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Leisure participation for school-aged children with Down syndrome

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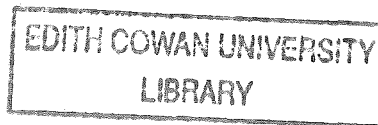
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Leisure Participation for School-aged Children with Down Syndrome



Alinta Oates

**A report submitted in Partial Fulfilment of the Requirements for the Award of
Bachelor of Science (Occupational Therapy) (Honours), Faculty of Computing,
Health and Science, Edith Cowan University.**

Submitted September 2009

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**Leisure for School-aged Children with Down
Syndrome: A Narrative Review on Participation**

ALINTA OATES

Leisure for School-aged Children with Down Syndrome: A Narrative Review on Participation

Abstract

Background. A review of existing literature is necessary to determine the future directions required in research exploring friendships and leisure for school-aged children with Down syndrome. **Purpose.** This review examines research published in peer-reviewed journals describing participation in friendships and leisure for school-aged children with Down syndrome. The review is guided by the theoretical framework of the World Health Organisation's *International Classification of Functioning, Disability and Health (ICF)*. **Methods.** Electronic searches of PubMed, PsychInfo, CINAHL, SportsDiscus and ERIC were conducted using the key terms Down syndrome, leisure and friendships. Keywords identified while using the ICF framework to explore factors impacting on friendship and leisure for school-aged children with Down syndrome were also searched. Relevant studies were critically analysed and discussed. **Results.** Electronic searches yielded 25 potential studies fulfilling components of the search criteria. Only 8 of these related to friendships and leisure in particular for this population. Other studies were identified using the keywords identified as impairment and contextual factors for school-aged children with Down syndrome under the ICF theoretical framework. A systematic review was not possible due to the paucity of research describing participation in friendships and leisure for this population. School-aged children with Down syndrome can have as few as no friends and friendships may not be confirmed by all parties eg, the child with Down syndrome, their parents and their designated friend. The most frequently participated in leisure pursuits are television watching, listening to music, playing independently with toys, games, reading and writing, shopping or running errands, going to the movies, or spending times with family members. Parents are instrumental in directing both friendships and leisure experiences for children with Down syndrome. **Practice Implications.** The majority of relevant studies identified in this review are descriptive, cross-sectional and observational in nature and do not address the ongoing need for the provision and evaluation of social interventions for school-aged children with Down syndrome to ensure a greater quality of life. Additionally, current research on factors of body structure or function, environment, and person affecting participation for school-aged children with Down syndrome does not encompass outcome measures or relate to changes in functional performance or participation. Further research is required to investigate the effect of factors described within the ICF theoretical framework on friendships and leisure for school-aged children with Down syndrome. This research would support the development and delivery of quality and evidence-based leisure programs for school-aged children with Down syndrome.

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Helen Leonard and Ms Jenny Bourke, Telethon Institute for Child Health Research

Leisure for School-aged Children with Down Syndrome: A Narrative Review on Participation

ALINTA OATES

Introduction

Down syndrome is one of the most common forms of intellectual disability. The chromosomal anomaly accounts for 14 to 15% of persons with intellectual disability receiving services in Western Australia [1] and approximately 1 in every 650-1000 births [2]. At birth, infants with Down syndrome typically display dysmorphic features such as short stature, oblique eye fissures, epicanthal folds, flat nasal bridge, protruding tongue [3]. Intellectual disability and hypotonia appear to be the two constant characteristics observed in individuals with Down syndrome [3, 4]. However, children with Down syndrome can experience additional chronic health conditions and resultant hospitalisations, which present a burden for their families and the health system [5, 6]. Of these associated health conditions, cardiac defects and respiratory infections have accounted for the majority of infant fatality and comorbidity reported for children with Down syndrome in Australia [7, 8].

Historically, the seriousness of life-threatening health conditions overshadowed the importance of research investigating the impact of both physiological and contextual factors on the functional, academic and leisure performance and participation of children with Down syndrome [9-11]. Advances in medical interventions such as improved surgical techniques and the introduction of antibiotics in the 1950's, have improved the health of children and adults with Down syndrome by successfully correcting, preventing or managing much of the comorbidity associated with Down

syndrome [6, 12, 13]. Adult life expectancy for individuals with Down syndrome has increased to 60 years and nearly parallels that of the Australian population [12].

Survival rates for children born with Down syndrome have dramatically improved in the last century also, with 85% now surviving to ten years of age as opposed to 45% in 1940-1957 [14].

The focus of research for children with Down syndrome is shifting from survival to encompass broader areas impacting on quality of life such as friendships and leisure participation [15]. One priority for research is the distinct need to document the effects of social inclusion and community-based social leisure on outcomes for children with Down syndrome [16]. These areas pertain to play, and play is every child's primary occupation and means of future development [17].

Necessary for supporting the cognitive, social, physical and emotional development of all children and adolescents [17-19], the United Nations considers play a right for all children [20]. Play is beneficial for children as it develops problem solving, perspective-taking, emotional and social skills [21] by facilitating interactions between a child and their environment [17]. Consequently, these interactions lead to a child's understanding about their place in the world, as well as cause-and-effect relationships on which they can base future interactions and exploration [17, 18].

Both social relationships and leisure are components of play. Together they encourage smoother transition between life stages, greater adaptation skills, better social skills, and increased academic achievement for children [22]. Conversely, limited or

negative social and leisure experiences in the early phase of life can have adverse effects on the acquisition of developmental milestones [23], health and wellbeing [24], and happiness [25] for all children.

Theoretical Framework

Participation in situations of life, such as friendships and leisure, is impacted by an individual's ability to carry out activities involved in the particular situation [26]. Due to its ability to examine comprehensively a combination of factors influencing participation, the World Health Organisation's *International Classification of Functioning, Disability and Health* (ICF) is used in this review to provide a framework to identify factors experienced by children with Down syndrome that facilitate or act as barriers to participation in friendships and leisure. Participation in activity can be restricted by an individual's impairments to body structure and function and the limitations often presented by contextual factors (personal and environmental) [27].

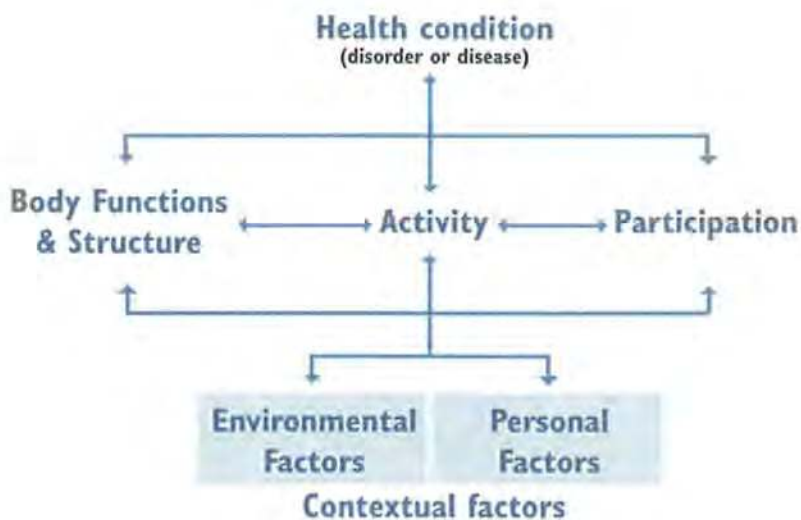


Figure 1. Dynamic interactions between the components of the ICF [27].

For example, running a race is a leisure activity requiring short bursts of running (activity), which is supported by the individual's cardiovascular and respiratory system (body structure and function). These two systems are often impaired in children with Down syndrome [28, 29], and negatively impact on the performance of the activity and the motivation to continue to participate in active leisure. Despite the noted barriers to participation, the social orienting nature of children with Down syndrome and their positive regard for their own academic and physical performance can be counteracting facilitators [30, 31] which may support further participation in running races. The ICF posits that though Down syndrome presents certain genotypical and phenotypical traits, the outcome for participation is different for each individual depending on their individual circumstances and the particular factors acting as either barriers or facilitators. Furthermore, the components in the ICF exist in dynamic relationship with one another and not always on a one-to-one level. The presence of one component may directly alter the other/others, or the health condition itself.

The purpose of this review is three fold. Firstly, the review will describe participation in friendship and leisure for school-aged children with Down syndrome as reported in peer-reviewed literature. Secondly, it will discuss possible contributing factors identified by the ICF theoretical framework and terminology. Finally, it will provide recommendations for the direction of future research and the development of disability service programs improving the participation of school-aged children with

Down syndrome in friendships and leisure.

Methods

Search processes

Electronic searches of the Pubmed, PsychInfo, CINAHL, Sportdiscus, and ERIC databases were carried out to identify appropriate studies for use in the review. In consultation with a librarian, search terms were truncated, exploded and adjusted to match individual databases used for the search. The search was performed in two parts. The first including the keywords child, youth, Down syndrome (Down's syndrome, Downs syndrome), friend, peer, social, interpersonal, relation, leisure, recreation, and sports. The second part incorporated searches on key words identified by the *ICF* theoretical framework including: Down syndrome, congenital heart defects, sleep, sensory impairments, hearing, ear, eye, thyroid, gastrointestinal, health, comorbidity, siblings, orthopaedic, atlantoaxial instability, functional ability, Down syndrome behavioural phenotype, family, maternal, paternal, sibling, transport, income. The search was applied to title and/or abstract and where possible given the limits of 'children and youth' (aged 5-17 years), 'English', and 'Clinical Trial, Meta-analysis, review, bibliography or Journal article'. The reference lists of all identified relevant studies were manually searched for other appropriate studies.

Inclusion and exclusion criteria

Studies were included if they were on the subject of friendship and leisure for children or youths with Down syndrome and conducted between the years of 1980 to 2009.

Other studies exploring the factors identified by the theoretical framework and their potential impact on participation in friendship and leisure were also included.

Studies were excluded if they were irrelevant to the topic or conducted prior to 1980.

Conference proceedings were excluded from searches.

Results

There is limited research available on the number of friends, the frequency of friendship interactions occurring outside of school, the types of leisure pursuits participated in and the factors impacting on participation in friendships and leisure for school-aged children with Down syndrome. The methodological quality of relevant available research is often of a lower level, with the majority of studies descriptive, cross-sectional and observational in nature. Due to the scarcity of research available, a systematic review was not possible and a narrative review was undertaken to summarise findings.

Friendships for school-aged children with Down syndrome

Electronic searches located 4 articles pertaining to friendships for children with Down syndrome. One study was conducted with infants with Down syndrome [32], two with school-aged children with Down syndrome [33, 34], and the last study was on both friendships and leisure for youths and adults aged up to 30 years [35].

Children with Down syndrome have few friendships. Guralnick (2002) compared peer interactions in 64 children with Intellectual disability and 21 infants with Down syndrome aged between 48 to 71 months. Children with Down syndrome had at least one regular playmate (on average two), spent 8-14 hours per week with each

playmate, and participated in one or two occasions of play with their playmates per week. Children with Down syndrome had playmates with greater variances in age than did children with Intellectual disability [32]. No differences between groups were found for the frequency of interactions and the nature of their social networks. However, mothers of children with Down syndrome rated inclusion and its benefits for their children, higher than did mothers of children with other Intellectual disability [32].

These findings mirror reported friendship numbers for school-aged children with Down syndrome who identify as few as one friend, and sometimes none [33, 34]. The characteristics of friendships between 27 school-aged children with Down syndrome and their chosen friends were examined in an observational study by Freeman and Kasari (2002). The study, designed to simulate a play date, revealed only 20 of the parent-reported friendships responded in ways that conformed to the strict friendship criteria outlined by the study. Moreover, the parents reported more best friends and more general friends for their child than do the children with Down syndrome themselves [34]. When asked to nominate their child's best friends, the parents and their child agreed in only 30% of cases. These friendships were often also disputed by the nominated friend [34]. This highlights a discrepancy in the meaning of friendship for parents, children with Down syndrome and their peers, and also questions the quality of these friendships.

Despite these findings, parents of children with Down syndrome can be instrumental in encouraging and guiding friendships and selecting opportunities for their child's play and leisure activity [32, 36]. The need for their active involvement has been attributed to a lack of social competence and communication abilities they perceive in

their child with Down syndrome [37, 38]. Studies report that parents can encourage a greater quality of friendship for their child with disability by pairing them with a typically developing child of the same gender and chronological age, and ensuring the two children have multiple play experiences together [32, 34, 39]. For school-aged children with Down syndrome, parent-initiated friendships are often longer lasting than school or community initiated friendships [34].

Leisure for school-aged children with Down syndrome

Research examining the leisure pursuits of children with Down syndrome is limited. Electronic searches retrieved 4 relevant studies on leisure pursuits for children with Down syndrome in particular. In general it is reported that school-aged children with Down syndrome have lower rates of participation in community activities than their typically developing peers, and the majority of their leisure is solitary and passive in nature, with sports being the least favoured [39]. Identified barriers to participation in community social or leisure activities for children with Down syndrome include the absence of someone to accompany them, reduced activity skill, and lack of available leisure activities [35].

For youths and young adults with Down syndrome the most frequently reported leisure activities are television watching, listening to music, playing independently with toys, games, reading and writing, shopping or running errands, going to the movies, or spending times with family members [35]. Although a high preference for television watching reflects the leisure choices of typically developing school-aged children [40] individuals with Down syndrome experience higher rates of obesity [41] and lower motor performance than their typically developing peers [42]. These

physical factors make sedentary leisure a particular concern for children with Down syndrome also given the finding that active and passive leisure pursuits, such as television and video games, are associated negatively with well-being [24].

Parents of primary school aged children with Down syndrome are aware of the risk of obesity and recognise the benefit of physical activity and diet as preventative measures in maintaining a healthy body weight [43].

Friendships are important in facilitating the leisure participation of children with Down syndrome. In a qualitative case study examining the parental experience of leisure participation for individuals with Down syndrome, three of four mothers of school-aged children with Down syndrome between the age of seven and nine report that participation in physical activity at this age occurs only when a sibling or playmate initiates the play and provides the motivation [43]. Parents report their children with Down syndrome reduce their participation in physical activities during their primary school years, as a result of the increasing gap between their abilities and that of their typically developing playmates. This can be problematic for their child's participation and health [43]. For this reason, programs targeting active leisure for children with Down syndrome are often necessary to encourage participation and foster achievement.

ICF Factors impacting on participation for children with Down syndrome

Body function and structure factors

Approximately three quarters of children with Down syndrome experience two or more confounding health issues [5], the most frequent are cardiac, gastrointestinal, sensory (ear or eye related), respiratory, thyroid, orthopaedic and oncology concerns

[5, 8, 12]. These impairments to body functions and body structures can contribute to activity limitations and participation restrictions relating to friendships and leisure.

Congenital heart defects

Congenital heart defects (CHD) affect up to 44% of infants with Down syndrome [28] and of those affected, as many as 22.4% have multiple defects [44]. Atrioventricular septal defects (45%) followed by ventricular septal defects (35%) [28] are the most common. Most congenital heart defects can be corrected by surgery during infancy [44]. However, unmanaged symptoms associated with CHDs such as shortness of breath and early fatigue often occur during exercise or activity [45] and can affect the amount of time spent in leisure and the types of leisure activities chosen.

Gastrointestinal defects

Gastrointestinal defects are over 67 times more likely to occur in children with Down syndrome than those without Down syndrome [46]. The most frequently acquired gastrointestinal defects are atresia or stenosis of the small intestine and Hirschsprung's disease [46]. Both defects cause intestinal obstruction and can be corrected through surgical intervention [47]. The management of constipation with laxatives and suppositories represents the majority of ongoing gastrointestinal concerns [5]. To date no research has examined the impact of ongoing gastrointestinal concerns on the friendships and leisure participation of children with Down syndrome.

Thyroid dysfunction

Children with Down syndrome experience higher incidences of thyroid dysfunction than their typically developing peers [48]. The symptoms associated with thyroid dysfunction in children with Down syndrome such as shortened stature, hair and skin conditions, appetite, bowel function, increased weight or family history of autoimmune disease are varied and often attributable to other underlying health conditions such as cardiac defect or autoimmunity [49]. Research is required to determine the affect thyroid dysfunction has on leisure participation.

Sensory impairments

Children with Down syndrome are 19 times more likely to have a sensory defect than children of the same age without Down syndrome [46]. Hyperopia is the most frequently occurring of the ocular abnormalities and is present in over 50 percent of children with Down syndrome, followed by astigmatism (28%), strabismus (36%) and congenital nasolacrimal duct obstruction (22%) [50]. School-aged children with Down syndrome are over 5 times more likely to wear glasses than typically developing children to correct and manage vision-related impairments [5]. Additionally, up to two thirds of children with Down syndrome have a measurable hearing loss which can adversely impact on speech, language and intellectual development [51]. Children experiencing sensory deficits may experience stigma, coupled with poor sensory performance [52, 53] which can decrease the motivation to play [43].

Sleep impairments

Sleep respiratory disturbance and sleep apnoea are not uncommon in children with Down syndrome [54, 55]. Sleep fragmentation and sleep-disordered breathing may adversely impact on a child's cognitive performance, learning and memory, and academic learning [10]. As a result these children may also experience excessive daytime sleepiness and/or hyperactivity [29]. This could result in poorer performances of cognitive and recall components in leisure activities or leisure activities requiring alertness, concentration or energetic participation [29].

Orthopaedic conditions

Atlantoaxial instability is an orthopaedic condition present in 10-20% of individuals with Down syndrome [56]. It is commonly the result of laxity of the transverse joint which stabilises and supports the odontoid process. As a result of the instability of the joint, the integrity of the C1-C2 articulation is compromised [57] and the displaced odontoid may compress the spinal cord in 1-2% of cases [58] which can result in paralysis or death. In response to these findings, all individuals with Down syndrome participating in contact sports at the Special Olympics are required to have a radiograph confirming the absence of atlantoaxial instability [57]. While atlantoaxial instability can be a greater health concern for school-aged children with Down syndrome than children without Down syndrome, it does not necessitate a withdrawal from active leisure, but requires the adaptation of certain contact physical sports or the selection of active leisure with less contact.

The performance of motor skills is often sub-optimal in school-aged children with Down syndrome [42] as a result of physiological and environmental factors. Lengthy

hospitalisations during infancy due to surgical interventions can contribute to delayed development of motor milestones [59]. Additionally, impairments in the perception of complex motion cues [60], atlantoaxial instability, patellar instability, metatarsus primus varus with hallux valgus or varus, pes planus, poor muscle tone, and scoliosis contribute to the lower performance of motor skills for school-aged children with Down syndrome [57]. The higher body mass and risk of obesity experienced in children with Down syndrome in comparison to typically developing children [41, 61] can act as a restriction to participation in active leisure pursuits [62] and social acceptance.

Functional ability

Functional ability is the term used to describe an individual's performance of everyday functional tasks within the domains of self-care, continence, transfers, locomotion, communication and social skills [63]. Poor functional performance is a strong predictor for activity limitations in individuals with intellectual disability [64]. The impairments experienced by school-aged children with Down syndrome often result in reduced functional ability in the social skills domain [11]. This could negatively impact their participation in friendship activities. Although children with Down syndrome rarely exhibit severe functional impairments, they often require assistance with complex self-care, communication and social skills tasks [11]. For this reason, parents of children with Down syndrome often postpone their entry to school [9] which can result in a further delay in the development of emotional and social skills for children with Down syndrome. Research reports a lower participation rate and performance in leisure activities for individuals with greater activity limitations

[65]. For these reasons, functional ability can restrict participation in friendships and leisure for school-aged children with Down syndrome.

In summary, impairments in body functions and structures contribute to financial hardship for families and in serious cases, hospitalisations for children with Down syndrome [6, 8]. Hospitalisations are more common in cases of respiratory conditions, congenital heart defects and gastrointestinal disease [59]. Clearly hospitalisation results in absences from school and reduces the opportunities providing social and leisure development for children with Down syndrome.

Although there appears a large body of descriptive research documenting the high levels of comorbidity experienced by children with Down syndrome, research is required to describe their impact on participation in other areas of a child's development such as friendships and leisure.

A more comprehensive understanding of how these conditions impact friendships and leisure would be useful to better manage the condition or alter the activity demands to enable greater participation for children with Down syndrome. This reinforces the need for appropriate active leisure programs addressing the abilities and taking in to account the physical and health needs of children with Down syndrome.

Personal factors

Positive social characteristics observed in children with Down syndrome, such as social orientation and engagement capacity advantage children with Down syndrome in social situations [31]. This effect has been labelled the Down syndrome behavioural phenotype [66]. However, these favourable skills do not automatically

transfer to more complex social cognition in later development [67]. High level social skills such as the ability to understand, regulate and reciprocate emotions are significantly reduced in children with Down syndrome in contrast to their typically developing peers [68]. They often do not understand more complicated social processes required for relating these basic skills to on-task behaviour or activities [67, 69]. It follows that the differences in social competence of school-aged children with Down syndrome and their peers may result in social isolation and marginalisation of school-aged children with Down syndrome. Despite these difficulties, many children with Down syndrome view themselves positively, as physically competent and socially accepted which may support their participation in friendships and leisure [30].

Environmental

Family Functioning and Maternal Health

A review of the literature failed to identify any research investigating the effect of family functioning and maternal health on friendships and leisure participation for children with Down syndrome. Studies of families with a child with disability confirm raised levels of depression, marital instability, role tensions and lower socioeconomics [70]. Healthy family functioning has been associated with fewer feelings of loneliness in middle childhood [71] and higher self-sufficiency in children [72]. Positive family physical and mental health outcomes are achieved for families of children with Down syndrome when they identify individual characteristics in the child with Down syndrome contributing to or reducing family stress [73] and adapt family coping skills to successfully manage these [74].

Although they report greater wellbeing than mothers of children with other intellectual disabilities [75], mothers of children with Down syndrome have poorer mental health than the general population [76]. It is important maternal health is monitored and family functioning is optimal, as parents are paramount in arranging and supporting their child with Down syndrome's friendships [32], leisure, and their child's social and emotional development.

Place of residence and transport

Limited research has explored the impact place of residence and access to transport has on participation in friendships and leisure. Australian research shows there are no significant differences in lifestyle habits such as shopping, leisure and sport participation for children with disabilities in general and their typically developing peers in rural areas [77]. These findings may be explained by the access restrictions that all children living in rural areas experience [39]. The impact of lack of transport on participation in leisure is questionable. Though it has been identified as a barrier to participation in leisure [39], transportation problems are often viewed as minimal in comparison to other barriers experienced by individuals with Down syndrome [35].

Socio-economic status

Lower socioeconomic status has been acknowledged as a barrier to participation in leisure activities for children with disabilities [78]. Temple (2007) reported cost to be the third highest barrier to leisure participation after health and absence of motivation for individuals with intellectual disabilities [79]. Lower maternal financial and educational attainment has been associated with greater risk of having a child with

intellectual disability [80, 81]. Evidence suggests that while families with a child with Down syndrome may have on average a lower income than the general population, they often have a greater family income than families with children of other intellectual disabilities [82]. Research investigating the impact of socio-economic status on participation in leisure in particular is required.

Settings of friendships and leisure

The number of friendships children with disabilities have may vary according to the setting where reported. There is conjecture in research regarding the number of friends reported by children with Down syndrome in special education and mainstream schools [83, 84]. D'haem (2007) compared the efficacy of school-based friendships with mixed-aged community-based friendships for 3 groups of children with Down syndrome over 5 years. Only one of the three students with Down syndrome maintained their friendship with a same-aged school friend outside the study. School-based friendships were found to be temporary in nature and rarely extend outside of school hours or into community settings. Alternatively, a mixed-age network of friendships occurring outside of school, taking advantage of peer, family and child-interests were ongoing at follow up two years later [33].

Discussion

The findings of this review have clear implications for parents, teachers and disability service program co-ordinators. With limited literature on the subject, the methodological quality of relevant research is also of a lower level, with the majority of studies descriptive, cross-sectional and observational in nature.

Friendships

School aged-children with Down syndrome often have difficulty establishing and maintaining quality friendships for a number of reasons.

Firstly, there is a discrepancy in the definition of friendship and the nomination of friends by parents and their school-aged children with Down syndrome [34]. Parental involvement in directing friendships [32, 36] and the child with Down syndrome's passive nature in these processes [37, 38], result in the discrepancy in definitions of friendship and the number of friends reported by the two parties. A greater understanding of the process of friendships and the definitions subscribed to friendship by parents, their school-aged child with Down syndrome, as well as their nominated friends, may support the development of appropriate interventions able to facilitate a higher quality of friendships for these children. Research and educational programs focussing on the characteristics and quality of friendships as described by children with Down syndrome and their parents may assist in developing ways to align the meaning of friendship and contribute to more beneficial friendships for school-aged children with Down syndrome.

Furthermore, the question as to whether mixed age group friendship networks or same-age group friendships yield longer and more successful friendships [33] should be investigated. It is possible that friendships with children of the same chronological age in comparison to the same developmental age may provide a greater quality of friendship and provide the school-aged child with Down syndrome a longer-lasting friendship and greater feelings of acceptance, belonging and satisfaction.

No research to date has examined the influence family size has on friendships for children with Down syndrome. The increased opportunity for social interaction and communication in larger families may be a facilitator for friendships. Conversely, larger family size may be a barrier to leisure due to the greater demands on parental time and finances. Research is required to examine what influence family size has on friendships and leisure for school-aged children with Down syndrome.

Finally, as friendships extending into the community appear to be more successful than those occurring at school only [33], research is needed which describes the number of interactions with friends outside of school and the impact on the quality of friendship setting has for children with Down syndrome. In addition, it would be useful to examine barriers and facilitators to community friendships and participation in community social groups in the context of body structure and functions, person and environmental factors using the ICF as a theoretical framework [27]. The application of the ICF provides a set terminology and structure that can be used and reproduced in comparison studies between studies of similar populations [85].

Leisure

Many factors relating to the ICF domains of body structure and function, person and environment can act as either barriers or facilitators to participation in leisure for school-aged children with Down syndrome. However, research investigating the effectiveness of interventions and programs for friendships and leisure is required. Further, research exploring and developing appropriate outcome measures for these interventions and programs is needed to test the relevance of ICF factors associated

with activity and participation. In particular, exploration of the impact of body function and structures and comorbidity is an area that has not been examined in terms of leisure for school-aged children with Down syndrome. School-aged children with Down syndrome participate in physical leisure through school and structured and unstructured extracurricular activities in the community and home. They are enthused by the social aspects of leisure and are challenged by a lack of motivation, limited inclusive programs or their participation in segregated programs, and the need for prior skills and knowledge of rules [43].

However, due to their preference for sedentary and technological home-based activities and their limited participation in active leisure, inclusive active leisure programs which encourage higher emotional and social gains for children with Down syndrome should be promoted. Children with intellectual disabilities participating in integrated active leisure with their typically developing peers report higher levels of physical self-concept than those in segregated leisure [86]. Thus, research exploring the benefits of inclusive as opposed to segregated physical activity for school-aged children with Down syndrome may assist in the development of a best practice active leisure program, targeting the physical, cognitive and social skill levels of school-aged children with Down syndrome.

Reduced parental expectations for children with Down syndrome result in a maternal tendency to direct and encourage the play of the young child with Down syndrome using a greater number of supportive interactions. Studies have highlighted a need for parents to develop adept task-analysis skills, in deconstructing and grading tasks for their child to ensure a degree of autonomous achievement and encourage further participation [39]. Others have further called for provision of these skills extended to programs of home, school and community based leisure [43]. Parents favour

programs developed and delivered by an external expert with information appropriate to their child's age and developmental level delivered at school during regular meetings. They assert the program should include a range of activities suitable for the interest of the child with Down syndrome and their family, specific instructions, descriptions and illustrations for families to carry out in the home as well as community [43].

Conclusion

School-aged children with Down syndrome experience a limited number of friendships and lower rates of participation in community active leisure. The findings report young children with Down syndrome may have no friends, but few studies examined the number of friendships and occasions of play for school-aged children. Leisure preferences appear to be home-based, solitary and sedentary in comparison to active group pursuits in the community.

The body of literature suggests there are numerous factors contributing to participation in both friendships and leisure for this population, some are barriers and some are facilitators. Yet the impact of such factors is yet to be investigated and tested. Research addressing these is required for the provision of quality and evidence-based leisure programs for school-aged children with Down syndrome. Additionally, research investigating both social interventions and leisure programs for school-aged children with Down syndrome requires appropriate and valid outcome measures and should report baseline and follow-up performance and participation rates for school-aged children with Down syndrome.

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References

1. Bower C, Leonard H, Petterson B. Intellectual disability in Western Australia. *Journal of Paediatrics and Child Health*. 2000;36(3):213-5.
2. Bittles AH, Glasson EJ. Clinical, Social and Ethical Implications of Changing Life Expectancy in Down Syndrome. *Developmental Medicine and Child Neurology*. 2004;46:282 - 6.
3. Ranweiler R. Assessment and care of the newborn with Down syndrome. *Advances in Neonate Care*. 2009;9(1):17-24.
4. Sherman SL, Allen EG, Bean LH, Freeman SB. Epidemiology of Down syndrome. *Mental Retardation & Developmental Disabilities Research Reviews*. 2007;13(3):221-7.
5. Leonard S, Bower C, Petterson B, Leonard H. Medical aspects of school-aged children with Down syndrome. *Developmental Medicine and Child Neurology*. 1999;41(10):683-8.
6. So S, Urbano R, Hodapp R. Hospitalizations of infants and young children with Down syndrome: evidence from inpatient person-records from a statewide administrative database. *Journal of Intellectual Disability Research*. 2007;51(12):1030-8.
7. Bell JA, Pearn JH, Firman D. Childhood deaths in Down's syndrome. Survival curves and causes of death from a total population study in Queensland, Australia, 1976 to 1985. *Journal of Medical Genetics*. 1989;26(12):764-8.
8. Leonard S, Bower C, Petterson B, Leonard H. Survival of infants born with Down's syndrome: 1980-96. *Paediatric and Perinatal Epidemiology*. 2000;14(2):163-71.
9. Dolva A, Lilja M, Hemmingsson H. Functional performance characteristics associated with postponing elementary school entry among children with Down syndrome. *American Journal of Occupational Therapy*. 2007;61:414-20.
10. Kaemingk K, Pasvogel A, Goodwin J, Mulvaney S, Martinez F, Enright P, Rosen G, Morgan W, Fregosi R, Quan S. Learning in children and sleep disordered breathing: findings of the Tucson Children's Assessment of Sleep Apnea (TuCASA) prospective cohort study. *Journal of the International Neuropsychological Society*. 2003;9:1016-26.
11. Leonard S, Msall M, Bower C, Tremont M, Leonard H. Functional status of school-aged children with Down syndrome. *Journal of Paediatrics and Child Health*. 2001;38:160-5.

12. Bittles AH, Bower C, Hussain R, Glasson EJ. The four ages of Down syndrome. *European Journal of Public Health*. 2006 Jul 19;17(2):221-5.
13. Gairdiner C, Lanigan B, O'Keefe M. Postcataract surgery outcome in a series of infants with Down syndrome. *British Journal of Ophthalmology*. 2008;92:1112-6.
14. Glasson EJ, Sullivan SG, Hussain R, Petterson BA, Montgomery PD, Bittles AH. The changing survival profile of people with Down's syndrome: implications for genetic counselling. *Clinical Genetics*. 2002;62(5):390-3.
15. The World Health Organisation Quality of Life Group. The development of the World Health Organisation Quality of Life Assessment Instrument (the WHOQoL). . In: Orley J, Kuyken W, editors. *Quality of life assessment: international perspectives*. Heidelberg: Springer-Verlag; 1994.
16. Rasmussen SA, Whitehead N, Collier S, Frias J. Setting a public health research agenda for Down syndrome: summary of a meeting sponsored by the Centers for Disease Control and Prevention and the National Down Syndrome Society. *American Journal of Medical Genetics -A*. 2008;146A:2998-3010.
17. Case-Smith J. *Occupational therapy for children: 5th Edition*. St. Louis: Elsevier Mosby; 2005.
18. Ginsburg K, Committee on Communications., Committee on Psychosocial Aspects of Child and Family Health. The importance of play in promoting healthy child development and maintaining strong parent-child bonds. *American Academy of Pediatrics*. 2007;119(1):182-91.
19. Isenberg J, Quisenberry N. Play: a necessity for all children. *Childhood Education*. 1988;64(3):138-45.
20. Office of the United Nations High Commissioner for Human Rights. Convention on the rights of the child. General assembly resolution 44/25 of 20 November 1989. General Assembly 20 November 1989; 1989. 1989.
21. Ashiabi G. Play in the preschool classroom: its socioemotional significance and the teacher's role in play. *Early Childhood Education Journal*. 2007;35(2):199-207.
22. Ladd G, Kochenderfer B, Coleman C. Friendship Quality as a Predictor of Young Children's Early School Adjustment. *Child Development*. 1996;67(3):1103-18.
23. Center on the Developing Child at Harvard University. A science-based framework for early childhood policy: using evidence to improve outcomes in learning, behaviour, and health for vulnerable children. *Journal [serial on the Internet]*. 2007 Date: Available from: http://www.developingchild.harvard.edu/content/downloads/Policy_Framework_k.pdf.

24. Holder M, Coleman B, Sehn Z. The contribution of active and passive leisure to children's wellbeing. *Journal of Health Psychology*. 2009;14(3):378-86.
25. Holder M, Coleman B. The contribution of social relationships to children's happiness. *Journal of Happiness Studies*. 2009;10:329-349.
26. Wright F, Rosenbaum P, Goldsmith C, Law M, Fehlings D. How do changes in body functions and structures, activity, and participation relate in children with cerebral palsy? *Developmental Medicine and Child Neurology*. 2008;50:283-9.
27. World Health Organization. *International classification of functioning, disability and health: ICF: short version*. Geneva: World Health Organization; 2001.
28. Freeman S, Taft L, Dooley K, Allran K, Sherman S, Hassold T, Khoury M, Saker D. Population-based study of congenital heart defects in Down syndrome. *American Journal of Medical Genetics*. 1998;80:213-7.
29. Melendres C, Lutz J, Rubin E, Marcus C. Daytime sleepiness and hyperactivity in children with suspected sleep-disordered breathing. *Pediatrics*. 2004;114(3):768-75.
30. Begley A. The self-perceptions of pupils with Down syndrome in relation to their academic competence, physical competence and social acceptance. *International Journal of Disability, Development and Education*. 1999;46(4):515-29.
31. Fidler DJ, Most D, Booth-LaForce C, Kelly J. Emerging social strengths in young children with Down syndrome. *Infants and Young Children*. 2008;21(3):207-20.
32. Guralnick M. Involvement with peers: comparisons between young children with and without Down's syndrome. *Journal of Intellectual Disability Research*. 2002;46(5):379-93.
33. D'Haem J. Special at school but lonely at home: an alternative friendship group for adolescents with Down syndrome. *Down Syndrome Research & Practice*. 2008;12(2):107-11.
34. Freeman SB, Kasari C. Characteristics and qualities of play dates of children with Down syndrome: emerging or true friendships? *American Journal on Mental Retardation*. 2002;107(1):16-31.
35. Putnam J, Puschel S, Holman J. Community activities of youths and adults with Down syndrome. *The British Journal of Mental Subnormality*. 1988;34(1):47-53.

36. Heah T, Case T, McGuire B, Law M. Successful participation: the lived experience among children with disabilities. *Canadian Journal of Occupational Therapy*. 2007;74(1):38-47.
37. Price J, Roberts J, Vandergrift N, Martin G. Language comprehension in boys with fragile X syndrome and boys with Down syndrome. *Journal of Intellectual Disability Research*. 2007 Apr;51(Pt 4):318-26.
38. Yoder P, Warren S. Early predictors of language in children with and without Down syndrome. *American Journal on Mental Retardation*. 2004;109:285-300.
39. Buttimer J, Tierney E. Patterns of leisure participation among adolescents with a mild intellectual disability. *Journal of Intellectual Disabilities*. 2005;25(9):25-42.
40. Australian Bureau of Statistics. Children's participation in cultural and leisure activities, Australia, April 2000. Canberra: Australian Bureau of Statistics; 2000 DOI: 4901|.
41. De S, Small J, Baur L. Overweight and obesity among children with developmental disabilities. *Journal of Intellectual & Developmental Disability*. 2008;33(1):43-7.
42. Vicari S. Motor development and neuropsychological patterns in persons with Down syndrome. *Behavior Genetics*. 2006;36(3):355-64.
43. Sayers Menear K. Parents' perceptions of health and physical activity needs of children with Down syndrome. *Down Syndrome Research and Practice*. 2007;12(1):60-8.
44. Nisli K, Oner N, Candan S, Kayserili H, Tansel T, Tireli E, Karaman B, Omeroglu R, Dindar A, Aydogan U, Basaran S, Ertugrul T. Congenital heart disease in children with Down's syndrome: Turkish experience of 13 years. *Acta Cardiologica*. 2008;63(5):585-9.
45. Mayo Clinic. Congenital heart defects in children. Mayo Foundation for Medical Education and Research; 2008 [updated 2008; cited 2009 July 8]; Available from: <http://www.nlm.nih.gov/medlineplus/congenitalheartdefects.html>.
46. Cleves M, Hobbs C, Cleves P, Tilford J, Bird T, Robbins J. Congenital defects among liveborn infants with Down syndrome. *Birth Defects Research*. 2007;79(Part A):657-63.
47. Merck & Co. Digestive Tract Defects. New Jersey: Merck & Co.; 2006 [updated 2006; cited 2009 July 8]; Available from: <http://www.merck.com/mmhe/print/sec23/ch265/ch265e.html>.

48. Shaw C, Thapalial A, Nanda S, Shaw P. Thyroid dysfunction in Down syndrome. *Kathmandu University Medical Journal*. 2006;4(2):182-6.
49. Gibson P, Newton R, Selby K, Price D, Leyland K, Addison G. Longitudinal study of thyroid function in Down's syndrome in the first two decades. *Archives of Disease in Childhood*. 2005;90:574-8.
50. Fimiani F, Iovine A, Carelli R, Pansini M, Sebastio G, Magli A. Incidence of ocular pathologies in Italian children with Down syndrome. *European Journal of Ophthalmology*. 2007;17(5):817-22.
51. Balkany T, Downs M, Jafek B, Krajicek M. Hearing loss in Down's syndrome: a treatable handicap more common than generally recognised. *Clinical Pediatrics*. 1979;18(2):116-8.
52. Brunnberg E. The school playground as a meeting place for hard of hearing children. *Scandinavian Journal of Disability Research*. 2005;7(2):73-90.
53. Koklanis K, Abel L, Aroni R. Psychosocial impact of amblyopia and its treatment: a multidisciplinary study. *Clinical and Experimental Ophthalmology*. 2006;34:743-50.
54. Cotton S, Richdale A. Brief report: parental descriptions of sleep problems in children with autism, Down syndrome, and Prader-Willi syndrome. *Research in Developmental Disabilities*. 2006;27:151-61.
55. Shott S, Amin R, Chini B, Heubi C, Hotze S, Akers R. Obstructive sleep apnea. *Archives of Otolaryngology Head & Neck Surgery*. 2006;132:432-6.
56. Ali F, Al-Bustan M, Al-Busairi W, Al-Mulla F, Esbaita E. Cervical spine abnormalities associated with Down syndrome. *International Orthopaedics*. 2006;30(4):284-9.
57. Platt L. Medical and orthopaedic conditions in Special Olympics athletes. *Journal of Athletic Training*. 2001;36(1):74-80.
58. Peuschel S, Herndon J, Gelch M, Senft K, Scola F, Goldberg M. Symptomatic atlantoaxial subluxation in persons with Down syndrome. *Journal of Pediatric Orthopaedics*. 1984;4(6):682-8.
59. van Trotsenburg P, Heymans H, Tijssen J, de Vijlder J, Vulsma T. Comorbidity, hospitalisation, and medication use and their influence on mental and motor development of young infants with Down syndrome. *Pediatrics in Review*. 2006;118(4):1633-9.
60. Virji-Babul N, Kerns K, Zhou E, Kapur A, Shiffar M. Perceptual motor deficits in children with Down syndrome: implications for intervention *Down Syndrome Research and Practice*. 2006;10(2):74-82.

61. Fujiura G, Fitzsimons N, Marks B. Predictors of BMI among adults with down syndrome: the social context of health promotion. *Research in Developmental Disabilities*. 1997;18(4):261-74.
62. Jobling A. Life be in it: lifestyle choices for active leisure. *Down Syndrome Research and Practice*. 2001;6(3):117-22.
63. Msall ME, DiGaudio K, Rogers BT, LaForest S, Catanzaro NL, Campbell J, Wilczenski F, Duffy LC. The Functional Independence Measure for Children (WeeFIM). Conceptual basis and pilot use in children with developmental disabilities. *Clinical Pediatrics*. 1994;33(7):421-30.
64. Van Naarden Braun K, Yeargin-Allsop M, Lollar D. Activity limitations among young adults with developmental disabilities: a population-based follow-up study. *Research in Developmental Disabilities*. 2009;30:179-91.
65. Van Naarden Braun K, Yeargin-Allsop M, Lollar D. Factors associated with leisure activity among young adults with developmental disabilities. *Research in Developmental Disabilities*. 2006;27:567-83.
66. Fidler DJ. The emergence of a syndrome-specific personality profile in young children with Down syndrome. *Down's Syndrome, Research And Practice: The Journal Of The Sarah Duffen Centre / University Of Portsmouth*. 2006;10(2):53-60.
67. Wishart JG. Socio-cognitive understanding: a strength or weakness in Down's syndrome? *Journal of Intellectual Disability Research*. 2007;51:996-1005.
68. Williams K, Wishart JG, Pitcairn T, Willis D. Emotion recognition by children with Down syndrome: investigation of specific impairments and error patterns. *American Journal on Mental Retardation*. 2005;110(5):378-92.
69. Hamilton D. An ecobehavioural analysis of interactive engagement of children with developmental disabilities with their peers in inclusive preschools. *International Journal of Disability, Development and Education*. 2005;52(2):121-37.
70. Hodapp RM. Families of persons with Down syndrome: New perspectives, findings, and research and service needs. *Mental Retardation & Developmental Disabilities Research Reviews*. 2007;13(3):279-87.
71. Howell A, Hauser-Cram., Kersh J. Setting the stage: early child and family characteristics as predictors of later loneliness in children with developmental disabilities. *American Journal on Mental Retardation*. 2007;112(1):18-30.
72. Sloper P, Turner S. Progress in social-independent functioning of young people with Down's syndrome. *Journal of Intellectual Disability Research*. 1996;40(Pt 1):39-48.

73. Crnic K, Friedrich W, Greenberg M. Adaptation of families with mentally retarded children: a model of stress, coping, and family ecology. *American Journal of Mental Deficiency*. 1983;88(2):125-38.
74. Minnes PM. Family resources and stress associated with having a mentally retarded child. *American Journal of Mental Retardation*. 1988;93(2):184-92.
75. Blacher J, McIntyre L. Syndrome specificity and behavioural disorders in young adults with intellectual disability: cultural differences in family impact. *Journal of Intellectual Disability Research*. 2006;50(3):184-98.
76. Bourke J, Ricciardo B, Bebbington A, Aiberti K, Jacoby P, Dyke P, Msall M, Bower C, Leonard H. Physical and Mental Health in Mothers of Children with Down Syndrome. *The Journal of Pediatrics*. 2008;153(3):320-6.e3.
77. Pretty G, Rapley M, Bramston P. Neighbourhood and community experience, and the quality of life of rural adolescents with and without intellectual disability. *Journal of Intellectual & Developmental Disability*. 2002;27(2):106-16.
78. Law M, King G, King S, Kertoy M, Hurley P, Rosenbaum P, Young N, Hanna S. Patterns of participation in recreational and leisure activities among children with complex physical disabilities. *Developmental Medicine and Child Neurology*. 2006;48:337-42.
79. Temple V, and Walkley, J. Perspectives of constraining and enabling factors for health-promoting physical activity by adults with intellectual disability. *Journal of Intellectual & Developmental Disability*. 2007;32(1):28-38.
80. Chapman D, Scott K, Mason C. Early risk factors for mental retardation: role of maternal age and maternal education. *American Journal on Mental Retardation*. 2002;107(1):46-59.
81. Leonard H. Some socio-demographic trends and technological trends in the developed world and their impact on Down's syndrome. *Italian Journal of Pediatrics*. 2005;31:213- 6.
82. Hodapp R. Parenting children with mental retardation. In: Bornstein M, editor. *Handbook of Parenting 2nd Edition Volume 1: Children and Parenting*. New Jersey: Erlbaum; 2002.
83. Buckley S, Bird G, Sacks B, Archer T. A comparison of mainstream and special education for teenagers with Down syndrome: implications for parents and teachers. *Down Syndrome Research and Practice*. 2006;9(3):54-67.
84. Buysse V, Davis Goldman B, Skinner M. Setting effects on friendship formation among young children with and without disabilities. *Exceptional Children*. 2002;68(4):503-17.

85. World Health Organization. Towards a common language for functioning, disability and health ICF. Geneva: World Health Organisation; 2002
86. Duvdevany I. Self-concept and adaptive behaviour of people with intellectual disability in integrated and segregated recreation activities. *Journal of Intellectual Disability Research*. 2002;46(5):419-29.

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Book

2. Bird GA, Buckley SJ. *Number skills for individuals with Down syndrome - An overview*. Portsmouth, UK: Down Syndrome Education International; 2001.

Book chapter

3. Buckley SJ, Bird GA, Byrne A. The practical and theoretical significance of teaching literacy skills to children with Down's syndrome. In: Rondal JA and Perera J, editors. *Down's syndrome: psychological, psychobiological and socio-educational perspectives*. London: Whurr; 1996. p. 119-128.

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Leisure participation for School-aged Children with Down Syndrome

Abstract

Background/Aim. The aim of this study was to describe leisure participation for school-aged children with Down syndrome in 2004, and to investigate how impairment and contextual factors classified by the World Health Organisation's International Classification of Functioning, Disability and Health (ICF) influence their leisure participation. **Methods.** Data was collected from the 2004 Down Syndrome Needs, Opinions, & Wishes (NOW) questionnaire. **Results.** One third of families report one or no friends for their school-aged child with Down syndrome. Cases participated in predominantly solitary and sedentary leisure types. **Conclusion.** Leisure participation is affected by complex factors both within and external to the child with Down syndrome. Further investigation of the relevance of these factors to leisure may provide more satisfying and meaningful participation in leisure for school-aged children with Down syndrome.

KEY WORDS Down syndrome, friendships, International Classification of Functioning, Disability and Health, leisure, participation

ALINTA OATES

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September 18 2009

Leisure participation for School-aged Children with Down Syndrome

ALINTA OATES

Introduction

The participation of school-aged children with Down syndrome in friendships and leisure has largely been unexplored. To date, considerable research has focused on infant and child health and development, and on the medical complications of Down syndrome. Over time, advances in medical interventions, such as improved surgical techniques and the introduction of antibiotics in the 1950's, have improved the health of children and adults with Down syndrome by successfully correcting, preventing or managing many of the associated co-morbidities (Bittles, Bower, Hussain, & Glasson, 2006; Gairdiner, Lanigan, & O'Keefe, 2008; So, Urbano, & Hodapp, 2007). However, play, has received little research.

The importance of play in a child's life is well recognised as it supports the cognitive, social, physical and emotional development of children and adolescents (Case-Smith, 2005; Ginsburg, Committee on Communications., & Committee on Psychosocial Aspects of Child and Family Health, 2007; Isenberg & Quisenberry, 1988). It is attributed with developing problem solving, perspective-taking, emotional and social skills (Ashiabi, 2007) by facilitating interactions between a child and their environment (Case-Smith, 2005). In this way, children gain an understanding of their place in the world and cause-and-effect relationships. In play, children can acquire knowledge on which they can base future interactions and exploration (Case-Smith, 2005; Ginsburg et al., 2007).

It is foreseeable that limited or negative social and leisure experiences in the early phase of life can adversely affect the acquisition of developmental milestones (Center on the Developing Child at Harvard University, 2007), health, wellbeing (Holder, Coleman, & Sehn, 2009), and happiness (Holder & Coleman, 2007) of all children. For children with Down syndrome in particular, who represent approximately 1 in every 650-1000 births (Bittles & Glasson, 2004), participation in friendships and leisure is often limited. The small body of literature reports school-aged children with Down syndrome can have as few as no friends (D'Haem, 2008) and their forms of leisure often tend to be sedentary and solitary (Buttimer & Tierney, 2005; Putnam, Puschel, & Holman, 1988). These issues present a unique challenge for education, provision of disability services, and support for families of children with Down syndrome.

The purpose of this study was to describe friendships and leisure for school-aged children with Down syndrome and explore the factors affecting development of friendships and participation in leisure activities. In doing so, this study specifically aimed to investigate how for these children the ICF components of impairment of body function or structure, as well as personal and environmental factors related to their participation in friendships and leisure. We had three main assumptions: First, it was anticipated that the majority of parents/caregivers would report low numbers of both friendships (one or none) and friendship interactions (less than once per week) for their child with Down syndrome. Second, it was anticipated that greater participation in sedentary and solitary leisure pursuits, with the greatest participation in technologically-based sedentary activities would be reported for the majority of cases. Finally, we expected impairment factors (the number of co-morbidities), person factors (the level of function, behaviour and communication of the child) and environmental factors (number of siblings, access to transport,

parent health status, income and availability of time) to relate to participation in friendships and leisure for school-aged children with Down syndrome.

Methods

The *Intellectual Disability Exploring Answers (IDEA)* database (Pettersen et al., 2004) was used to identify all individuals with Down syndrome aged between 0 and 25 years living in Western Australia in 2004. A letter of invitation was sent to parents and guardians requesting their participation in the *Down syndrome NOW* study by completing a questionnaire pertaining to their child or youth with Down syndrome. The questionnaire consisted of two parts. Part One was titled *Your Child* and contained questions about the child's medical and therapeutic care; socio-economical, emotional, behavioural, and social circumstances; as well as their everyday functioning. Part Two, *Your Family*, collected information on family characteristics, wellbeing and support. During 2005, data was collected from families on paper (75%), online (12.6%) and by telephone interview (12.4%) (Bourke et al., 2008). The total response fraction was 73% (363/500) of the population with Down syndrome receiving services from Disability Services Commission in Western Australia. This current analysis was restricted to those who were school-aged children and/or youth aged 5 to 18 years in 2004 providing a resultant sample of 208 subjects. The cases were then split into two age groups for analysis: those of primary school age between 5 and 13 years and those of high school age between 14 and 18 years of age. Ethical approval for the study was granted by the Ethics Committee of the Woman's and Children's Health Services in Western Australia (Bourke et al., 2008) and the Edith Cowan University Human Research Ethics Committee.

Data Collection Instruments

A literature search and clinical judgement were utilised to identify the factors likely to impact on participation in leisure. Factors were further classified into child impairment factors, person factors and environmental factors according to the framework set out by the World Health Organisation's *International Classification of Functioning, Disability and Health (ICF)* (World Health Organization, 2001). The child impairment factors for analysis included number of co-morbidities and episodes of illness, and were represented by numerical counts of both co-morbidity and illness in the last twelve months respectively. The child or person factors selected as relevant to leisure participation were the level of independent functioning as measured by a modified version of the WeeFIM (Leonard, Msall, Bower, Tremont, & Leonard, 2001), the Child Developmental Behaviour Checklist (DBC) score (Einfeld & Tonge, 1992), the Social Communication Questionnaire score (SCQ) (Rutter, Bailey, & Lord, 2003) and the Body Mass Index (National Health and Medical Research Council., 2003). Higher scores indicate greater functional independence on the WeeFIM, greater behavioural issues on the DBC, and poorer social communication on the SCQ. The environmental factors selected were number of siblings, access to transport, income, availability of parental time and parental physical and mental health status (Ware, Kosinski, & Keller, 1996). Parental health was measured by the SF-12®, where Physical Component Scores (PCS) and Mental Component Scores (MCS) above or below 50 represent scores above or below that of the population norm (Bourke et al., 2008). Data collection instruments are standardised and the SF-12® in particular has been validated for use with an Australian population (Sanderson & Andrews, 2002).

Data Analysis

Leisure participation was operationalised as participation in friendships, friendship interactions,

sports, hobbies and clubs. Descriptive statistics were used to explore participation in different types of leisure. Sport was further separated into independent sports (those that can be played as an individual) or team sports for further descriptive analysis. Performance in leisure was scored as a count of each response, not an average per child, and parents often reported several leisure pursuits for their child. Where information was not provided for participation in sport, hobbies or clubs, the individual cases were included in the analysis as reporting no participation in that specific type of leisure. Relevant data was exported from Filemaker Pro into STATA10, which was used for the statistical analysis. Uni-variate and multi-variate logistic regression analyses of the factors were conducted with number of friendships (low or high), number of friendship interactions (low or high), and low or high participation in sports, clubs and hobbies as the outcomes of interest. Low participation was viewed as participating in one or no friendships, sports, clubs and hobbies. High participation was coded as participation in two or more friendships, sports, clubs and hobbies. Friendship interactions were classified such that cases participating in interactions occasionally or less than once a week were determined to have a low number of friendship interactions per week. Those with interactions occurring once or twice or three or more times a week were considered to have high friendship interactions. We identified age group and gender as potential confounders. Statistically significant factors ($P < 0.05$) were then imputed into a multi-variate model to determine whether their effect on the outcome was independent of other factors.

Results/ Findings

In two thirds ($n=138$) of families the child with Down syndrome was of primary school-age (between 5 and 12 years old) and in the remaining third ($n=70$) of high school-age (aged between 13 and 18 years). There were slightly more males ($n=118$) than females ($n=90$): 59 female and 79

male cases of primary school age, and 31 female and 39 male cases in high school. Current or ongoing health conditions were reported for 80.3% of cases. Over half of these (n=105) reported two or more additional current or ongoing health conditions. Information on episodes of illness in the twelve months prior to the 2004 study was provided for by 89.4% of responding families. Of the most frequently reported episodes of illness 13% of the total sample had one, 14.9% two, 13.9% three, 8.6% four, and 9.2% had six episodes of illness. The majority (78.8%) of families lived in the metropolitan area. The 2004 combined gross income was reported for 89.9% of families with the following distributions: exceeding \$78,000 (36.3%), \$52,000 to \$77,999 (18.2%), less than \$20,800 (18.2%), and \$41,600 to \$51,999 (12.3%).

Table 1 reports participation in leisure for school age children with Down syndrome.

Our investigation found the majority of children with Down syndrome had a high number of friendships (52.5%) and a low number of weekly friendship interactions (75.3%). Approximately one third of children were reported to have no friends, 14.5% had one, 32% two or three, and 20.5% four or more. Those children with greater functional independence in daily tasks were more likely (OR: 1.02, 95% CI 1.01-1.04) to participate in a greater number of friendships than those with lesser functional independence. After adjustment for mothers' mental and physical health, the odds of having a high number of friends remained the same, representing an increase of 2.6% with each additional single score in the total WeeFIM score (OR=1.02, 95% CI 1.01-1.04). The likelihood of experiencing a high number of friends increased by 4% for each additional score on either the PCS (OR=1.04, 95% CI 1.01 - 1.08) or the MCS (OR=1.04, 95% CI 1.00 - 1.08).

Children with higher total DBC scores, translating to greater behavioural issues, had 2.8% less odds of having a high number of friendships (OR=0.97, 95% CI 0.96-0.99). In particular, a reduced likelihood of having high numbers of friendships was found in those with higher scores in the disruptive and antisocial ($P<0.001$), self-absorbed ($P<0.001$) and social-relating behaviours ($P<0.001$) components of the DBC. See Table 2 for individual DBC analysis.

Children with higher Social Communication Questionnaire scores, equating to more difficulty in social communication were less likely to have a high number of friendships, but this effect was removed after adjusting for behavioural score (OR=0.99, 95% CI 0.93- 1.05). Those whose parents had greater availability of time had greater odds of having a high number of friendships even after adjusting for the level of family and social support (OR=1.05, 95% CI 1.00-1.09) and the child's social communication (OR=1.04, 95% CI 1.01-1.09). Greater parental availability of time was also associated with higher number of friends after separately adjusting for PCS (OR=1.05, 95% CI 1.01-1.09) and MCS (OR=1.04, 95%CI 1.00-1.08) in the multi-variate model. However, when combined with WeeFIM score (OR=1.03, 95% CI .99-1.07), and the co-occurrence of MCS and PCS (OR=1.02, 95% CI .98-1.07) parental availability of time had less of an effect on number of friendships. Children with parents exhibiting better mental (OR=1.04, 95% CI 1.01-1.07) and physical (OR=1.03, 95% CI 1.00-1.07) health and more family and community support (OR=1.05, 95% CI 1.01-1.08) were also found to have increased odds of having a high number of friendships.

Of those with friendships, ten (7.0%) participated in friendship interactions less than once a week, 79 (55.6%) occasionally, 32 (22.5%) once or twice a week, and ten (7.0%) three or more times per week. Information was not provided for 11 (7.75%) cases reporting friends and 23 cases reporting having no friends. High numbers of friendship interactions were over three times

(OR 3.65, 95% CI 1.53- 8.69) more likely for those of primary school-age even after adjusting for availability of parental time and family and community support. The odds of having high friendship interactions decreased by 2.5% with every additional current and ongoing health condition experienced (OR=0.74, 95% CI 0.55- 0.98), and were slightly increased with greater child functional independence (OR= 1.02, 95% CI 1.00- 1.04). Interestingly, an increase of one standard deviation on the BMI z-score from the mean BMI z-score for the age group, as determined from normative data (National Health and Medical Research Council., 2003), also increased the odds of high friendship interactions (OR=1.6, $p<0.054$, 95% CI 0.99- 2.61). Families with “almost always adequate” access to public transport had over ten times (OR= 10.23, 95% CI 1.12- 93.33) the odds of participating in high friendship interactions compared to those with “not at all adequate” access to public transport. Additionally, children with parents or guardians with higher mental health scores (OR= 1.06, 95% CI 1.01- 1.12) and family and community support (OR= 1.05, 95% CI 1.01-1.09) were also more likely to have a high number of friendship interactions.

The majority (84.1%) of respondents believed the number and quality of their child’s friendships had been affected by Down syndrome. The remainder either answered they did not believe friendships had been affected by Down syndrome (11.1%) and/or did not provide information (4.8%).

Participation in sports, hobbies and clubs are reported in Table 1. School-age children in our study participated in a high number of clubs (50.5%), and low numbers of sports (65.4%), and hobbies (58.9%). After adjusting for age group, greater functional independence increased the odds for participation in a high number of sports (CI=1.03, 95% CI 0.51- 1.93). The sports in

which the children most commonly participated were swimming (44.7%), bowling (15.9%), soccer (8.2%), basketball (7.2%), and dancing (5.3%). Age group ($p = 0.169$) and gender ($p=0.808$) were not associated with participation in independent sports. However, 91.3% of primary school-aged children with Down syndrome participated in one or fewer team sports compared to 74.3% of high school students ($p = 0.003$). No primary school-aged child with Down syndrome participated in three team sports in comparison with three cases or 4.3% of high school-aged children with Down syndrome.

The majority of respondents (62.9%) reported that their children performed below average in sport, almost one third (31.4%) reported average performance, and fewer than 4% above average performance. Of these, sports with the highest frequencies of above average performance were swimming (3 cases), soccer (2 cases), as well as gymnastics, football, bowling and basketball (1 case each).

The distribution of children participating in hobbies is shown in Table 1. There was no association between number of hobbies and age group ($p=0.37$) or gender ($p=0.705$). The hobbies with the highest frequencies were reading (29.8%), computers (26.4%), drawing (11.5%), games and musical instruments (8.65%), and singing, dancing and music (8.2%). Those with “usually adequate” (OR= 4.33, 95% CI 1.26-14.81) and “always using private transport” (OR= 2.74, 95% CI 1.02-7.40) were more likely to participate in a high number of hobbies when compared to participating families with less access to public transport. In the presence of parental availability of time (OR= 1.04, 95% CI 1.00- 1.01) and age group, cases with greater functional independence had increased odds (OR=1.02, 95% CI 1.00-1.04) of participation in a high number

of hobbies. Similarly, the odds of participating in a high number of hobbies was increased for cases with better social communication (OR=0.94, 95% CI 0.89- 0.99).

One quarter (25.5%) of children were reported to be involved in one club, 6.7% in two and 2.4% in three clubs. Participation was highest in ten-pin bowling (11.5%), sports association (7.7%), church (4.3%), and swimming (3.9%) clubs.

Over half (58.1%) of parents who responded reported below average performance in their child's respective activities (hobbies and clubs), 27.1% average performances, 7.2% above average and 7.63% of cases were uncertain. The majority of cases that performed above average participated in console games (2), drawing (2), pets (2), puzzles and games (2), singing, and dancing and music (2). The most frequent activities receiving a below average rating for performance were computers (36), reading (32), musical instruments (16) and drawing (14).

For the respondents to the three questions on time spent in computer games, television and hand held computer games, the majority reported less than seven hours (including those reporting no usual usage) in television-based computer games (93.94%), hand held computer games (99.49%) and general computer-based activities (94.92%). Of the 200 responding specifically about television and video usage, nearly one quarter (24%) spent over 14 hours each week, just under a half (48%) between seven and fourteen hours, and just under a quarter (23.50%) less than seven hours, whilst 4.5% reported no regular weekly usage of television. The time spent in technological leisure was further totalled and 10.6% reported a high technology use of over 15 hours per week, a half (50.5%) a moderate use of technology representing between 15 and 28

hours per week, and 38.9% reported low use of technology amounting to between 0 and 14 hours per week.

For participation in sedentary activities such as reading and drawing, low participation (less than fourteen hours per week) was reported for 62%, moderate participation (15 to 28 hours per week) for 33.50%, and high participation (29 hours or more per week) was reported for 4.5% of children. Participating families reported no usual strenuous physical activity during the week for 23.5% of children, less than seven hours of strenuous physical activities per week for 47.0%, between approximately seven and fourteen hours of strenuous exercise for 22.0% and over fourteen hours of strenuous exercise for 7.5%.

Discussion

This study found that parents of school-aged children with Down syndrome report the majority of their children's leisure to be sedentary and solitary and generally resulting in lower performance than the performance of typically developing children of the same age. Our investigation found the majority of children with Down syndrome had a high number of friendships (52.5%) and clubs (50.5%), and low numbers of weekly friendship interactions (75.3%), sports (65.4%), and hobbies (58.9%).

We anticipated that the majority of parents/caregivers would report low numbers of both friendships (one or none) and friendship interactions (less than once per week) for their child with Down syndrome. Not surprisingly, we found the majority of families (84.1%) believed Down syndrome had impacted on the number and quality of their child's friendships and one third

reported no friends for their children with Down syndrome. However, as two thirds of cases had two or more friendships we partly reject our first hypothesis. The second part of the hypothesis, pertaining to number of friendship interactions, was accepted. Our findings on friendship interactions closely mirror previous studies suggesting that maintaining friendships is difficult for school-aged children with Down syndrome (D'Haem, 2008). Opportunities for improving social relations with friends may be limited for over half (55.6%) of the responding families reporting occasional friendship interactions occurring less than once a week. We are unaware of available studies examining the frequency of friendship interactions for school-aged children with Down syndrome with which to compare our study. Nonetheless, our results contradict previous studies reporting on average 8-14 hours and one or two occasions of play with playmates per week for young children with Down syndrome between 4 and 6 years of age (Guralnick, 2002). Findings from this study report the friendships of school-aged children with Down syndrome are suffering and the opportunities to practice and model social skills are being missed. Child characteristics such as more appropriate behaviour, and superior social communication were found to be strong predictors positively affecting participation in friendships.

Furthermore, the children with parents who had a greater availability of time, better mental and physical health and more family and community support were also more likely to experience high friendship numbers. This finding is a concern, as mothers of children with Down syndrome have been identified as having worse mental and physical health than the general population (Bourke et al., 2008). These aspects are important to a child with Down syndrome's participation in leisure and as such are areas of concern for health professionals, disability services and policy makers alike. We recommend research describing parental use of respite and community support

and the effects of such interventions on leisure outcomes for their child with Down syndrome. We also suggest policy revisions to aid the provision of important respite and support services to appropriate families, and education of the availability and importance of these services to health professionals and disability workers. This may improve not only health outcomes for the parent, but social outcomes for their child with Down syndrome.

Greater functional independence in everyday activities was shown to increase the odds of participation in activities such as friendships, friendship interactions, sports and hobbies. This finding is similar to that of studies reporting activity limitations as predictors of leisure participation for children with developmental disabilities (Van Naarden Braun, Yeargin-Allsop, & Lollar, 2006).

Our second hypothesis was based on our anticipation of greater participation in sedentary and solitary leisure pursuits, with the greatest participation in technologically based sedentary activities for the majority of cases. We accept this hypothesis as leisure pursuits for our sample of school-aged children with Down syndrome were largely sedentary and solitary. Our findings paralleled those of Putnam et al. (1988) for youths and young adults with Down syndrome aged to 31 years (Putnam et al., 1988). The most common leisure pursuits were reading (29.8%), computers (26.4%), drawing (11.5%), games and musical instruments (8.65%), and singing, dancing and music (8.2%). Unfortunately, these same activities were also the most frequent activities receiving a below average rating for performance. Hence, children with Down syndrome report suboptimal performances in their chosen leisure pursuits.

Clearly, there is great opportunity for interventions which grade and adapt these leisure pursuits, and facilitate greater degree of achievement and success. Such interventions are likely to encourage more child satisfaction in participation. Studies have highlighted a need for parents to develop adept task-analysis skills in deconstructing and grading tasks for their child to ensure a degree of autonomous achievement and encourage further participation (Buttimer & Tierney, 2005). A parent led focus-group study on participation in leisure by Sayers Menear recommended the provision of these skills to be extended to programs of home, school and community based leisure (Sayers Menear, 2007). Sayers Menear found parents favour programs developed and delivered by an external expert with information appropriate to their child's age and developmental level delivered at school during regular meetings. They assert the program should include a range of activities suitable for the interest of the child with Down syndrome and their family, specific instructions, descriptions and illustrations for families to carry out in the home as well as community (Sayers Menear, 2007). This finding supports our recommendation for grading and adaptation of leisure to improve performances and satisfaction in leisure for children with Down syndrome.

This study found unhealthy use of computer and technological leisure pursuits in the majority of cases. A maximum of two hours in technological activities per day (Department of Health and Aging, 2004a, 2004b) is recommended for school-aged children and was reported for only 38.9% of cases, signifying that the majority reported use of technology above what is considered healthy. Similarly, the guideline for 60 minutes of moderate to vigorous exercise a day for school-aged children (Department of Health and Aging, 2004a, 2004b) was also met by less than one third of cases despite over two-thirds of cases reporting participation in sports. In particular,

only 22% reported between approximately seven and fourteen hours of vigorous exercise and 7.5% over fourteen hours of vigorous exercise each week. This means the majority (70.5%) of cases did not meet the recommendations by the Australian government for school-aged children each day amounting to only 7 hours per week (Department of Health and Aging, 2004a, 2004b).

Participation in sport and active leisure is essential for maintaining a healthy weight and cardiovascular system in children with Down syndrome. Additionally, other studies have investigated the negative effect of sedentary leisure for child body weight and obesity and report a higher risk of obesity in children with Down syndrome than typically developing children (De, Small, & Baur, 2008; Fujiura, Fitzsimons, & Marks, 1997; Jobling, 2001). For this reason, it is important that children with Down syndrome participate in regular physical activity. To enable this, parents, teachers, and sporting coaches should also grade and adapt sporting activities to the individual child's level of skill and ability.

Higher levels of functional independence in everyday activities appeared to be a significant predictor for greater participation in sport. This study found the sports in which the children most commonly participated were swimming (44.7%), bowling (15.9%), soccer (8.2%), basketball (7.2%), and dancing (5.3%). Encouragingly, the majority of sports most commonly yielding above average performance were the same sports: swimming, soccer, gymnastics, football, bowling and basketball. However, as performance responses were analysed in isolation of individual child factors, it is unclear what factors contributed to the reported performance of sports and leisure activities for cases. Further research examining the factors contributing to greater performance in sport would address this problem.

Finally, we expected impairment factors (the number of co-morbidities), person factors (the level of function, behaviour and communication experienced by the child) and environmental factors (number of siblings, access to transport, parent health status, income and availability of time) to relate to participation in friendships and leisure for school-aged children with Down syndrome.

This study found child factors such as greater functional independence, better behaviour and communication to be associated with a higher number of friendships for school-aged children with Down syndrome. Additionally, contextual factors such as greater parental physical and mental health, availability of time and family and community support have greater odds for a high number of friendships.

The odds of a higher number of friendship interactions were increased when children had fewer current and ongoing health conditions, greater functional independence, and improved access to transport. Similarly to friendships, participation in interactions increased for those with parents who had better mental health, availability of time and family and community support.

Greater hobby participation occurred in the presence of superior child functional independence, social communication, access to public transport and availability of parental time. Higher levels of functional independence in everyday activities appeared to also be a significant predictor for greater participation in sport.

The strengths of our study include a large population-based cohort of participating families with children with Down syndrome. Their collaboration in the Down syndrome NOW study represents 73% of all individuals with Down syndrome receiving Disability Services Commission services in Western Australia and means that results are largely generalisable to the population. The data

collection instrument, the Down syndrome NOW questionnaire, was a comprehensive tool allowing for collection of multi-dimensional data about impairment and contextual factors for the school-aged children with Down syndrome which could then be used in analysis. Similarly, the structure of the ICF provided complex classification of relevant factors to leisure participation and their dynamic interactions. Our study found the terminology of the ICF a strength due to its universality, which allows for ease of comparison between studies. However, we do acknowledge some limitations in the study. Despite the benefits of such a comprehensive questionnaire, the format and length of questionnaires can produce fatigue and there is also a degree of recall error associated with retrospective parent-report. However, we believe these limitations were minimal due to the fact parents were able to complete the questionnaire in their own time and in multiple sittings and most questions required prior knowledge of the last twelve months only.

Conclusions

In summary, this study found leisure impaired in the majority of our cases. However, occupational therapists, teachers, disability service co-ordinators and families of children with Down syndrome may improve participation in leisure for school-aged children with Down syndrome by addressing the ICF, person and contextual factors identified in this study. We recommend further investigation of the relevance of these factors to leisure, in particular the affect of respite and community support for parents and its contributions to leisure. The provision of education regarding skill grading and adaptation to families and teachers may also provide more satisfying and meaningful participation in leisure for school-aged children with Down syndrome.

Key Messages:

- Children with Down syndrome participated in a high number of friendships and clubs, and low numbers of weekly friendship interactions, sports, and hobbies.
- Investigation into how leisure can be adapted to accommodate impairment, person and environment factors may result in higher participation in leisure.

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References

- Ashiabi, G. (2007). Play in the preschool classroom: its socioemotional significance and the teacher's role in play. *Early Childhood Education Journal*, 35(2), 199-207.
- Bittles, A. H., Bower, C., Hussain, R., & Glasson, E. J. (2006). The four ages of Down syndrome. *European Journal of Public Health*, 17(2), 221-225.
- Bittles, A. H., & Glasson, E. J. (2004). Clinical, Social and Ethical Implications of Changing Life Expectancy in Down Syndrome. *Developmental Medicine & Child Neurology*, 46, 282 - 286.
- Bourke, J., Ricciardo, B., Bebbington, A., Aiberti, K., Jacoby, P., Dyke, P., et al. (2008). Physical and Mental Health in Mothers of Children with Down Syndrome. *The Journal of Pediatrics*, 153(3), 320-326.e323.
- Buttimer, J., & Tierney, E. (2005). Patterns of leisure participation among adolescents with a mild intellectual disability. *Journal of Intellectual Disabilities*, 25(9), 25-42.
- Case-Smith, J. (2005). *Occupational therapy for children: 5th Edition*. St. Louis: Elsevier Mosby.
- Center on the Developing Child at Harvard University (2007). A science-based framework for early childhood policy: using evidence to improve outcomes in learning, behaviour, and health for vulnerable children. *Journal*. Retrieved from http://www.developingchild.harvard.edu/content/downloads/Policy_Framework.pdf
- D'Haem, J. (2008). Special at school but lonely at home: an alternative friendship group for adolescents with Down syndrome. *Down Syndrome Research & Practice*, 12(2), 107-111.
- De, S., Small, J., & Baur, L. (2008). Overweight and obesity among children with developmental disabilities. *Journal of Intellectual & Developmental Disability*, 33(1), 43-47.
- Department of Health and Aging. (2004a). Australia's physical activity recommendations for 5-12 year olds. Canberra: Commonwealth of Australia.
- Department of Health and Aging. (2004b). Australia's physical activity recommendations for 12-18 year olds. Canberra: Commonwealth of Australia.
- Einfeld, S., & Tonge, B. (1992). *Developmental Behaviour Checklist*. Clayton, Victoria: Monash University.
- Fujiura, G., Fitzsimons, N., & Marks, B. (1997). Predictors of BMI among adults with down syndrome: the social context of health promotion. *Research in Developmental Disabilities*, 18(4), 261-274.

- Gairdiner, C., Lanigan, B., & O'Keefe, M. (2008). Postcataract surgery outcome in a series of infants with Down syndrome. *British Journal of Ophthalmology*, *92*, 1112-1116.
- Ginsburg, K., Committee on Communications, & Committee on Psychosocial Aspects of Child and Family Health. (2007). The importance of play in promoting healthy child development and maintaining strong parent-child bonds. *American Academy of Pediatrics*, *119*(1), 182-191.
- Guralnick, M. (2002). Involvement with peers: comparisons between young children with and without Down's syndrome. *J Intellect Disabil Res*, *46*(5), 379-393.
- Holder, M., & Coleman, B. (2009). The contribution of social relationships to children's happiness. *Journal of Happiness Studies*, *10*, 329-349.
- Holder, M., Coleman, B., & Sehn, Z. (2009). The contribution of active and passive leisure to children's wellbeing. *Journal of Health Psychology*, *14*(3), 378-386.
- Isenberg, J., & Quisenberry, N. (1988). Play: a necessity for all children. *Childhood Education*, *64*(3), 138-145.
- Jobling, A. (2001). Life be in it: lifestyle choices for active leisure. *Down Syndrome Research and Practice*, *6*(3), 117-122.
- Leonard, S., Msall, M., Bower, C., Tremont, M., & Leonard, H. (2001). Functional status of school-aged children with Down syndrome. *J Paediatr Child Health*, *38*, 160-165.
- National Health and Medical Research Council. (2003). *Clinical practice guidelines for the management of overweight and obesity in children and adolescents*. Canberra: Commonwealth of Australia.
- Petterson, B., Leonard, H., Bourke, J., Sanders, R., Chalmers, R., Jacoby, P., et al. (2004). IDEA (Intellectual Disability Exploring Answers): A population based database for intellectual disability in Western Australia. *Annals of Human Biology*(in press).
- Putnam, J., Puschel, S., & Holman, J. (1988). Community activities of youths and adults with Down syndrome. *The British Journal of Mental Subnormality*, *34*(1), 47-53.
- Rutter, M., Bailey, A., & Lord, C. (2003). *Social Communication Questionnaire* Los Angeles, CA: Western Psychological Services.
- Sanderson, K., & Andrews, G. (2002). The SF-12 in the Australian population: cross-validation of item selection. *Australian and New Zealand Journal of Public Health*, *26*, 343-345.
- Sayers Menear, K. (2007). Parents' perceptions of health and physical activity needs of children with Down syndrome. *Down Syndrome Research and Practice*, *12*(1), 60-68.

- So, S., Urbano, R., & Hodapp, R. (2007). Hospitalizations of infants and young children with Down syndrome: evidence from inpatient person-records from a statewide administrative database. *Journal of Intellectual Disability Research, 51*(12), 1030-1038.
- Van Naarden Braun, K., Yeargin-Allsop, M., & Lollar, D. (2006). Factors associated with leisure activity among young adults with developmental disabilities. *Research in Developmental Disabilities, 27*, 567-583.
- Ware, J., Kosinski, M., & Keller, S. (1996). A 12-item short form health survey: construction of scales and preliminary tests of reliability and validity. *Medical Care, 34*(3), 220-233.
- World Health Organization. (2001). *International classification of functioning, disability and health: ICF: short version*. Geneva: World Health Organization.

Table 1. Count of frequencies for friendships, friendship interactions, number of sports, hobbies and clubs participated in.

Outcome	Total		Male		Female		Primary School		High School	
	n=	%	n=	%	n=	%	n=	%	n=	%
Outcome	200	Resp.	112	Male	88	Female	130	Primary	70	High
# Friendships										
None	66	33.0	39	34.8	27	30.7	40	30.8	26	37.1
One	29	14.5	20	17.9	9	10.2	19	14.6	10	14.3
Two or three	64	32.0	31	27.7	33	37.5	41	31.5	23	32.9
Four or more	41	20.5	22	19.6	19	21.6	30	23.1	11	15.7
Low # Friendships	95	47.5	59	52.7	36	40.9	59	45.4	36	51.4
High # Friendships	105	52.5	53	47.3	52	59.1	71	54.6	34	48.6
Outcome	174	Resp.	97	Male	77	Female	118	Primary	56	High
# Friendship Interactions										
Occasionally	113	64.9	63	65.0	50	64.9	84	71.2	29	51.8
Less than once/ week	18	10.3	9	9.3	9	11.7	12	10.2	6	10.7
Once or twice/ week	33	19.0	17	17.5	16	20.8	16	13.6	17	30.4
Three or more times/week	10	5.8	8	8.2	2	2.6	6	5.0	4	7.1
Low # Interactions	131	75.3	72	74.2	59	76.6	96	81.4	35	62.5
High # Interactions	43	24.7	25	25.8	18	23.4	22	18.6	21	37.5
Outcome	208	Resp.	118	Male	90	Female	138	Primary	70	High
# Sports										
0	75	36.1	47	39.8	28	31.1	54	39.1	21	30.0
1	61	29.3	28	23.7	33	36.7	41	29.7	20	28.6
2	40	19.2	25	21.2	15	16.7	27	19.6	13	18.6
3	23	11.1	12	10.2	11	12.2	12	8.7	11	15.7
4	9	4.3	6	5.1	3	3.3	4	2.9	5	7.1
Low # Sports	136	65.4	75	63.6	61	67.8	95	68.8	41	58.6
High # Sports	72	34.6	43	36.4	29	32.2	43	31.2	29	41.4
Outcome	208	Resp.	118	Male	90	Female	138	Primary	70	High

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# Independent Sports														
0	97	46.6	57	48.3	40	44.4	67	48.5	30	42.9				
1	89	42.8	50	42.4	39	43.4	53	38.4	36	51.4				
2	19	9.1	10	8.5	9	10.0	15	10.9	4	5.7				
3	3	1.5	1	0.8	2	2.2	3	2.2	0	0.0				
# Team Sports														
0	134	64.4	77	65.3	57	63.3	97	70.3	37	52.9				
1	44	21.2	21	17.8	23	25.6	29	21.0	15	21.4				
2	27	13.0	17	14.4	10	11.1	12	8.7	15	21.4				
3	3	1.4	3	2.5	0	0.0	0	0.0	3	4.3				
Outcome	n=	%	n=	%	n=	%	n=	%	n=	%				
	202	Resp.	113	Male	89	Female	134	Primary	68	High				
# Hobbies														
0	70	34.6	39	34.5	31	34.8	49	36.6	21	30.9				
1	49	24.3	31	27.4	18	20.2	29	21.6	20	29.4				
2	42	20.8	21	18.6	21	23.6	25	18.7	17	25.0				
3	30	14.9	17	15.1	13	14.6	22	16.4	8	11.8				
4	11	5.4	5	4.4	6	6.8	9	6.7	2	2.9				
Low # Hobbies	119	58.9	70	61.9	49	55.1	78	58.2	41	60.3				
High # Hobbies	83	41.1	43	38.1	40	44.9	56	41.8	27	39.7				
Outcome	n=	%	n=	%	n=	%	n=	%	n=	%				
	208	Resp.	118	Male	90	Female	138	Primary	70	High				
# Clubs														
0	136	65.4	82	69.5	54	60.0	100	72.5	36	51.4				
1	53	25.5	27	22.9	26	28.9	31	22.5	22	31.4				
2	14	6.7	6	5.1	8	8.9	7	5.0	7	10.0				
3	5	2.4	3	2.5	2	2.2	0	0.0	5	7.2				
Low # Clubs	103	49.5	56	47.5	47	52.2	73	52.9	30	42.8				
High # Clubs	105	50.5	62	52.5	43	47.8	65	47.1	40	57.2				

Table 2. Analysis of Developmental Behaviour Checklist components affecting number of friendships

Component of DBC	OR	95% Conf. Interval	p value
Disruptive/ Antisocial	0.93	0.89- 0.97	0.001
Self-absorbed	0.93	0.88- 0.96	<0.001
Communication Disturbance	0.92	0.85-1.00	0.053
Social relating	0.83	0.74- 0.93	0.001

Usually adequate	0.95	0.17- 5.27	0.96							
Almost always adequate	1.15	0.22- 5.88	0.88							
Access to Public transport										
Seldom adequate	0.83	0.16- 4.18	0.82							
Sometimes adequate	1.43	0.36- 5.61	0.61							
Usually adequate	2.60	0.80- 8.41	0.11							
Almost always adequate	2.00	0.62- 6.49	0.25							
Not Applicable- use own car	2.14	0.86- 5.32	0.10							
Place of residence										
Rural	0.65	0.33- 1.28	0.22							
Number of siblings	0.91	0.73-1.13	0.41							
MCS	1.04	1.01-1.07	0.01	1.03	1.00-1.07	0.03	1.02	0.98-1.05	0.18	
PCS	1.03	1.00- 1.07	0.03	1.02	0.98- 1.06	0.19	1.02	0.99-1.06	0.12	
ADAS	1.01	0.96- 1.07	0.56							
Parent available time	1.05	1.01- 1.09	0.01							
Mcmaster	0.90	0.84- 0.97	0.01							
FSS	1.04	1.01-1.08	<0.001							
Outcome 2: Number of Friendship Interactions										
Impairment	OR	95% CI	P value	Adjusting for WeeFIM			Adjusting for Current and ongoing health conditions			
				OR	95%	P value	OR	95%	P value	P value

factors	CI			CI		
Current ongoing health conditions	0.74	0.55- 0.98	0.04	0.72	0.53-0.97	0.03
EOI	0.92	0.81- 1.03	0.18			
Person factors						
Age group						
High school	2.62	1.28- 5.38	0.01			
Male	1.13	0.56- 2.28	0.72			
BMI	1.60	0.99- 2.61	0.05			
WeeFIM	1.02	1.00-1.04	0.03			
DBC	0.98	0.96-1.00	0.17			
SCQ	0.99	0.92- 1.06	0.85			
Environment factors						
Income						
\$26,000- \$31,199	2.20	0.47- 10.30	0.32			
\$36,400- \$41,599	0.88	0.08- 9.29	0.92			
\$41,600- \$51,999	1.17	0.27- 5.10	0.83			
\$52,000- \$77,999	1.10	0.29- 4.12	0.89			
\$78,000 or more	2.26	0.74- 6.85	0.15			
Access to Private transport						
Sometimes adequate	**	**	**			
Usually adequate	0.56	0.80- 3.94	0.56			
Almost always adequate	0.47	0.75- 2.94	0.42			
Access to Public transport						
				1.01	0.98- 1.03	0.33

Seldom adequate	5.43	0.42- 69-66	0.19
Sometimes adequate	8.14	0.72- 91-88	0.09
Usually adequate	8.14	0.88- 75.47	0.06
Almost always adequate	10.23	1.12- 93.33	0.04
N/A-- Use own car	6.7	0.85- 52.82	0.07
Place of residence			
Rural	0.96	0.40- 2.34	0.94
Number of siblings	0.87	0.65-1.15	0.34
MCS	1.06	1.01-1.12	0.01
PCS	1.02	0.97- 1.07	0.28
ADAS	1.04	0.96-1.12	0.30
Parent available time	1.05	0.99- 1.11	0.05
Memaster	0.92	0.84-1.02	0.12
FSS	1.05	1.01- 1.09	0.01
Outcome 3: Number of Hobbies			
	Adjusted for age group and parent availability of time		Adjusted for age group and weeFIM
	OR	95% CI	P value
Impairment factors	OR	95% CI	P value
Current/ ongoing health conditions	0.89	0.72- 1.10	0.30
Episodes of illness	1.00	0.92- 1.09	0.84
Person factors			
Age group			

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High school	0.92	0.51-1.66	0.78
Male	0.75	0.42- 1.32	0.32
BMI	0.92	0.70-1.19	0.53
WeeFIM	1.01	1.00-1.03	1.02
DBC	0.98	0.97- 1.00	1.00- 1.04
SCQ	0.94	0.89- 0.99	0.03
Environment factors			
Income			
\$20,800- \$25,999	**	**	**
\$26,000- \$31,199	1.22	0.29- 5.10	0.78
\$32,000- \$36,399	0.98	0.16- 5.99	0.98
\$36,400- \$41,599	1.83	0.34- 9.89	0.48
\$41,600- \$51,999	1.57	0.50- 4.92	0.44
\$52,000- \$77,999	2.30	0.82- 6.46	0.11
\$78,000 or more	1.92	0.78- 4.80	0.16
Access to Private transport			
Sometimes adequate	**	**	**
Usually adequate	1.16	0.23- 5.81	0.86
Almost always adequate	0.87	0.19- 4.05	0.86
Access to Public transport			
Seldom adequate	0.83	0.13- 5.03	0.84
Sometimes adequate	2.08	0.49- 8.81	0.32
Usually adequate	4.33	1.26- 14.81	0.02

SCQ	0.99	0.94- 1.04	0.77
Environment factors			
Income			
\$20,800- \$25,999	**	**	**
\$26,000- \$31,199	1.80	0.49- 6.64	0.33
\$32,000- \$36,399	0.84	0.16- 4.36	0.68
\$36,400- \$41,599	2.81	0.48- 16.56	0.31
\$41,600- \$51,999	0.60	0.20- 1.78	0.58
\$52,000- \$77,999	2.06	0.78- 5.46	0.13
\$78,000 or more	1.19	0.52- 2.72	0.61
Access to Private transport			
Sometimes adequate	*	*	*
Usually adequate	0.83	0.18- 3.76	0.81
Almost always adequate	1.06	0.25- 4.38	0.94
Access to Public transport			
Seldom adequate	1.00	0.23- 4.30	1.00
Sometimes adequate	2.50	0.62- 10.04	0.20
Usually adequate	1.88	0.59- 5.93	0.28
Almost always adequate	0.69	0.22- 2.18	0.53
N/A- use own car	0.86	0.37- 2.03	0.73
Place of residence	0.98	0.50- 1.90	

Outcome 5: Number of Sports						
	Unadjusted			Adjusted for age group		
	OR	95% CI	P value	OR	95% CI	P value
Number of siblings	1.10	0.89- 1.37	0.37			
MCS	1.00	0.97- 1.03	0.99			
PCS	1.01	0.98- 1.04	0.53			
ADAS	0.97	0.92- 1.03	0.33			
Parent available time	1.03	0.99- 1.07	0.11			
Memaster	1.00	0.93- 1.07	0.91			
FSS	1.02	0.99- 1.05	0.24			
Impairment factors						
Current/ ongoing health conditions	1.18	0.95-1.46	0.13			
Episodes of illness	0.99	0.91- 1.08	0.94			
Person factors						
Age group						
High School	1.56	0.86- 2.83	0.14			
Gender						
Male	1.20	0.67- 2.15	0.53			
BMI	1.16	0.86- 1.57	0.32			
WeeFIM	1.03	1.01- 1.05	<0.0001	1.03	1.01- 1.05	<0.0001
DBC	1.00	0.98- 1.01	0.82			

SCQ	1.00	0.95- 1.05	0.80
Environment factors			
Income			
\$20,800- \$25,999	**	**	**
\$26,000- \$31,199	1.23	0.30- 5.02	0.77
\$32,000- \$36,399	1.11	0.18- 6.78	0.91
\$36,400- \$41,599	2.08	0.39- 11.17	0.39
\$41,600- \$51,999	1.48	0.47- 4.67	0.50
\$52,000- \$77,999	1.72	0.61- 4.81	0.30
\$78,000 or more	1.94	0.79- 4.79	0.15
Access to Private transport			
Sometimes adequate	*	*	*
Usually adequate	1.26	0.22- 7.07	0.79
Almost always adequate	1.67	0.32- 8.59	0.54
Access to Public transport			
Seldom adequate	0.81	0.16- 3.91	0.79
Sometimes adequate	1.42	0.37- 5.36	0.60

Usually adequate	1.45	0.45- 4.60	0.52
Almost always adequate	1.90	0.59- 6.04	0.28
N/A- use own car	0.76	0.30- 1.88	0.55
Place of residence			
Rural	0.65	0.31- 1.35	0.25
Number of siblings	0.94	0.75-1.19	0.66
MCS	0.97	0.95- 1.00	0.16
PCS	1.02	0.98- 1.06	0.19
ADAS	0.99	0.93- 1.05	0.81
Parent available time	0.99	0.95- 1.02	0.62
Mcmaster	1.01	0.94- 1.09	0.62
FSS	1.01	0.98- 1.05	0.22

* Data predicts success perfectly and was dropped from analysis

** Data predicts failure perfectly (and consequently will have low participation in the particular leisure)

Guidelines for Contributions by Authors

For Research Report Only

British Journal of Occupational Therapy: Author's Guide

Guidelines for Authors

Introduction

The *British Journal of Occupational Therapy (BJOT)* is the official journal of the College of Occupational Therapists. Its purpose is to publish contributions of papers relevant to theory, practice, research, education and management in occupational therapy.

- **Vision:** A monthly journal presenting high quality international research and practice related papers that informs the knowledge and evidence base of occupational therapy and is easily accessible through online searches.

Online submission of articles

From March 2008, the submission of articles is online, through Manuscript Central, available at:
<http://mc.manuscriptcentral.com/bjot>

Categories of submission

Please note that the *word counts* given for the different categories apply to the main text only; the abstract, references, tables, figures and appendices are not included. *Abstracts* are obligatory; their maximum word counts are shown.

1. Research

Research papers are particularly welcomed and will be given publishing priority. Quantitative, qualitative and mixed method studies are all eligible for submission.

Manuscripts may be submitted as 5,000-word full papers or 2,000-word short papers.

Shorter papers are actively encouraged for studies that report small-scale projects, pilot studies or preliminary findings. We encourage authors to contact the editor if they are unsure of whether to submit a short or a full paper.

Manuscript format

The format of the manuscript will vary depending on the focus and methodology but, where appropriate, must include the following:

Abstract, 200 words (100 words for short papers):

A succinct summary of the purpose, procedures, findings and conclusions of the study, stating the relevance of the work to occupational therapy.

Introduction: A brief rationale for the study and an outline of the primary aims, hypotheses or questions.

Literature review: A critical appraisal of current relevant literature. The review should identify limitations in knowledge and provide a rationale for the study.

Methods: Methods of data collection and analysis must be fully and sufficiently described to allow replication of the study, with coherence between methodology, data collection and analysis. Issues concerning validity, reliability, trustworthiness, credibility and ethics must be addressed.

Results/findings: The results must be presented in a way that is accessible to readers and clearly linked to the aim(s) of the research and methods employed.

Discussion: The implications of the study for occupational therapy must be outlined and the contribution of the study to the current state of knowledge stated. Methodological limitations must be addressed and the implications for practice and further areas of work outlined.

Conclusions: A clear summary of the main points of the paper.

Key messages: Authors are required to submit the following:

- (i) Key findings – a summary statement of two or three key findings. These should not be more than 30 words in total (that is, 10-15 words each).
- (ii) What the study has added – a statement of how the study has contributed to the relevant field. This should not be more than 30 words in total.

This information will be printed in highlighted boxes within the article to assist its readability.

2. Critical Reviews

Critical reviews will address clinical, conceptual, theoretical, methodological or ethical issues relevant to occupational therapy. They will:

- (a) Describe and summarise the literature within a particular area
- (b) Synthesise and evaluate this literature, based on a critical appraisal of the quality of the work described
- (c) Distil the most important elements for the benefit of readers and make recommendations about areas in which further evidence is required.

Manuscript format

Abstract (200 words): A succinct summary of the background, source of review data, how papers were selected and evaluated, the main findings and implications for practice.

Introduction: An explanation of the area or topic and the rationale for conducting the review. It should also make a clear case for the relevance and significance of the review for occupational therapy.

Methods: An explanation of the approach taken to searching the literature, the search parameters and key terms used, the inclusion and exclusion criteria used to identify key papers, the criteria used to judge the papers and how key information was extracted from each paper.

Findings: Presentation of the main evidence and a summary of its quality.

Discussion: This should outline the implications of the review for occupational therapy, highlight the methodological limitations of the review, identify any gaps in the literature and make recommendations for further work.

Conclusion: A clear summary of the main points of the paper.

Key messages: Authors are required to submit the following:

- (i) Key findings – a summary statement of two or three key findings. These should not be more than 30 words in total (that is, 10-15 words each).
- (ii) What the study has added – a statement of how the study has contributed to the relevant field. This should not be more than 30 words in total.

The maximum word count for a critical review will be 5,000 words.

3. Practice Analysis

The aim of a practice analysis is to present a brief critical analysis of an instance of occupational therapy practice. This might include the consideration of work with a client, patient, family or group; it might focus on a particular assessment, treatment method, educational approach; or it might report a novel practice venue.

Manuscript format

Abstract (100 words): A succinct summary of the context, critical reflection on the instance of practice and implications for practice.

Statement of context: An outline of the context of the practice

Critical reflection on practice: This will describe what took place and will include a critical reflection on either (i) how the practice was informed by relevant policy, occupational therapy theory and/or occupational therapy research, or (ii) how the practice contributes to our understanding of relevant policy and occupational therapy.

Summary: The piece will end with a short summary, which highlights issues for future consideration.

Key messages: Authors are required to submit a summary statement of two or three key messages. These should not be more than 30 words in total (that is, 10-15 words each).

Where relevant, authors submitting a practice analysis will be required to provide signed consent for publication from the participants using the *BJOT* consent form (available on Manuscript Central).

Collaborative work with clients, patients or other professionals is welcome.

The maximum word count for a practice analysis will be 2,000 words.

4. Case Reports

Case reports will discuss an interesting case (one to three clients or patients or a single family) that raises a problem or challenge and has implications for occupational therapy. They may also report novel approaches or adverse events, or illuminate the wider side of clinical practice.

Manuscript format

Abstract (100 words): A succinct summary of the case report and implications for practice.

Text: Should include:

- A brief history and context
- An explanation of what happened (the therapy process and outcome)
- Engagement in problem solving, reasoning and reflection.

Summary: A short summary highlighting the relevance to evidence-based practice.

Key messages: Authors are required to submit a summary statement of two or three key messages. These should not be more than 30 words in total (that is, 10-15 words each).

Signed consent for publication from the participants in the case report will be required, using the *BJOT* consent form.

Collaborative work with service users is welcome.

The maximum word count for a case report will be 2,000 words.

5. Personal Journeys

These should describe how it feels to face a specific situation related to the role of being a client, patient, therapist or student. It must involve or be of interest and relevance to occupational therapists.

Manuscript format

Abstract (100 words): A succinct summary of the personal journey and the implications for practice.

Text: Should include:

- A brief outline of the personal situation and context
- Using the idea of a journey, a description of what happened over time, focusing on, for instance, an aspect of care, therapy or education. It will address issues such as the impact on day-to-day life, relationships, families and quality of life; coping strategies; and practical information and advice.

Summary: A short summary highlighting the relevance to evidence-based practice.

Any person mentioned who is not an author must give signed consent for publication. Co-authors are accepted, but the first author must be the person giving the account.

The maximum word count for a personal journey will be 1,500 words.

6. Opinion Pieces

These provide authors with the opportunity to express an opinion concerning any aspect of occupational therapy. These submissions are designed to encourage topical

debate and an exchange of ideas. Contributors may discuss specific aspects of occupational therapy or debate the impact on the profession of the current political or financial climate. Irrespective of the topic discussed, opinions should be supported by evidence or theory.

Opinion pieces should:

- Include an abstract (100 words)
- Be structured and incorporate headings
- Include a list of references, following the guidelines for references below.

The maximum word count for an opinion piece will be 1,500 words.

7. Editorials

These raise issues of importance to the profession. Editorials should not exceed 500 words. Editorials including more than three references must be shorter to fit the journal page.

8. Letters to the editor

These offer comment on previous articles in the journal or on any relevant topic. The editor reserves the right to shorten letters.

Letters should not exceed 500 words. They should be submitted by email to the editor.

9. Executive summaries

This category is designed to provide an effective mechanism for communicating official College of Occupational Therapists' (COT's) reports to the membership and readership in a concise and timely manner; therefore, it will not be a category of submission open to authors other than those working on COT reports.

Executive summaries will be used to provide a précis or summary of substantial COT documents, such as strategic or policy documents or commissioned research. The purpose of the summary is to communicate key aspects of the document to readers, the full version of which will be available via COT, the COT website or both.

The executive summary should contain:

- An introduction explaining the rationale for the document, including reference to how the activity reported relates to the business plan or strategic development of COT
- The main body of text containing a few paragraphs, each with subheadings
- A conclusion paragraph.

If the summary is of commissioned research, it must contain a brief outline of the methodology. In this case, the body of the text should present the key findings and the conclusion should include recommendations for the COT and the profession.

If the summary is of a document other than commissioned research, it must contain the key messages and conclude with recommendations for the COT and the profession.

Executive summaries will be reviewed by an appropriate senior officer of COT, such as a Head of department.

The executive summary should not exceed 1,500 words.

Multiple-part articles

Authors are discouraged from submitting multiple-part articles.

Ethics and consent

Ethics for research

Research articles must state how ethical and/or research governance approval was obtained and state the reference number, where appropriate. Authors must confirm that anonymity and confidentiality are assured and that ethics approval has been gained where appropriate.

Consent*

Consent for publication of personal information (case reports, personal journeys): The publication of any personal information about an identifiable living patient requires the signed consent of the person (this is a requirement under the UK's Data Protection legislation). Authors should use the *BJOT* consent form.

Information or illustrations that may identify a person, service or organisation must state that consent has been obtained giving permission for the material to be published. The consent form must be signed and dated by the author(s), the patient(s) and a witness, with their names printed underneath. The original consent form should be sent to the editor at the same time as the manuscript is submitted. The manuscript will not be sent for review unless the consent form is received.

Publication without the consent of the person (or family) will be permitted only if all of the following conditions are met:

- (a) The person is dead and his or her family is untraceable to seek consent from
- (b) The article contains a worthwhile clinical lesson or public health point which could not be made as effectively in any other way. ('Worthwhile' is intended to sit on a spectrum between 'interesting', which is the publication threshold with an individual's consent, and 'overriding public health importance', which is the publication threshold over refusal of consent.)
- (c) A reasonable person in the position of the person's relatives would not be expected to object to the publication of the case. (This requires an assessment of the intrusiveness of the disclosure and the potential that it has for causing the patient's family embarrassment or distress. Particular attention must be paid here to differences of cultural and social attitudes. It must not be assumed that what is a matter of indifference in one society will have the same status in another.)

*The sections on Consent and Conflict of Interests are adapted and reprinted by kind permission of the *British Medical Journal* from:

– http://resources.bmj.com/bmj/authors/editorial-policies/copy_of_patient-confidentiality
– <http://resources.bmj.com/bmj/authors/checklists-forms/competing-interests>

- (d) The risk of identification of the patient is minimised by measures designed to prevent the identity of the patient being revealed either to others or to the patient's relatives. (These measures will include anonymisation of the case and/or the author. The publication of photographs without consent will require particular scrupulous attention to anonymisation.)

Conflict of interests*

All authors will be required to submit, via Manuscript Central, a statement disclosing conflicts of interest before publication can proceed.

A conflict of interest exists when professional judgement concerning a primary interest (such as a person's welfare or the validity of research) may be influenced by a secondary interest (such as financial gain or personal rivalry).

It may arise for the authors when they have a financial interest that may influence – probably without their knowing – their interpretation of their results or those of others.

We believe that to make the best decision on how to deal with a paper, we should know about any such conflicts of interest that authors may have. We are not aiming to eradicate conflicts of interests – they are almost inevitable and we will not reject papers simply because you have declared a conflict of interest, but we will make a declaration, within the published manuscript, on whether or not you have a conflict of interests to enable the reader to interpret the work with this in mind.

To ascertain whether or not you have a conflict of interest which must be declared, please answer the following questions (all authors must answer):

1. Have you in the past 5 years accepted the following from an organisation that may in any way gain or lose financially from the results of your study or the conclusions of your review, editorial, or letter:
 - Reimbursement for attending a symposium?
 - A fee for speaking?
 - A fee for organising education?
 - Funds for research?
 - Funds for a member of staff?
 - Fees for consulting?
2. Have you in the past 5 years been employed by an organisation that may in any way gain or lose financially from the results of your study or the conclusions of your review, editorial, or letter?
3. Do you hold any stocks or shares in an organisation that may in any way gain or lose financially from the results of your study or the conclusions of your review, editorial or letter?
4. Have you acted as an expert witness on the subject of your study, review, editorial or letter?
5. Do you have any other competing financial interests?
If so, please specify.

If you have answered 'yes' to any of the above five questions, we consider that you may have a conflict of interest, which, in the spirit of openness, should be declared when you submit your paper.

If you declare a conflict of interest, you will be required to submit a statement to publish with the article. It might, for example, read:

Conflict of interests: AB's NHS Trust paid a consultancy fee to CD's university in payment for services and CD has been reimbursed for attendance at a conference to present the results of this study.

If you did not answer 'yes' to any of the five questions above, we will publish '*Conflict of interests:* None declared.'

Submission and review

All manuscripts must be typed double spaced. It is essential that all pages are numbered consecutively. An anonymised copy of the manuscript should be submitted to enable the double-blind peer review process to take place. Manuscript Central will guide you through the submission procedure.

Text

Abbreviations

Abbreviations should first be written in full, followed by the abbreviation in parentheses. Following this, the abbreviation can be used within the text. Avoid using abbreviations in the title and abstract. 'Occupational therapy' and 'occupational therapist' should always be written in full and never abbreviated to 'OT'.

Measurements

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Acknowledgements

The contributions of persons, institutions and agencies, particularly those that provided funding, must be acknowledged. It is the author's responsibility to ensure that each individual is willing to be acknowledged.

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Journals

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Books

Wilcock AA (2002) *Occupation for health, volume 2: a journey from prescription to self health*. London: College of Occupational Therapists.

Chapter in a book

Lougher L (2002) Child and adolescent mental health services. In: J Creek, ed. *Occupational therapy and mental health*. Edinburgh: Churchill Livingstone, 393-413.

World Wide Web

Department of Health (2001) National Service Framework for Older People. Available at: <http://www.doh.gov.uk/nsf/olderpeople.htm> Accessed on 15.01.02.

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