adulthood (Anaby et al., 2014). In addition, participation is associated with improved skills, social relationships, mental, and physical health as well as improved academic performance (World Health Organization, 2007; Miller et al., 2013). Despite this, adolescents with neurodevelopmental disorders (NDD) may experience limitations related to participation in everyday activities due to their impairment. Adolescents with NDD (e.g., intellectual disability, ADHD, autism spectrum disorder) in Sweden have lower self-reported wellbeing than their typically functioning peers (Statens Folkhälsoinstitut, 2011). This might indicate that they also experience lower participation. This was also concluded in a Canadian study investigating patterns of participation for children and young adolescents with neurodevelopmental disabilities aged 5–14. The conclusion was that they may not experience participation to the same extent as other children and that there is a need for policies to support subgroups of children with NDD (Mâsse et al., 2013). In Sweden, Ullenhag et al. (2014) compared leisure participation in children with- and without disabilities. They found that children with disabilities participated less in everyday activities than their typically developing peers and the activity patterns differed in the frequency of attending different activities. Their conclusion was that participation can be best described as a pattern of functioning dependent on several factors.

Maturity and Changes in Life Roles During Adolescence

This study concerns adolescents who are entering early adolescence. Adolescence is characterized by a series of emotional, physical, and psychological maturity processes (Hilbrecht et al., 2008). Socially, adolescents are also required to handle changes related to the shift in life roles associated with the transition from childhood to adulthood. Within this period in life, a major challenge is how to handle the changes related to adolescence and at the same time preserve one's own identity. During this time in life, mental functions related to the awareness of one's identity and one's body as well as one's position in relation to time and in relation to others develop rapidly (World Health Organization, 2007). Children entering early adolescence also face significant changes in their neurobehavioral development in conjunction with educational and social challenges. Middle school represents a central context for functioning that has an important impact not only on academic achievements but also on social functioning. Understanding adolescents own experiences of their school situation is important for understanding the social forces that influence motivation to learn (Roeser et al., 1998). Regarding emotional functioning, some forms of distress, such as anger and certain problematic behavior (e.g., school truancy, and misconduct) increase during early and middle adolescence (Roeser and Eccles, 1998).

Person-Based, Activity-and Environment-Focused Elements

Concerning predictors of change, Willis et al. (2017), in a scoping review, identified 10 elements contributing to meaningful experiences of participation in recreation and leisure activities in children with disabilities. These were grouped into

three types of elements: person-based elements, environment-focused elements, and activity-related elements. The person-based elements included having fun, a sense of belonging, the opportunity to explore, and develop an identity. These person-based elements relating to participation partly overlap with what Imms and Adair (2017) describe as aspects of sense of self related to participation. Several studies (Almqvist and Granlund, 2005; Clarke et al., 2011; Bertills et al., 2018) indicate that there is a moderate to strong relationship between having a strong autonomy or self-efficacy and the two dimensions of participation in children and adolescents with disability.

The activity-related elements (Willis et al., 2017) concern learning experiences such as skill exposure and acquisition, as well as children's own discoveries about themselves.

Activity competence is often operationalized as performing skills measured as capacity (performing a skill in a standardized environment), capability (level of support needed when performing a skill in a natural environment) or frequency of performing a skill. A systematic review of participation interventions (Adair et al., 2015) report only a weak relation between activity competence and participation. Furthermore, the results of the scoping review (Willis et al., 2017) demonstrate a relatively limited negative impact of impairments on a child's participation experience. In contrast, the scoping review demonstrated that children perceived their impairment as a positive contributor to part of their experiences.

The environment-focused elements (Willis et al., 2017) involve authentic friendship (having friends), the opportunity to participate, role models, and family support. The environmental elements identified by Willis et al primarily concern context. Lygnegård et al., in a cross-sectional cluster analysis, investigated patterns of participation in terms of frequency of attendance and perceived importance in domestic life and peer related activities for adolescents with and without self-reported NDD (Lygnegård et al., 2018). The study revealed that when clustering adolescents with and without disabilities while using one cluster analysis for all participants, adolescents with self-reported NDD were represented in all clusters. Frequency of attendance as well as level of perceived importance of peer relations seemed to be primarily associated with being able to take part in discussions, plus perceived support from siblings and experiencing an open family atmosphere with parental and child solicitation. In addition, children's own preferences as well as family preferences are considered to be important predictors of children's participation (King et al., 2003). However, the relationship between environmental elements, impairments and participation might vary depending on the environment in which children are involved.

Gaps and Limitations in the Existing Literature

Factors influencing participation in adolescents will probably vary depending on the context of participation, due to individual child characteristics and because of changes in maturity and life roles over time. There is a lack of studies investigating how participation changes over time (King et al., 2009). In addition, studies where adolescents themselves are invited to participate are rare (Adair et al., submitted). The scoping review by Willis et al. (2017) as well as the examples provided above about elements related to participation experiences does not provide information about how participation patterns and factors related to participation change over time. Cross-sectional studies comparing age groups indicate that a child's gender and age as well as the type of activity are related to a change in frequency of participation in leisure activities (King et al., 2009; Ullenhag, 2012). Activities with peers become more important with age while other activity types are less attended. These changes in patterns of participation, as well as factors predicting change need to be confirmed in longitudinal studies. In one of the few longitudinal studies of participation of children and adolescents with a disability, King et al. also reported differences in the longitudinal change regarding recreational and physical activities. However, few predictors for change were identified. It might therefore be argued that factors related to the level of participation in activities differ from factors related to change in participation patterns.

OBJECTIVE

The present study aims to investigate predictors of change in participation operationalized as frequency of attendance and perceived importance in domestic life activities, peer-related activities, and school activities as experienced by adolescents with and without self-reported NDD.

The following research questions were addressed:

Which factors related to body, activity and environment are associated with self-reported participation at home, with peers and in school for adolescents with and without self-reported NDD?

Do the associations between body, activity and environment and participation change with increasing age?

Do the associations differ between adolescents with and without NDD?

METHODS

Study Design and Setting

This is a prospective longitudinal cohort study that uses self-reported data from two waves of data collections (wave 1, referred to as time 1, and wave 3 referred to as time 2) from the on- going Swedish multidisciplinary research program LoRDIA (Longitudinal Research on Development in Adolescence). This program's primary aim is to investigate mental health and drug use. At time 1, the total population of adolescents in 6th grade and 7th grade aged 12–14 in four municipalities in south and southwest of Sweden were invited to participate in the study. These municipalities each have between 9,000 and 36,000 inhabitants and are relatively geographically close to one another. They were chosen as they represent variations in rural and urban density. Two of the municipalities (A & B) have a

relatively high degree of internal school migration: for example, adolescents from the minor municipality (B) usually attend senior high school in the somewhat larger municipality (A). Both municipalities are industrial and relatively small. Municipality C is somewhat larger than A and B and close to Sweden's second largest city, while D is smaller and more rural than A, B, and C.

Participants

The population consisted of 2,150 adolescents, of which 2,108 responded at time 1 and 1323 also at time 2, giving a total response-rate of 62%. Only adolescents who participated in time 1 and time 2 data collections and responded to the items in the dependent and independent variables were included. Due to internal attrition (31%) the sample was restricted to 916 adolescents. At time 1, adolescents were enrolled in grade 6 and 7 in Swedish compulsory schools and at time 2, adolescents were enrolled in grade 9 and the first year of the Swedish gymnasium (high school). In this study, adolescents who self-reported that they had a neurodevelopmental disorder (NDD) are compared to adolescents without NDD. They were grouped by questions regarding whether they perceived themselves as having an impairment or not. The examples of impairment given for NDD were for example, ADHD, autism, intellectual disability, speech, or language impairment/communication disorder (American Psychiatric Association, 2013). The mean age for adolescents with NDD was 13.13, and for adolescents without NDD, 12.98. The range was 11–14 years. At time 2, the mean age for adolescents with NDD was 14.43 and for adolescents without NDD, 14.32. The total number of adolescents with NDD was 154 and adolescents without NDD were 762. Among adolescents with NDD, 75 were girls (49%) and 79 were boys (51%) Among adolescents without self-reported NDD, 429 were girls (56 %) and 333 were boys (44 %).

Instruments and Variables Used in This Study

Data was collected using paper-based self-reported questionnaires responded to in class. At time 1 adolescents with intellectual disabilities were given the opportunity to use an adapted form of the questionnaire. The adapted version of the questionnaire was adapted and tested to make the questionnaire accessible for adolescents with intellectual impairments (more concrete language and fewer response options). The adaptations were based on strategies recommended for children and youths with cognitive impairments (Nilsson et al., 2012). Out of all participating adolescents at times 1,142 used the adapted version.

The items used in this study are originally used in scales previously developed, used and validated by Stattin and Kerr (2000), Arvidsson et al. (2012), Arvidsson (2013), and Kerr and Stattin (2000). Only items used at both time 1 and 2 were included. Before conducting analyses, the items from the original questionnaires were linked to codes within the ICF-CY components body, activity/participation, and environment. The dependent participation variables consisted of indices based on codes from chapters 6–9 within the activity/participation component in ICF-CY. Independent variables consisted of indices based on codes from the components body functions, activity (chapters 1–5 in activity/participation in ICF-CY), and the environmental component of the ICF-CY. For a further description of linking procedures, please see (Augustine et al., 2017). The rationale for this linking was that the ICF-CY classification provides a structure and a system for organizing information about a person's everyday functioning (Adolfsson et al., 2011) when compiling data from different instruments using different scales.

Dependent Variables

Six participation outcome variables are used in this study. These variables are based on indices representing the frequency of attendance as well as the perceived importance of: (a) frequency attending and importance of activities related to domestic life, (b) frequency of attendance and importance of peer relations and frequency of attendance and perceived importance of school. The items in the dependent variables are described in **Table 1**. The participation variables were chosen in accordance with the first alternative option for dividing activity and participation in the ICF-CY manual, annex 3. In this option the ICF-CY domains personal care (d5), domestic life (d6), interpersonal interactions and relationships (d7) (in this study referred to as peer relations) and major life areas (d8) (in this study measured as the school context), are referred to as participation. These chapters focus on involvement in a life situation while chapters (d1) to (d4) focus on individuals performing tasks. According to a conceptual article by Imms et al. (2016), frequency of attendance for an activity and involvement in an activity while being there, are key dimensions in the participation construct. In this study, the involvement dimension is operationalized as the perceived importance of the activity or context as experienced by the person and attendance as the frequency of physically being there. Probably, these two dimensions are influenced by partly different factors (Imms and Adair, 2017) which is a major reason for why both dimensions are included in predicting participation in domestic life, peer relations and school.

Independent Variables

Six variables based on indices were used as independent variables representing body functions, activity and environment (**Table 2**): (1) An index labeled Experience of time and self with the ICF-CY code b180 (the experience of time and self), (2) Stress with the ICF-CY code d240 (handling stress and other psychological demands), (3), Support from siblings with the ICF-CY code e3, and (4) Atmosphere in the family that was coded e4 (World Health Organization, 2007). The variables age and sex (representing personal factors) were used as control variables since earlier research has confirmed that both age and sex have an impact on patterns of participation (King et al., 2009). The selection of variables was informed by (a), correlations between the variables and previous research and (b), the possibility to compare results with an earlier cross-sectional study (Lygnegård et al., 2018), in which these indices were used.

Data Collection

Data for the first wave (time 1 in this study) was collected in 2013 and for the third wave (time 2 in this study) in 2015

TABLE 1 | Overview of items in the dependent variables category.

Outcome variable/indexes	Cronbach's alpha	Items included	Response scale
Frequency of participation in domestic life	0.54	*How often do you:* help out at home? do grocery shopping? prepare a meal? wash your clothes?	Three-point Likert scale: 1 = never 2 = sometimes 3 = often
Perceived importance of domestic life	0.62	*How important is it to?* help out at home? do grocery shopping? prepare a meal? wash your clothes?	Three-point Likert scale: 1 = no 2 = not really 3 = yes
Frequency of participation in peer relations	0.35	*How often do you:* make new friends? get along with friends? spend time with a girl- or boyfriend?	Three-point Likert scale: 1 = never 2 = sometimes 3 = often
Perceived importance of peer relations	0.31	*How important is it to?* make new friends? get along with friends? spend time with a girl- or boyfriend?	Three-point Likert scale: 1 = no 2 = not really 3 = yes
Frequency of participation in school/ school attendance	Only one item	Have you been truant a whole day from school this semester?	Three-point Likert scale: 1 = no, not once, 2 = sometimes, 3 = many times
Perceived importance of school	0.62	Do you try to do your best in school? Are you satisfied with your schoolwork? How do you like school?	Three-point Likert scale: 1 = mostly, 2 = sometimes, 3 = almost never 1 = very much, 2 = quite ok, 3 = not so much, 4 = not at all (reversed)

in four municipalities in the south- and south west regions of Sweden. Since several people were involved in the data collection, a written manual regarding the data collection procedure was developed based on pilot studies that took place prior to initiating the first data collection in 2013. The data collection took place within the school setting and adolescents were asked to fill in the questionnaires. Members of the research team was present to answer questions.

One of the purposes of the LoRDIA research program was to investigate mental health and drug misuse. For this reason, a so-called passive consent was used since it was important to be able to include adolescents coming from families where the parents themselves might not prioritize participation. Active consent from caregivers with low socioeconomic status was therefore assumed jeopardize participation for adolescents who would be able to provide valuable information in line with the aim and scope of the research program. All caregivers were informed via written information (sent home) about the study, both in Swedish and their native language. Caregivers were asked to inform the research group if they did not give consent for their children to participate. It was explained that not giving notice meant giving consent to participate. Prior to each data collection members of the research team informed the adolescents about the principle of informed consent and the possibility of withdrawing from the study without stating reasons why. The adolescents who participated in the study gave their active consent by writing their names on the first page of the questionnaire at time 1. Adolescents who declined to participate were given other tasks to work on by their teachers with prior to the data collection. Adolescents experiencing difficulty in answering the questions were offered to have the questions read aloud to them in a separate room. At time 2 adolescents who gave their consent by filling in the questionnaire had a code assigned to the questionnaire after responding. This code allowed a comparison with time 1 data.

Data Analysis

The analysis was done in two steps: first, after linking data to ICF-CY codes, we analyzed the association between indices for body, activity, and environment as independent variables and different types of participation as dependent variables. Multiple linear regressions were used for the analyses with all dependent variables except sex given linear representation. Analyses were run separately for time 1 and time 2 and for adolescents with and without self-reported NDD. Separate analyses for adolescents with and without NDD were performed since NDD was expected to have an impact on the experience of participation (Carlberg and Granlund, accepted). The separation of the groups made it possible for us to study the impact of factors other than

TABLE 2 | Overview of items in the independent variables.

Independent variable and ICF-CY code	Cronbach's alpha	Example of items included in the index	Response scale
Experience of time and self (b180)	0.70	Compared to peers at the same age, I feel: My friends treat me as if I were: Compared to most people my age, I look:	Three-point Likert Scale: 1 = younger 2 = about the same age 3 = older
Stress (d240)	0.44	How often do you feel under [time] pressure?	Three-point Likert Scale: 1 = never 2 = sometimes 3 = often
Support from siblings (e3)	0.86	If I argue with my parents, my sibling supports me. If I get into trouble, I can expect help from my sibling.	Four-point Likert Scale: 1 = I don't agree at all 2 = I partly agree 3 = I mainly agree 4 = I entirely agree
Atmosphere in the family (e4)	0.79	Items related to parental control[1] and parental solicitation[2] and child disclosure[3]: How often do your parents ask you to tell them about things going on in your leisure time? Do your parents always demand to know where you are in the evenings, who you meet with and what you do together?	Three-point Likert Scale: 1 = mostly 2 = sometimes 3 = seldom or never

[1]The extent to which parents require their child to ask for permission before going out and insist on getting information on their children's whereabouts.[2]The extent to which parents actively seek information on what their children do. [3]The extent to which children spontaneously disclose information about their whereabouts (Kerr and Stattin, 2000).

NDD, considering the fact that earlier research indicate that participation is multi-determined (Imms et al., 2016).

Secondly, we studied if and how the associations between independent and dependent variables differed between time 1 and time 2. Differences over time are possible due to maturation with increasing age and changing family roles. To explore this, we have included interaction terms between time (coded 0/1) and each of the independent variables (given linear representation). The interaction terms show if the associations differ between time 1 and time 2. The interaction terms *per se* are not presented, just their *p*-values (**Table 5**). The descriptive statistics as well as the multiple regression analyses were performed using the IBM Statistics SPSS version 24. For group comparisons in the descriptive statistics, *t*-tests were used for normally distributed variables and logistic regressions for non-normal variables (**Tables 3**, **4**). In sum, the aim of the analyses was not to predict T2 from T1. We have studied if and how the associations between independent and dependent variables differed between time 1 and time 2.

RESULTS

Results will be presented in accordance with the three research questions. Associations between body, activity and participation at times 1 and 2 are presented first followed by a presentation of whether the associations change over time and finally a comparison of patterns of associations for the two groups (adolescents with and without NDD).

Which Factors Relating to Body, Activity, and Environment Are Associated With Self-Reported Participation at Home, With Peers and in School for Adolescents With and Without Self-Reported NDD at Times 1 and 2 Respectively?

For adolescents with NDD at time 1 (see **Table 5**), there were few associations with participation for the measured body, activity, and environmental factors. Regarding frequency of participation in domestic life (d6), a positive association was found between the variable stress (d240) and participation. This indicated that the adolescents who experienced more stress engaged in domestic life activities more frequently. Support from siblings added significantly to the models predicting frequency and perceived importance of peer relations indicating that the more support an individual received from siblings, the higher the frequency and perceived importance of peer relations.

Several factors were associated with both frequency and perceived importance for adolescents without NDD at time 1 (see **Table 5**). Support from siblings (e3) added to the predictions in all the regression models for adolescents without NDD. Also, the variable atmosphere in the family (e4) added to the predictions in all the models, except frequency in peer relations (d7) for this group. The associations between support from siblings and frequency and perceived involvement in school (d8) were negative, meaning that the more support from siblings, the less absence from school and the higher rating of perceived importance in school.

TABLE 3 | Descriptive statistics for dependent variables regarding participation at home, with peers and in school.

Dependent variable with ICF-CY code*	Self-reported neurodevelopmental disorder (NDD)		No self-reported neurodevelopmental disorder (NDD)		*P-value* for difference between NDD/No NDD **
	Mean	Sd	Mean	Sd	
Frequency of participation in in domestic life (d6)					
Time 1	2.13	0.41	2.11	0.35	0.557
Time 2	2.09	0.43	2.12	0.35	0.523
Perceived importance of domestic life (d6)					
Time 1	2.55	0.43	2.54	0.42	0.796
Time 2	2.56	0.34	2.55	0.38	0.767
Frequency of participation in in peer relations (d7)					
Time 1	2.41	0.45	2.46	0.38	0.197
Time 2	2.40	0.44	2.45	0.36	0.211
Perceived importance of peer relations (d7)					
Time 1	2.69	0.41	2.74	0.36	0.182
Time 2	2.67	0.46	2.75	0.34	**0.030**
Frequency of participation in in school (d8)					
Time 1	1.24	0.54	1.12	0.42	**0.014**
Time 2	1.25	0.53	1.13	0.40	**0.011**
Perceived importance of school (d8)					
Time 1	0.52	0.43	0.31	0.36	**0.001**
Time 2	1.01	0.62	0.85	0.55	**0.003**

**International Classification of Functioning, Disability and Health, Children and Youth version (ICF-CY) (World Health Organization, 2007). D6, domestic life; d7, interpersonal interactions and relationships (in this study; peer relations); d8, major life areas such as education.*

*** Independent sample T-test. Bold values indicate significant differences ($p < 0.05$) between groups.*

At time 2 several associations between participation and body, activity and environmental factors were found for both groups. Concerning adolescents with self-reported NDD, atmosphere in the family (e4) added statistically to the models predicting frequency of participation in domestic life (d6) and peer relations (d7) as well as perceived involvement in peer relations (d7). This means that the more positive atmosphere in the family, and the more open communication, the less important peer relations were held to be. For adolescents without NDD, experience of time and self (b180), added to the predictions in the models predicting participation frequency in peer relations (d7) and frequency in school (d8) (positive associations). This means that the more mature adolescents without NDD perceived themselves in relation to others, the more often they spent time with friends and the less often they were truant in school. Stress (d240) was associated with all the outcome variables for adolescents without NDD.

Do the Associations Between Body, Activity and Environment and Participation Change With Increasing Age?

Five interaction effects were significant when all possible interaction effects of time between dependent and independent variables were tested. This means that five of the observed changes in relations between the variables representing body, activity, and environment and the participation variables seem to be affected by time. Four of these changes concern adolescents without self-reported NDD and one concern adolescents with self-reported NDD. For adolescents without NDD the relation between gender perceived involvement in peer relations (d7) decreased with time. At time 2 the perceived importance of involvement in peer relations was about the same for boys and girls while at time 1, girls tended to rate the perceived importance higher. The frequency of attending school (d8) had a stronger negative relation to stress at time 2 and was less related to support from siblings. At time 2, high attendance in school increased the probability that an adolescent without self-reported NDD perceived stress and was less related to their perception of receiving strong support from siblings. These interaction effects were not seen for adolescents with self-reported NDD. However, for this group the relation between family atmosphere and perceived involvement in peer relations became stronger with time. No such interaction effect was seen for adolescents without NDD.

Do the Associations Differ Between Adolescents With and Without NDD at the Two Time Points?

Patterns of significant relations between participation and body, activity, and environment changed between time 1 and time 2, especially for adolescents with self-reported NDD (see **Table 5**). For this group, more significant associations between participation and the independent variables are found at time 2, especially for participation frequency in domestic life (d6) and perceived involvement in school (d8). Concerning the experience

TABLE 4 | Descriptive statistics for independent variables regarding participation at home, with peers and in school.

Independent variable with ICF-CY code*	Self-reported neurodevelopmental disorder (NDD)		No self-reported neurodevelopmental disorder (NDD		*P*-value for difference between NDD and No NDD**
	Mean	Sd	Mean	Sd	
Experience of time and self (b180)					
Time 1	1.02	0.47	1.10	0.40	**0.024**
Time 2	1.05	0.32	1.08	0.29	0.282
Stress (d240)					
Time 1	1.42	0.51	1.50	0.47	0.055
Time 2	1.53	0.45	1.69	0.37	0.001
Support from siblings (e3)					
Time 1	1.81	0.83	1.87	0.77	0.347
Time 2	1.72	0.88	1.92	0.82	**0.008**
Atmosphere in the family (e4)					
Time 1	0.88	0.31	0.84	0.29	0.106
Time 2	0.95	0.34	0.87	0.28	**0.004**
Age					
Time 1	13.13	0.60	12.98	0.59	**0.005**
Time 2	14.43	0.67	14.32	0.63	**0.032**

**International Classification of Functioning, Disability and Health, Children and Youth version (ICF-CY) (World Health Organization, 2007). ** Based on logistic regression based on NDD Yes and NDD No. Bold values indicate significant differences ($p < 0.05$) between groups.*

of time and self (b180) the pattern of relations to participation were different when the two groups are compared.

For adolescents without NND, the relationship at time 1 regarding experience of time and self, i.e., maturity, was related to how frequently they attended school, but this association disappeared at time 2. On the other hand, for adolescents without NND, the feeling of maturity and frequency of school context did not t exist at time 1, but a relationship between maturity and perceived importance developed at time 2. For adolescents with self-reported NDD, no relation between experience of time and self and participation in school was found at time 1. At time 2, however, this variable had however a strong positive association with the perceived importance of school (d8). In contrast, the experience of time and self was associated with both frequency in peer relations and frequency of school at both time 1 and time 2 (stronger associations) for adolescents without NDD.

Regarding the association between stress and perceived importance of school, the pattern differed between the two groups. Stress was significantly associated with frequency and perceived involvement in school for adolescents without NND at both times, but only in perceived importance at time 2 for adolescents with NND. The associations between contextual variables such as support from siblings (e3) and frequency of participation in domestic life, were the same for both groups. This indicates that the more support an individual received from siblings, the more often they took part in domestic life activities. Concerning perceived involvement in school (d8), at time 2, support from siblings (e3) added to the prediction of perceived involvement in school (d8) both for adolescents with and without NDD at time 2. At time 1, perceived involvement on school added to the prediction for adolescents without NDD. The lower support from siblings was rated, the lower the importance of school was rated. Concerning the pattern of relations between atmosphere in the family and participation in peer relations the two groups are more similar at time 2, primarily because associations which are not seen at time 1 occur at time 2 for the group of adolescents with self-reported NDD. Several associations are still less evident for adolescents with NDD than for the other group at time 2. Few differences are seen in how gender is related to participation in the two groups. Girls tend to take participate more frequently in activities at home independently of NDD or not at time 1.

DISCUSSION

This study is an attempt to provide insight into the factors that predict participation in terms of frequency and perceived importance in domestic life (d6), peer relations (d7), and school (d8) for adolescents with and without NDD. The study also focused on whether participation changed over time in these three contexts. Hence, this study is an attempt to approach disability from a multidimensional perspective and to put everyday functioning in focus by addressing not only biological factors but also social and environmental aspects. The main findings are (1) more factors were associated with participation outcomes at time1 for adolescents without NDD than for adolescents with NDD, but this difference in the number of factors decreases with time; (2) only a few associations were related to time for both adolescents with and without NDD; and (3) patterns of predicting variables are different for adolescents with and without NDD.

TABLE 5 | Associations (presented as β-coefficients) between the independent variables experience of time and self, stress, support from siblings and atmosphere in the family and the dependent variables participation frequency and perceived involvement in domestic life, peer relations and school.

	Outcome variables						Outcome variables					
Independent variables ⇩	**Frequency of participation in domestic life (d6[a])**	**Perceived involvement of domestic life (d6)**	**Frequency of participation in peer relations (d7)**	**Perceived involvement of peer relations (d7)**	**Frequency of participation in school (d8)**	**Perceived involvement in school (d8)**	**Frequency of participation in domestic life (d6)**	**Perceived involvement of domestic life (d6)**	**Frequency of participation in peer relations (d7)**	**Perceived involvement of peer relations (d7)**	**Frequency of participation in school (d8)**	**Perceived involvement in school (d8)**
	Time 1	**Adolescents with NDD (*n* = 154)** β-coefficients					**Time 1**	**Adolescents without NDD (*n* = 762)** β-coefficients				
	Model 1	**Model 2**	**Model 3**	**Model 4**	**Model 4**	**Model 5**	**Model 6**	**Model 7**	**Model 8**	**Model 9**	**Model 10**	**Model 11**
Experience of time and self (b180[a])									0.056 $P = 0.027^a$		0.130***	
Stress (d240)	0.071*							0.098**	0.110***	0.148***	−0.061 $P = 0.001^a$	−0.111*** $P = 0.001^a$
Support from siblings (e3)			0.095*	0.092*			0.061***	0.058**	0.051**	0.044**	−0.061** $P = 0.041^a$	−0.098***
Atmosphere in the family (e4)				−0.19 $P = 0.03^a$			−0.138 **	−0.132**		−0.152***	0.177***	0.264***
Sex	−0.177**						−0.126***	−0.070*		−0.114*** $P = 0.022^a$		
Age											0.054*	0.079***
	Time 2						**Time 2**					
Experience of time and self						0.281*			0.184***		0.171***	
Stress	0.072*		0.203*			−0.386***	0.072*	0.145***	0.129***	0.099**	−0.234***	−0.546***
Support from siblings	0.051***					−0.102*	0.051***	0.036*	0.061***	−0.006	−0.006	−0.107***
Atmosphere in the family	−0.129**		−0.278*	−0.478***			−0.129**			−0.179***	0.139**	0.246***
Sex	−0.135***						−0.095***			−0.031		
Age						−0.124*						
R^2	0.120	0.032	0.087	0.104	0.070	0.296	0.076	0.045	0.059	0.084	0.066	0.395

*Separate analyses for adolescents with and without neurodevelopmental disorders (NDD). All independent variables included simultaneously. Only the significant associations and associations with significant differences between time 1 and time 2 are presented as "P=". *P ≤ 0.05, ** ≤ 0.01, *** ≤ 0.001 a = p-value for diff between time 1 and time 2 (i.e. the interaction effect). [a]ICF-codes: D6 = domestic life, d7 = interpersonal interactions and relationships (in this study; peer relations), d8 = major life areas such as education (World Health Organization, 2007).*

Body, Activity, and Environmental Factors Associated With Participation Outcomes for Adolescents With and Without NDD

Earlier research has demonstrated that participation is related to the specific context of an activity (Imms et al., 2016) but also to person characteristics such as sense of self. Using the first time point of the LoRDIA data, Carlberg and Granlund (accepted) have investigated participation in the school of setting for adolescents with and without NDD. They found that adolescents with self-reported NDD are particularly vulnerable and have an increased risk of participation restrictions in school even after controlling for body and environmental factors, e.g., maturity and family atmosphere. This study is a continuation of their study, aiming to shed light on the participation of adolescents with and without NDD in school and in areas outside school. By leaving self-reported NDD out of the equation we hoped to identify factors other than impairment which were important for participation. Based on our regression models, we found differences in patterns of factors related to participation between the groups. There are more associations between participation and body, activity and environmental factors for adolescents without NND and fewer factors associated with participation for adolescents with NDD, especially at time 1. This might indicate that NDD is a strong factor that partly "drives functioning" in childhood, especially in school (d8), but that NDD's influence on participation lessens with increasing age. The increased number of factors associated with participation, at time 2 especially in school, may indicate that with experience and increased skills (probably obtained from the family setting) the adolescents can manage their school situation differently, depending on the level of family support.

Willis et al. (2017) presented three types of elements relating to participation: person-based, activity-based and environment-based. In the current study, results indicate that a person- based elements' experience of time and self and gender have a stronger association with participation for adolescents without disabilities in relation to frequency of participation with peers and in school, both at times 1 and 2. For adolescents with disabilities these aspects are only associated with involvement in school at time 2. Sex was another personal factor relevant to participation for adolescents without NND, more so than age. This was probably due to the fact that the difference in age within each wave was not that great. Again, these associations between gender and participation were weaker for adolescents with NDD. It might be that the impact of having an impairment is so strong that it overshadows the impact of other person-based factors. However, our results suggest that the influence of impairment decreases with maturity and changes in life roles.

Activity- based elements, were represented in this study by stress. Handling stress seems to be relevant for both groups and has a negative association with perceived involvement in school, especially in wave 2 when the adolescents were about to transition from middle school to high school. In school, with its emphasis on cognitive function, the perception of stress is probably more frequent in adolescents with NDD. Perhaps one reason for this is that schools have difficulties in adapting their curriculum for adolescents with NDD (Nilsson Sjöberg, 2014). The results indicate that stress has the same impact on adolescents independent of having an impairment because of transitions and other normative events.

Environment-based factors measured in this study were support from siblings (e3) and family atmosphere (e4). Support from siblings was associated with all participation outcome contexts for adolescents without NDD at time1, but not for adolescents with NDD, where significant associations were found only for participation only in terms of frequency of participating in peer relations (d7) and the perceived importance of peer relations (d7). This can indicate that the more support from siblings, adolescents with NDD receives, the more often they will meet with peers and the higher they will rate the importance of peer relations. Atmosphere in the family was also associated with most participation outcomes for adolescents without NDD at both time 1 and time 2 but was not at all associated with participation in domestic life, in school or with peers at time 1 for adolescents with NDD. However, at time 2, atmosphere in the family was associated with frequency of participation in domestic life and peer relations as well as perceived involvement in peer relations for adolescents with NDD. Overall, the results indicate the importance of family factors for participation that takes place outside the family. The presence of family factors as influences only at time 2 for adolescents with NDD might suggest that the increased life role expectancy of peer relations that comes with increased age requires family support. Adolescents with NDD who develop an increased ability to communicate and interact within a positive family atmosphere could possibly manage peer relations more positively.

Participation Patterns and Their Associations With Time

The current study indicates few (five) significant associations between participation and time. This might be due to a number of reasons: for example, the 2-year duration of the study may be too brief to offer an in-depth understanding. Another reason might be that using only two time points does not offer enough scope to capture change in relation to the participation outcome variables. A third reason might be that adolescents perceive and rate participation in their specific niches related to the present situation or context, and that the contexts have not changed. Over time some associations do get stronger, such as frequency of participation in peer relations and the experience of time and self perhaps unsurprisingly as adolescents develop more of their own identity and strengthen time spent with peers. This is in line with Shanahan and Flaherty (2003), who report that when adolescents develop a stable sense of identity, their awareness of cultural values and behavioral expectations becomes prominent. Peers will be more important as a group of reference and can have quite a strong impact on determining actions, perceptions, and attitudes. Another aspect of maturation can be seen in the association between sex and the perceived importance of peer relations. Boys tended to rate the importance of peer relations as less important than girls at time 1, a difference that decreased at time 2. The negative associations between stress (d240) and

time in the models predicting frequency of participation and perceived involvement in school (d8) were stronger at time 2. In the Swedish school system, students receive grades for the first time in 6th grade and over time these grades gain in importance, affecting access to attractive high school programs, and thus increasing pressure in school, i.e., a contextual change. Time 2 data was collected just before the transition to high school. This increase in demands seems to be related to a decrease in the perceived importance of school. In addition, the influence of support from siblings (e3) on the degree of truancy decreases with age, perhaps because the influence of peers increases. The result indicates the importance of providing support in school to children with self-reported NDD as suggested by Måsse et al. (2013).

One could argue that the observed changes in associations are an indication of development/maturity or changes in life roles, where, for example, family relations and support from siblings (e3) are perceived as being less important as one gets older, whereas peers and the influence of peers (d7) become more prominent. In the current study, however, this was not as obvious for adolescents with NDD. The atmosphere in the family (e4) was associated with participation only at time 2 and the association with support from siblings was less associated with participation. Possibly, the process of change in the contexts for participation, from family activities to peer activities, is slower for children with NDD since they are dependent on the family for a longer time.

Differences in Participation Patterns Between the Two Time Points

The pattern of associations between body, activity and environment and the participation outcomes were more similar for adolescents without NDD than for adolescents with NDD when time 1 and time 2 were compared. Again, this might be explained by the fact that the typical life roles, i.e., contexts for participation, expected for adolescents without NDD at age 12 occur later for adolescents with NDD. While none of the independent variables were related to participation in school for adolescents with NND at time 1, school participation seems to be more associated with person-based and activity-based elements at time 2. In conclusion, the pattern of associations between body, activity and environment factors and participation for adolescents with and without NDD seems to be more similar at time 2. Probably, as adolescents with NDD get older and more mature, they acquire skills that are helpful in adjusting to their impairment in relation to participation both in terms of frequency of attendance and the perceived importance of everyday contexts. This might indicate that adolescents, with age, become more dependent on their own skills and activities themselves activity than on contextual factors such as support. It is not possible to tell from this study whether this change illustrates a situation where adolescents with self-reported NDD have voluntarily chosen a higher degree of independence (have become more autonomous) or whether they find themselves left without support from family and society.

Methodological Considerations

Some methodological considerations should be mentioned. First, the results in the current study are based on self-reported data. This could be considered a strength, since the children's own opinions are in focus, but it has not been possible to determine whether adolescents with self-reported problems have a neurodevelopmental disorder or not. Additionally, the relatively short period of time between time 1 and time 2 might have decreased the possibility of finding actual changes in the variables chosen to predict participation. The main outcome for participation was a series of indices with, in some cases, relatively low internal consistency, which is probably a consequence of the complexity in defining participation (Granlund, 2013; Imms et al., 2016). The low consistency might also be due to the fact that these indices were a result of an earlier linking procedure where the challenges in linking items with latent meaning to the ICF-CY was explored (Augustine et al., 2017). These indices were kept because of their clinimetric importance, with references to earlier research in which the ICF-CY was used to conceptualize participation in school (Maxwell et al., 2012). The relatively substantial difference in sample sizes is probably one of the reasons to why fewer significant associations were found among adolescents with NDD. Independent of effect size, power will be higher for a group of 762 adolescents (without NND) than for a group of 154 adolescents (with NND). Our sample is sufficient in finding relations with medium effect size, small in order to with higher security find relations with small effect size. Using for example an Exact test, H1 P^2, two tailed, would need a sample of 225, which indicate that our sample of 154 is too small for a power of 0.95, rather power for the NND groups is 0.80. Arguably this might be a reason for finding more significant relations in the norm group as sensitivity there is much greater. Regarding attrition, as there was no second attempt to include adolescents missing at the day of data collection, one possible reason for attrition is therefore absence from school. Finally, it should be underlined that the results from the present study are to be viewed from a group-level perspective. Individual variations between children need to be emphasized in clinical practice. Having a diagnosis does not mean that one child is like the other, but general patterns on a group level can be illustrated with the study design applied in this study.

Future Research

In the ICF-CY (2007), the use of a profile approach over different areas of functioning on body, activity and participation level is stressed, which the results of this study underscore. The relations between body, activity and environment factors and participation varied not only between the different types of activity for which participation was self-reported, but also regarding which body, activity and environmental factors were related to participation at different time points and for the two different groups. Changes over time in functioning are difficult to capture with the ICF-CY system. One possible solution is to use a person-centered longitudinal approach to try to understand children's experiences of participation in a holistic, interrelated, and dynamic manner. Person-centered approaches allow analyses of variability in functioning profiles among individuals whereas

variable-centered approaches like the one used in the present study, consider one variable at a time (Bergman et al., 2003). Further studies, in which both adolescents with and without disabilities are included, and where participation in specific types of activities is examined as participation profiles, would be of value. In such research, patterns of adolescent participation in diverse types of activities would be examined simultaneously.

CONCLUSIONS

This study reveals that patterns of participation are partly associated with different factors for adolescents with and without NDD, but that the patterns become more similar with time. Stress tends to be associated with participation both for adolescents with and without NDD and this association seems to increase over time. More variables regarding body, activity and environment were associated with participation at time1 for adolescents without NDD than for adolescents with NDD. The impact of self-reported NDD on participation in general may decrease as the adolescents get older and more skilled. The influence of factors related to context seems to increase, which might be explained by the fact that the adolescents acquire social skills that facilitate participation to different degrees: at home, with peers and in school. The importance of the family environment for acquiring these skills must be stressed. In school, there are more differences between groups, especially in relation to the impact of stress. Therefore, interventions need to be directed toward this context, where the impact of NDD seems to be more prominent.

ETHICS STATEMENT

This study was carried out in accordance with the recommendations of the Swedish Research Council's rules and guidelines for research with written informed consent from all subjects. All subjects gave written informed consent in accordance with the Declaration of Helsinki. The protocol was approved by the Regional Research Review Board in Gothenburg, Sweden (No. 362-13; 2013-09-25, and additional approvals for wave II 2014-05-20 (T446-14) and wave III 2015-07-31 (T553-15).

Since this study includes children, all caregivers were asked for consent and the children themselves gave their consent at the time of the data collection.

AUTHOR CONTRIBUTIONS

FL was responsible for the design, data collection, analysis, and interpretation of data as well as drafting and revising the manuscript. MG contributed in the design and the interpretation of data. IK assisted substantially in the data analysis. LA and KH contributed in interpretation of data. All authors have critically revised the article and contributed to its content.

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