

Title:

Social participation and interventions supporting teenagers and young adults living with developmental coordination disorder (DCD): Results from a Scoping Review

Short title:

Participation of youths with DCD

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ABSTRACT

Background: The impact of Developmental Coordination Disorder (DCD) on teenagers' and young adults' participation is not well documented. This article aims to synthesize the current knowledge on social participation, which is the performance of an individual in realizing his daily activities and social roles within its life environment. Strategies and interventions to support youths (15-25 years old) with DCD were also synthesized.

Methods: A scoping review interrogating three databases and using 'snowballing techniques' was performed to identify both scientific and grey literature published between 2004 and 2014. Over 1000 documents were screened and 57 were read in full; 28 met inclusion criteria. A charting form based on 12 life habits described in the Disability Creation Process (DCP) and developed by two reviewers was used to extract data and report the results.

Results: All life habits were reported to be affected for teenagers and young adults with DCD, with education and interpersonal relationships being the most frequently discussed. During adolescence and adulthood, new tasks and subsequent difficulties emerge, such as driving. Mental health difficulties emerged as a key theme. Few strategies and interventions were described to support social participation of youths with DCD.

Conclusion: Many life habits are challenging for youths with DCD, but few evidence-based strategies and interventions have been designed to help them to increase their social participation.

BACKGROUND

Developmental Coordination Disorder (DCD) is a condition affecting approximately 5-6% of children and is characterized by its impact on a youth's ability to learn and to perform activities requiring motor coordination (American Psychiatric Association 2013). According to the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), the diagnostic criteria for DCD are: 1) acquisition and execution of coordinated motor skills are below what is expected from peers of the same age, 2) motor skills deficit significantly interferes with activities of daily living (ADL) and impacts school, leisure and productive activities, 3) difficulties begin early in the development, and 4) difficulties are not attributable to another condition (e.g., cerebral palsy, intellectual disability) (American Psychiatric Association 2013). For children, it is well documented that DCD can interfere with many activities requiring gross and fine motor coordination, such as walking, tying shoe laces, throwing balls, writing and eating (American Psychiatric Association 2013; Asonitou *et al.* 2012; Magalhães *et al.* 2011; Prunty *et al.* 2013; Summers *et al.* 2008). DCD can also lead to secondary consequences, such as bullying and low self-esteem (Bejerot *et al.* 2013; Skinner & Piek 2001). Recently, Sylvestre *et al.* (2013) reported that children with DCD scored significantly lower on each of the 12 life habits of the Disability Creation Process (e.g., nutrition, fitness, personal care, communication) compared to their peers. They concluded that DCD negatively impact on children's social participation, which is defined as the performance of an individual in realizing his daily activities and social roles within its life environment (Fougeyrollas *et al.* 1998).

There is a consensus that DCD is a chronic, life-long condition (Cantell *et al.* 2003; Cousins & Smyth 2003; Losse *et al.* 1991). Coordination difficulties persist over time, as shown by studies demonstrating that young adults with DCD continue having poorer manual dexterity, balance,

gross motor skills and performance in handwriting tasks than their peers (Cousins & Smyth 2003; Rosenblum 2013). Moreover, adolescents and young adults are expected to perform new activities of daily living such as driving and social roles that require new skills. These create an extra challenge for those with DCD. For instance, Kirby et al. (2011c) found poorer driving behaviours in adolescents and adults with DCD compared to those without. Higher education can also bring new challenges: for instance, leaving home to go to college results in less parental support, which may increase the risks of mental health problems (e.g., depression, anxiety) (Hill & Brown, 2013; Kirby *et al.* 2011a). Consequently, it is not surprising to observe that youth with DCD are more likely to drop out of school, especially if they have a common comorbid condition such as Attention Deficit Hyperactivity Disorder (ADHD) (Rasmussen & Gillberg 2000). These are just some examples of the new challenges faced by youth with DCD. However, little is known about the overall impact of DCD on their social participation.

The aim of this paper was to synthesize the current knowledge on the social participation challenges faced by youth (15-25 years old) living with DCD and to present what is known about the strategies and interventions that may support them in their daily activities and social roles.

METHODS

Scoping reviews are increasingly used in research, mostly because they provide the opportunity to “map” the breadth and depth of knowledge in a field (Levac *et al.* 2010). They offer the advantage of including scientific and grey literature to establish the current status of knowledge, especially when systematic reviews cannot be done considering the paucity of research in the field. Scoping reviews may also help to identify the “gaps” in knowledge, as well as to evaluate the feasibility of conducting a systematic review (Arksey & O’Malley 2005). This scoping review followed the 6 stages developed by Arksey and O’Malley (2005) and refined by Levac and colleagues (2010).

Stage 1 identified the research question: in this study, we asked “*What are the social participation challenges faced by youth (15-25 years old) living with DCD?*”. We used the definition of social participation presented earlier and the 12 categories of life habits described in the DCP framework (e.g., nutrition, fitness) (Fougeyrollas *et al.* 1998). As a sub question, we asked: “*What are the recommended or trialled interventions to support participation for youth with DCD.*”

Stage 2 involved the identification of relevant studies. Scientific literature published in English between January 2004 and December 2014 was searched using three databases (PubMed, PsycInfo and CINAHL). Other inclusion criteria were: (1) the results or the recommendations were applicable for participants (a) who had received a diagnosis of - or for whom there was a suspicion of - DCD and (b) were aged between 15 and 25 years old. We selected this age group because of the new challenges generally faced by youth during this period, as they face new responsibilities, learn to drive, enter the labour market and transition to independent living; (2) the articles described the impacts of DCD on teenagers or young adults; and (3) the articles described impacts of DCD on social participation, or proposed strategies and interventions to increase participation. Keywords included were Developmental Coordination Disorder, Developmental Co-ordination Disorder and the Mesh term “Motor Skill Disorder”. Filters for the inclusion criteria with regards to age were also used. We decided not to use any specific key words about social participation to limit the risk of missing relevant articles. Rather, articles identified were reviewed and those focusing only on impairments and not discussion daily living and social participation were excluded. The same inclusion criteria and keywords were applied to the grey literature search on the web (review of the 100 first results on Google). A total of 1033 articles (127 from CINAHL, 247 from PsycInfo, 659 from PubMed) were found. This was reduced to 849 articles after the elimination of duplicates and non-English or non-French articles. A total of 170 articles remained after screening the titles for

relevance. After reading the abstracts, 57 articles remained. An email was sent to known experts in DCD in Canada and the UK to identify any additional relevant sources; four new documents were included for full review, leading to a total of 61 documents.

Stages 3 and 4 – these iterative stages included study selection and data charting. A data charting form based on the DCP was drafted by two of the authors (MGR and CC). After independently completing the data extraction from the first three articles, MGR and CC reviewed the data charting form in order to ensure consistency in the information extracted. The form included information about: (1) description of the social participation challenges of youth with DCD, according to the 12 DCP life habits; (2) strategies, interventions or recommendations (proposed or trialled) to improve social participation; and (3) type of document (author opinion, descriptive study, results of an empirical study, systematic review or grey literature). Because mental health challenges emerged as a key theme in the selected documents, information about the impact of DCD on mental health and quality of life was included in the revised version of the data charting form. Following consensus between MGR and CC on the data extracted and the revised version of the data charting form, MGR completed the revision of the remaining articles. Four additional articles were reviewed and discussed with a third reviewer (EJ) to ensure interrater reliability. Following the data charting and according to the inclusion criteria, 28 documents were included and analysed.

Stage 5 involved the data analysis. Frequency analysis was performed to identify the number of documents: 1) reporting challenges in each of 12 life habits, and discussing mental health and quality of life challenges; 2) describing strategies or recommendations for interventions (trialled or only proposed); and 3) pertaining to each of the types of documents included. With regards to social participation challenges and interventions, MGR performed a thematic analysis according to the DCP; CC and EJ reviewed the interpretation to ensure validity. Stage 6, the

consultation stage, is underway (presentations to rehabilitation students and DCD researchers and consultations with the DCD parent association have been undertaken to date). Discussion about the implications and future steps are ongoing.

RESULTS

Quantitative analysis

Of the 28 documents included in this scoping review, 3 were expert opinions, 16 were descriptive studies, 2 were empirical studies, 1 was a systematic review and 6 documents were from the grey literature. Seven (25 %) documents discussed adolescents only, 11 (39 %) were about young adults and 10 (35 %) concerned both.

Altogether, the documents reported challenges for youth with DCD in each of the 12 life habits. The majority of documents described challenges in education (n=15; 54%), interpersonal relationships (n=15; 54%) and recreation (n=14; 50%). Many documents also reported difficulties in employment (n=13; 46 %), mobility and communication (n=12; 43 %), personal care (n=7; 25 %), housing (n=6; 21%), nutrition (n=5; 18 %) and responsibilities (n=4; 14 %). Challenges in fitness (n=3; 11 %) and community life (n=1; 4 %) were also reported, but less frequently. Finally, 16 documents (57 %) discussed the quality of life and mental health of youth with DCD. Strategies, recommendations and interventions to support social participation were also described in 14 documents (50 %). However, none of these have been formally evaluated through an empirical study.

Qualitative analysis

Life Habits

Themes that emerged for each life habit are presented in Table 1 and discussed below.

(Insert table 1 about here)

Education

Numerous education challenges for youth with DCD were described in the literature. Handwriting and executive functioning difficulties (e.g., organization and planning, prioritizing, problem solving, multi-tasking) affected the ability of youth with DCD to perform academic activities adequately and in a timely manner (Kirby *et al.* 2008a, b, 2011a, b; Kirby 2004, 2011; Lingam *et al.* 2014; Rosenblum 2013; Tal-Saban *et al.* 2012, 2014; Zwicker *et al.* 2013). Adolescents and young adults with DCD were also reported to have difficulties with concentration and memory, abstract subjects such as mathematics, the use and manipulation of technical and technological equipment, and physical demands (e.g., in physical education) (Kirby, 2004; Kirby *et al.* 2008b; Lingam *et al.* 2014; Missiuna *et al.* 2008; Tal-Saban *et al.* 2012; Zwicker *et al.* 2013).

Communication

Difficulties with communication were also reported, mostly with written and non-verbal communication (Kirby *et al.* 2008, b, 2011a, b; Kirby 2011; Lingam *et al.* 2014; Missiuna *et al.* 2008; Rosenblum 2013; Tal-Saban *et al.* 2012; Zwicker *et al.* 2013). Difficulties with written communication were related mostly to poorer handwriting skills of adolescents and young adults living with DCD compared to their peers (e.g., slower performance, lower legibility, pain when writing). Non-verbal communication difficulties were associated to the fact that youth with DCD may not be able to pick up on social cues and recognize who is a real friend (Kirby 2011). Awareness of spatial and social rules may also be problematic, as the individual find it difficult to adequately judge social distance and the best way to interact with others, including appropriate physical distance and eye contact (Kirby 2004). Nonetheless, oral communication (e.g. communicating and speaking in public) was reported as a strength by almost half of youth with DCD (Kirby *et al.* 2008b).

Interpersonal relationships

Social difficulties (e.g., marginalization, bullying, difficulties with sexual relationships) and isolation were reported in youth with DCD, as well as shyness and a lack of confidence (Drew 2005; Kirby *et al.* 2011b; Kirby 2011; Lingam *et al.* 2014; Missiuna *et al.* 2008; Tal-Saban *et al.* 2014). Some individuals with DCD reported an improvement of their social status as they aged; they reported making friends who accepted them despite their motor deficits (Tal-Saban *et al.* 2014). Relationships with family members were described to be easier than relationships with peers (Tal-Saban *et al.* 2014). Nevertheless, youth with DCD often needed more support and help from their parents which may create tension between family members and frustration for parents (Kirby *et al.* 2011b; Missiuna *et al.* 2008).

Community Life

Little is known about community life. According to Drew (2005), individuals with DCD participated in fewer community activities than their peers but no more details were provided.

Recreation

Many individuals with DCD reported having difficulties with physical activities (e.g., riding a bike, catching and throwing balls) and sports, especially with team sports (Barnett *et al.* 2013; Kirby *et al.* 2008a; Lingam *et al.* 2014). Consequently, youth with DCD were less likely to participate in sports and group activities, or to go dancing in nightclubs; they tended to engage in more sedentary activities (Kirby *et al.* 2008a, 2010, 2011b; Kirby 2011). Nevertheless, an improvement in their functional-social status was reported by some, as they were no longer obligated to participate in challenging activities and could decide which activities they wanted to engage in or not (Tal-Saban *et al.* 2014).

Fitness

Researchers suggested that individuals with DCD were at risk of withdrawing from physical activities and be less motivated to engage in sports, which may cause fewer opportunities to develop proficient motor skills and fitness (Dunn & Goodwin 2008). They also reported being easily tired when doing physical activities (Barnett *et al.* 2013; Drew 2005). Consequently, youth with DCD tended to be less fit than their peers (Cantell *et al.* 2008; Gísladóttir *et al.* 2013).

Employment

Similar to Education, executive functioning and working memory difficulties were reported to affect youth's performance of their job; for example, many individuals with DCD reported that learning the techniques for a new job was challenging (Kirby *et al.* 2011a, b, 2013; Missiuna *et al.* 2008). Manual labour may be difficult for them as well, and they may experience more physical injuries (Missiuna *et al.* 2008). Moreover, a higher proportion of individuals with DCD were reported to be unemployed or under-employed (in less skilled jobs) compared to their peers, and the severity and persistence of DCD seemed to negatively impact the opportunities to gain specialized jobs (Missiuna *et al.* 2008).

Mobility

Only difficulties relating to driving were discussed in the literature. As a novel task, many adolescents and young adults reported difficulties learning how to drive, which may explain why fewer individuals with DCD drove compared to their peers (de Oliveira & Wann 2011; Kirby *et al.* 2011c; Missiuna *et al.* 2008). In addition, they tended to travel fewer miles per week and to have more difficulties parking (Kirby 2011; Missiuna *et al.* 2008). Recently, de Oliviera and Wann (2011, 2012) found that individuals with DCD may be less safe when driving: in addition to

difficulties with distance perception, sequencing and dual-tasking, youth with DCD had slower reaction times and made less precise adjustments with the steering wheel.

Personal Care

Personal care becomes easier for youth with DCD as they age. Self-care skills can be automated with time as they are usually undertaken in stable environments such as the youth's home (Kirby *et al.* 2011a, b; Tal-Saban *et al.* 2014). However, novel tasks, tasks involving executive functioning demands (e.g., packing a bag), fine motor tasks (e.g., shaving legs, hair styling, putting on makeup) or activities being undertaken without vision were challenging for adolescents and young adults with DCD (Kirby, 2004; Kirby *et al.* 2008b, 2011a).

Nutrition

Activities such as using cutlery were automated over time by youth with DCD (Kirby *et al.* 2011b). However, meal preparation (e.g., organisation, food manipulation, operation of electrical equipment) were reported to be challenging and time-consuming (Drew, 2005; Kirby, 2004).

Housing

Challenges at home included difficulties organizing and finding things in their room, operating and using electrical equipment such as washing machines, and carrying out household chores (Drew, 2005; Kirby *et al.* 2008a, 2010, 2011b). Adolescents and young adults with DCD were also more likely to live longer at their parent's home than their peers (Kirby *et al.* 2008a, b).

Responsibilities

As a new life habit, financial, civil and family responsibilities were particularly affected in youth with DCD. Reported difficulties included financial management, planning and form completion (Kirby 2004; Kirby *et al.* 2011b; Tal-Saban *et al.* 2014).

Quality of Life and Mental Health

Researchers suggested that the secondary emotional problems associated with DCD may have more impact on the quality of life of youth with this condition than the primary motor difficulties (Hill *et al.* 2011). Consequently, youth with DCD reported poor quality of life and life satisfaction as well as low self-esteem and self-worth (Hill *et al.* 2011; Kirby 2011; Missiuna *et al.* 2008; Tal-Saban *et al.* 2012). Their lower perception of their capacities in addition to the social isolation and withdrawal from activities may also explain the higher proportion of mental health problems (e.g. anxiety and depression symptoms) reported in individuals with DCD compared to their peers (Hill *et al.* 2011; Hill & Brown 2013; Kirby, 2004; Kirby *et al.* 2008a; Piek *et al.* 2007; Tal-Saban *et al.* 2014). These mental health challenges may be exacerbated when they move to college or university, where the lack of parental support may increase loneliness (Kirby *et al.* 2011a). Unemployment was also associated with a higher level of anxiety and depression (Kirby *et al.* 2013). Themes and supporting references are presented in Table 2.

(Insert Table 2 about here)

Interventions

Five principal types of strategies, recommendations and interventions to support social participation of youth with DCD emerged: (1) Compensatory strategies; (2) Development of coping strategies; (3) Information; (4) Addressing co-morbidities and secondary consequences; and (5) Practice and development of functional abilities (see Table 3).

(Insert Table 3 about here)

In many research studies, a range of *compensatory approaches* were recommended to improve participation. This type of intervention could be used, for example, to facilitate driving (e.g., driving an automatic transmission vehicle, reducing travelling speed) and to support the

individual with DCD at school or in their work environment (e.g., using a computer for writing, managing daily timetables, using checklists with instructions broken down into detailed tasks and clearly written by the employer) (de Oliveira & Wann 2012; Kirby *et al.* 2008a; Lingam *et al.* 2014). *Coping strategies* included choosing activities that matched their abilities and avoiding those that didn't, as well as using humour to deflect attention from their difficulties (Kirby *et al.*, 2008a, 2010; Missiuna *et al.* 2008). *Informing* people in the youth's environment (e.g., employers and teachers) about DCD was recommended as these individuals can modify expectations and tasks, and can help the teenagers or young adults to compensate for their difficulties (Kirby *et al.* 2011c). The information may be given by youth themselves or by therapists (e.g., through school-based intervention for teachers) (Lingam *et al.* 2014). Furthermore, *addressing co-morbidities and secondary consequences* was recommended, as many have a co-occurring condition such as ADHD or a mental health condition that can be secondary to DCD (e.g., depression, anxiety) which may need to be differently treated (Piek *et al.* 2007). It appeared essential to consider both the social and psychological spheres in order to prevent secondary mental health problems, as they might considerably impact on youth's participation. Finally, *practice and development of functional abilities* such as practicing driving skills on a simulator (e.g., coping with oncoming traffic, estimating distance) or social skill in a controlled environment (e.g., interpreting non-verbal gestures) may improve day to day life and promote the development of a more positive self-perception (Kirby 2004; Kirby *et al.* 2011). All of the above strategies and recommendations for interventions were suggested, but have not been formally trialled or evaluated.

DISCUSSION

All of the 12 life habits described in the Disability Creation Process (DCP) may be affected for adolescents and young adults with DCD, and are similar to those reported for children with DCD

(Sylvestre *et al.* 2013). These results are also congruent with previous research identifying the persistent nature of this condition (Cantell *et al.* 2003; Cousins & Smyth 2003; Losse *et al.* 1991). Transition to independent life may bring supplementary challenges (e.g., driving, financial management, household chores, employment), especially given the fact that youth are expected to undertake them with less parental support (Kirby *et al.* 2011a). Furthermore, challenges faced by individuals with DCD in some life habits exacerbate challenges in others. As proposed by Kirby *et al.* (2011c), driving difficulties and mobility limitations may interfere with social and community activities, employment, education and responsibilities. Difficulties in education, communication and fitness may also influence career choices (Kirby *et al.* 2011a; Missiuna *et al.* 2008). Leisure, fitness and communication might influence interpersonal relationships, as youth with DCD may not have the same interests and opportunities to network than more-skilled peers, and might have more limited non-verbal communication skills (Kirby 2004). Challenges experienced by youth in any given area may consequently reduce participation in other life habits and compound their difficulties.

Moreover, quality of life and mental health challenges emerged as key themes in the DCD literature (Zwicker *et al.* 2013). According to Missiuna *et al.* (2006), mental health problems emerge in early adolescence and continue into adulthood, which could explain the importance of this theme in this scoping review. This is also consistent with research showing that the emotional impacts of DCD may be greater than the primary motor difficulties on the youth's quality of life (Hill *et al.* 2011; Missiuna *et al.* 2007). Overall, individuals with DCD reported poor self-esteem and self-worth (Hill *et al.* 2011; Hill & Brown 2013; Kirby *et al.* 2008; Tal-Saban *et al.* 2014), which might result from the difficulties and the high demands they experienced in their day-to-day life (academic, social, etc.). Social isolation and lack of social support may also increase the risk of mental health problems, as they are associated with reduced self-worth and depressive symptoms

(Chou *et al.* 2011; Hall-Lande *et al.* 2007; Hefner & Eisenberg 2009). Reduced social participation can probably negatively impact mental health, while mental health issues probably reduce the opportunities for participation, resulting in a vicious circle for youth with DCD.

Nonetheless, some improvements and strengths were reported in adolescence and adulthood compared to childhood. This is congruent with some studies that found an improvement in functional-social status and the potential to “catch up” with their peers (Cantell *et al.* 2003; Tal-Saban *et al.* 2014). Participation in several life habits may improve with practice along with the development of coping strategies, such as using humour and choosing activities according to their abilities (Missiuna *et al.* 2008, Kirby 2004). Using coping strategies might explain why some individuals experience improvements in adulthood while others do not; however, the severity of DCD might also be an important factor explaining why more motor and perceptual difficulties can persist over time (Cantell *et al.* 2003). In addition to using strategies to compensate for their difficulties, young adults might also learn to build on their strengths. For instance, few children with DCD have oral communication difficulties (Rodger *et al.* 2007) so they may learn to use their oral skills as a strength as they get older.

This scoping review identified five types of strategies, interventions and recommendations to support youth’s participation (compensatory strategies, development of coping strategies, information, addressing co-morbidities and secondary consequences and development of abilities). There is currently no published evidence to support clinical service managers and therapists to wishing to implement interventions to help youth with DCD. Further empirical studies are needed to implement and evaluate these recommendations for interventions. Kirby (2015) has used goal-setting approaches in a clinical setting with youth to prioritise the areas where change needs to take place (personal communication). Some good websites also provide practical information and resources for youth with DCD (<http://www.movementmattersuk.org/dcd-dyspraxia-adhd->

spla/developmental-disorders-documentation/dcd-and-employment.aspx) but the effectiveness of these resources has not been documented.

This scoping review provides a clear vision of the actual knowledge concerning the adolescents and young adults with DCD. The study followed a rigorous method and consulted with experts in the field to ensure that the most relevant documents were included and that the interpretation of the findings was valid. However, despite an extensive research and “snowball process”, some relevant documents may have been missed. For example, some articles focusing on childhood might have included relevant information concerning adolescents and young adults but were discarded from this scoping review. Likewise, many documents published before 2004 might have shed some light on the subject. Nonetheless, inclusion of reviews and books reduced the impact of these limitations, as they reported conclusions from older articles. Finally, variations in the definitions of skills and life habits across documents may have introduced a bias in how our results were categorized; we are however confident that they provide, overall, a comprehensive picture of participation and interventions for youth with DCD.

Considering the numerous challenges faced by youth with DCD on a daily basis, the impact on their mental health and social participation, and the lack of knowledge concerning evidence-based intervention, there is a need for research to develop and to evaluate interventions for this population. Clinicians and researchers need to work in collaboration with youth and families to implement interventions, to ensure knowledge transfer and ultimately, to improve the social participation and quality of life of youth with DCD.

KEY MESSAGES

- Many life habits (daily activities and social roles) may be negatively affected in youth with DCD.
- New participation challenges emerge during adolescence and adulthood.
- Few evidence-based interventions are available for youth with DCD.

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Table 1: Emerged themes for each of the 12 life habits and supporting references

Life Habits (Challenges)		Expert Opinion	Descriptive Studies	Empirical Studies	Systematic Review	Grey Literature
		References	References	References	References	References
Education (n=15)	Handwriting difficulties	<ul style="list-style-type: none"> - Kirby (2011) - Kirby et al. (2011b) 	<ul style="list-style-type: none"> - Kirby et al. (2008a, b, 2011c) - Lee et al. (2007) - Lingam et al. (2014) - Missiuna et al. (2008) - Rosenblum (2013) - Tal-Saban et al. (2014) 	<ul style="list-style-type: none"> - Tal-Saban et al. (2012) 	<ul style="list-style-type: none"> - Zwicker et al. (2013) 	<ul style="list-style-type: none"> - Drew (2005) - Kirby (2004) - Sahagian-Whalen et al. (2010)
	Executive functioning difficulties					
	Concentration and working memory deficits					
	Difficulties using technology					
	Difficulties in mathematics					
Low performance in physical activity classes						
Communication (n=12)	Difficulties in handwriting	<ul style="list-style-type: none"> - Kirby (2011) - Kirby et al. (2011b) 	<ul style="list-style-type: none"> - Kirby et al. (2008a, b, 2011c) - Lingam et al. (2014) - Rosenblum (2013) 	<ul style="list-style-type: none"> - Kirby et al. (2010) - Tal-Saban et al. (2012) 	<ul style="list-style-type: none"> - Zwicker et al. (2013) 	<ul style="list-style-type: none"> - Kirby (2004) - Movement Matters [website]
	Difficulties in communicating with others (nonverbal)					

Interpersonal Relationship (n=15)	Decreased communication and social skills Social isolation Bullying Possible tensions between family members	- Kirby (2011) - Kirby et al. (2011b)	- Kirby et al. (2008a, b, 2011a, c) - Lee et al. (2007) - Lingam et al. (2014) - Missiuna et al. (2008) - Tal-Saban et al. (2014)	- Tal-Saban et al. (2012)	- Zwicker et al. (2013)	- Drew (2005) - Kirby (2004) - Sahagian-Whalen et al. (2010)
Community Life (n=1)	Less likely to participate in community activities	-	-	-	-	- Drew (2005)
Recreation (n=14)	Difficulties with sports More likely to participate in individual leisure, withdrawal from team sports	- Kirby (2011)	- Barnett et al. (2013) - Kirby et al. (2008a, 2011a, c) - Lee et al. (2007) - Lingam et al. (2014) - Missiuna et al. (2008) - Tal-Saban (2014)	- Kirby et al. (2010)	-	- Drew (2005) - Dunn and Goodwin (2008) - Kirby (2004) - Sahagian-Whalen et al. (2010)

Fitness (n=3)	<p>Less fit compared to peers</p> <p>Withdraw from physical activities</p> <p>Easily exhausted</p>	<p>-</p>	<p>- Barnett et al. (2013)</p> <p>- Gísladóttir et al. (2013)</p> <p>- Cantell et al. (2008)</p>	<p>-</p>	<p>-</p>	<p>- Dunn and Goodwin (2008)</p> <p>- Drew (2005)</p>
Employment (n=13)	<p>Executive functioning and working memory difficulties</p> <p>Difficulties learning job techniques</p> <p>Difficulties with manual labor, physical injuries</p> <p>Higher proportion of unemployed individuals</p>	<p>- Kirby (2011)</p> <p>- Kirby et al. (2011b)</p>	<p>- Kirby et al. (2011c, 2013)</p> <p>- Missiuna et al. (2008)</p> <p>- Rosenblum (2013)</p> <p>- Tal-Saban et al. (2014)</p>	<p>- Tal-Saban et al. (2012)</p>	<p>- Zwicker et al. (2013)</p>	<p>- Drew (2005)</p> <p>- Kirby (2004)</p> <p>- Thomas et al. (2012)</p> <p>- Beaumont (2013)</p>
Mobility (n=12)	<p>Difficulties with driving (learning to drive, to park, to accurately perceive distance, to avoid hazards)</p>	<p>- Kirby (2011)</p> <p>- Kirby et al. (2011b)</p>	<p>- De Oliveira and Wann (2011, 2012)</p> <p>- Kirby et al. (2008b, 2011a, c)</p> <p>- Lee et al. (2007)</p> <p>- Missiuna et al. (2008)</p>	<p>- Tal-Saban et al. (2012)</p>	<p>-</p>	<p>- Movement Matters [website]</p>

			- Tal-Saban et al. (2014)			
Personal Care (n=7)	Potential improvement compared to childhood years Difficulties with personal care involving fine motors tasks, executive functioning or undertaken without vision	- Kirby et al. (2011b)	- Kirby et al. (2008a, b, 2011c) - Tal-Saban et al. (2014)	-	-	- Kirby (2004) - Sahagian-Whalen et al. (2010)
Nutrition (n=5)	Improvement in utilisation of cutlery compared to childhood years Difficulties to prepare meals	-	- Kirby et al. (2011c)	-	-	- Drew (2005) - Kirby (2004) - Movement Matters [website] - Sahagian-Whalen et al. (2010)
Housing (n=6)	More likely to live with their parents Difficulties organizing their room and performing household chores	-	- Kirby et al. (2008a, b, 2011c)	- Kirby et al. (2010)	-	- Drew (2005) - Movement Matters [website]

Responsibilities (n=4)	Difficulties in planning and managing money	-	- Kirby et al. (2011c) - Lee et al. (2007) - Tal-Saban et al. (2014)	-	-	- Kirby (2004)
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Table 2: Emerged themes for quality of life and mental health and supporting references

Quality of life and Mental Health (n=16)	Expert Opinion	Descriptive Studies	Empirical Studies	Systematic Review	Grey Literature
	References	References	References	References	References
Poorer quality of life and life satisfaction Increased anxiety and depression symptoms Increased psychiatric issues	- Kirby (2011) - Kirby et al. (2011b)	- Hill and Brown (2013) - Hill et al. (2011) - Kirby et al. (2008a, 2011c, 2013) - Missiuna et al. (2008) - Piek et al. (2007) - Rosenblum (2013) - Tal-Saban et al. (2014)	- Tal-Saban et al. (2012)	- Zwicker et al. (2013)	- Dunn and Goodwin (2008) - Kirby (2004) - Movement Matters [website]

Table 3: Emerged themes concerning interventions and recommendations, and supporting references

Interventions and recommendations	Expert Opinion	Descriptive Studies	Empirical Studies	Systematic Review	Grey Literature
	References	References	References	References	References
Compensatory strategies (n=11)	-	- De Oliveira and Wann (2012) - Kirby et al (2008a, 2010, 2011a, b) - Lee et al. (2007) - Lingam et al. (2014) - Missiuna et al. (2008)	-	-	- Drew (2005) - Sahagian-Whalen et al. (2010) - Thomas et al. (2012)
Development of coping strategies (n=6)	-	- Kirby et al. (2010, 2011b) - Lee et al. (2007) - Missiuna et al. (2008)	-	-	- Sahagian-Whalen et al. (2010) - Thomas et al. (2012)
Information (n=7)	-	- Kirby et al. (2011a, b, 2013) - Lingam et al. (2004)	-	-	- Drew (2005) - Sahagian-Whalen et al. (2010) - Thomas et al. (2012)
Consideration of comorbidities and long-term implication	- Kirby (2011)	- Kirby et al. (2011b, 2013) - Piek et al. (2007)	-	-	-

(n=4)					
Development of abilities (n=5)	-	<ul style="list-style-type: none"> - Kirby et al. (2011a) - Lee et al. (2007) - Lingam et al. (2004) - Missiuna et al. (2008) 	-	-	- Kirby (2004)