

# **Exploring opportunities available and perceived barriers to physical activity engagement in children and young people with Down syndrome.**

**Key words** Down syndrome, physical activity, PA opportunities, barriers, children, young people

## **Abstract**

*Primary objective:* The aim of this study was to explore physical activity amongst children and young people with Down syndrome.

*Method and procedures:* The Youth Physical Activity Promotion Model (YPAP) (Welk 1999) was used to inform semi-structured interviews to explore physical activity of children and young people with Down syndrome. Participants were 3 males and 5 females, aged between 6 and 21 years (16.38 + 5.04 years (mean + SD)) who had been diagnosed with the condition Down syndrome. Dyadic interviews were conducted with the participant and their parent(s). The interviews were recorded, transcribed and inductive and deductive analyses of the data were completed.

*Main outcomes and results:* The results were structure around the YPAP Model's (Welk 1999) key themes included; enabling factors (seasonal variation, transport, type of activity, independence); predisposing factors (enjoyment, social interaction, dislikes of PA, following instructions, understanding of PA); reinforcing factors (support and opportunities, parents, and care providers); and barriers to PA engagement (ear problems).

*Conclusion:* The children and young people with Down syndrome in the study typically only engaged in fun, unstructured activities. Key facilitators for physical activity participation were social interactions and parental support. Increasing the level of independence for people with Down syndrome within adolescence may have beneficial effects for physical activity participation in later life.

## **Introduction**

Down syndrome is the most common genetic cause of intellectual disability (ID) (Mahy et al. 2010). The Down Syndrome Association (2012) recorded that approximately 750 children are born with Down syndrome (DS) each year in the UK. DS is associated with various chronic health problems, including Alzheimer disease, obesity, congenital heart defects, low cardiovascular fitness, sight and hearing problems (NHS 2010), decreased muscle strength, muscle hypotonicity and joint hypermobility, (Croce et al. 1996). People with DS tend to be shorter in height and heavier in weight than people without DS. Many people with DS are susceptible to conditions that could increase the risk of weight gain such as an under active thyroid gland and having a lower basal metabolic rate compared to that of the general population (Down Syndrome Association 2002).

This propensity for gaining weight in combination with an increased risk of cardiovascular disease in children with Down syndrome highlights the need for effective interventions to promote healthy body mass and physical fitness for this population. Physical activity (PA) is an important health behaviour and positively contributes to the management and prevention of more than 20 chronic diseases and conditions (Department of health 2005; Chief Medical Officer 2011). PA promotes energy expenditure in children and is often targeted when attempting to prevent or treat obesity. Furthermore, cardiorespiratory fitness, an independent determinant of health and in particular cardio-metabolic health (Anderson et al. 2008) is the product of PA (Ortega et al. 2008).

Luke et al. (1994) found that prepubescent children with DS have decreased resting metabolic rate in comparison to children without DS and therefore have lower resting energy expenditure than their non-DS peers. Furthermore, the findings of a review article by Frey,

Standish and Temple (2008) concluded that children with ID were less active than the groups without ID. Whitt-Glover, O'Neill and Stettler (2006) explored the PA patterns of children with DS compared to their non-affected siblings and noted there were no differences in low to moderate intensity PA. Further, children with DS accrued both less total and sustained vigorous PA (VPA) and had higher BMI levels than their non-affected siblings. Increasing children's involvement in VPA could therefore be suitable in the prevention of obesity and contribute to general lifelong health. Recent research compared levels of PA of individuals with ID to those with DS using accelerometers and concluded that participants with ID performed significantly more total PA, and moderate-vigorous physical activity (Phillips and Holland 2011). It should be noted, however, that no participants in the study met the current PA recommendations of 60 minutes of MVPA every day (Chief Medical Officer, 2011).

Jobling and Cuskelly (2006) conducted a study investigating the individual knowledge of young people (aged between 11 – 18 years) with DS with regard to health maintenance and prevention of illness. The majority of the young people (69%) engaged in swimming (the most frequent type of exercise) followed by walking. Only 53% of the participants understood the benefits of exercise yet 72% reported that exercise would be part of their life as they grew older. None of the young people were aware of the frequency of exercise needed to be beneficial and maintain good health (Jobling and Cuskelly 2006). It is proposed, therefore, that physical activity opportunities involving vigorous intensity PA on a regular basis are needed for children and young people with DS in order to minimize risks associated with DS such as being overweight or obese and lower levels of cardiorespiratory fitness. Furthermore, the Chief Medical Officer (2011) emphasizes the need to intervene at a young age in order to maintain high amounts of PA

into adulthood, essentially reducing the risk of morbidity and mortality from chronic diseases in later life.

Mahy et al. (2010) explored PA barriers and facilitators for adults with DS and also amongst their support network (i.e. parents and support workers). Three key themes were identified in relation to facilitation of PA: 1) support from others 2) PA was fun or had an interesting purpose and 3) routine and familiarity. The barriers identified also involved three key themes, 1) lack of support 2) not wanting to participate within PA and 3) medical and physiological factors. The authors emphasised the importance of the research to enable suitable programmes to be designed for people with DS stating that support networks play a key role for engagement in PA by adults with DS. Barr and Shields (2011) identified both barriers and facilitators to PA amongst children with DS to their engagement in PA and noted that the key themes were comparable to those of adults with DS with similarities including the family influence on PA and social interaction with peers, friends or family. The authors suggested that future research should investigate successful methods and interventions to encourage PA informed by fun and social interactions and ensuring that the physical activities are appropriate for children with DS. To date research has not explored in any depth such detail within preferred physical activities aimed at children and young people with DS within the UK.

The aim of the present study was to explore PA of children and young people with DS from birth, specifically exploring the opportunities available to young people with DS and perceived barriers to PA. The research outcomes will provide future researchers and policy makers with further understanding of PA throughout the early life of people with DS and thus inform appropriate research methodologies and intervention design appropriate to the DS population.

## **Method**

### ***Participants***

A total of eight families participated within the study, all families gave written parent/carer consent and child assent before any data were collected. Data were collected from five females and three male participants with DS, aged between 6 to 21 years ( $16.38 \pm 5.04$  years (mean  $\pm$  SD)) and at least one parent per child. Seven of the participants were 'Regular Trisomy 21' and one participant was 'Translocation' (P3). When the study took place three of the young people were attending Special Educational Needs (SEN) Colleges or day centers, one attended mainstream College, two in mainstream Schools, one in SEN School, and finally one in a residential SEN School (see Tables 1 and 2). The recruitment process targeted families through Down Syndrome Liverpool (<http://downsyndromeliverpool.org.uk/>) reaching 121 members. Other participants were recruited through personal contacts of the researcher within Leeds, UK. Interviews were arranged between the researcher and parents and scheduled for places and times that were convenient to the participants.

[Table 1 and 2 near here]

### ***Procedure***

This study was approved by Liverpool John Moores University Research Ethics Committee. The researcher developed a semi-structured interview informed by enabling, reinforcing, and predisposing factors from the YPAP Model (Welk 1999) to explore the PA engagement, and identify the PA opportunities and barriers for children and young people with DS and their families. Prior to the data collection taking place the interview guide was discussed with the Chair at DS Liverpool and the parents of a young person with DS to ensure face validity and the

structure/question format and tone were appropriate for the participants with DS. Minor modifications were made following this consultation process.

After gaining informed parental consent and participant assent the researcher met with the participant and their parent/s. Prior to the interview taking place the parent/s received information about the content of the interviews and time was given to fully explain the procedure of the interview to their child. Interviews were recorded with an Olympus WS-605S Dictaphone. A semi-structured interview guide (available on request to author 1) was used first requesting demographic information followed by open-ended questions to allow exploration of detail, expression of opinion and examples where appropriate. Intensity of PA was not objectively assessed, however when asking questions related to intensity the researcher explained that typically when someone engages in VPA physiological effects occur such as, sweating, breathlessness, changes in skin tone. The interview was also responsive to the participants allowing time for explanation of any words that the participant did not understand and/or rephrased words and sentences where necessary. At the request of one set of parents their son was not present as they felt that their child would interfere with the interview, making it difficult to complete. Also, in consultation with these parents prior and on occasion during the interview the child was unable to answer the questions due to speech defects. Here, questions were aimed at the parent/s of the child although in the spirit of inclusivity the researcher ensured gaze and direction of the questions were to all participants. Interview duration ranged from 30 – 40 minutes. All the interviews were conducted by the same researcher (author 1), who had considerable credibility for this role having gained experience of working, communicating and socializing with people with DS within schools and play schemes and has a younger sibling who has DS.

### ***Data coding and analysis***

Interviews were transcribed verbatim and created 206 pages of typeset data font 12 double spaced. The researcher read the transcripts numerous times in order to become familiar with both the participant and the transcripts. The transcripts were further reduced to identify quotes indicative of meaningful themes and discarding irrelevant quotes with no meaning. Comparing and contrasting the meaningful quotes enabled the researcher to unite quotes with similar meaning and to separate quotes with different meanings clustering quotes into categories and essentially highlighting common themes between participants' experiences. A frequency count was then conducted for the meaningful quotes, noting how many participants noted such various points. Four figures have been developed to display themes within the data three of these figures were developed using the YPAP Model (Welk 1999) as a framework.

### **Results**

Results were structured under aspects of the YPAP Model (Welk 1999); enabling factors to PA, predisposing factors to PA, and reinforcing factors to PA. The results were not presented in any particular order. An additional heading (barriers to PA) has been included within the results section that does not directly link to the categories of the YPAP Model (Welk 1999). However during the interviews some emergent issues were raised by participants and were described as a prevention of PA engagement for children and young people with DS and therefore are included. Throughout the following section P is used to demote participant number assigned for the purpose of the study.

[Figure 1 near here]

### ***Enabling factors of PA (Figure 1)***

#### *Type of PA (skills & fitness)*

The types of PA all of the participants were engaged in were similar in nature and had been a part of the participant's life for some time. Only one participant engaged in vigorous PA on a regular basis with the remaining seven participants engaging in low to moderate PA.

Swimming was the most popular PA activity engaged in by all the participants. Five participants were still currently engaged in the activity at the time of the interview and three participants had taken part previously but hoped to participate again. For example:

*“Swimming started seriously about 5 years ago and that has built up to going once a week to now going 4 times a week training for 8 hours...it's very competitive.”*

*(Mother of participant 5 (MP5))*

*“Now she's a really really strong swimmer and can swim under water.”(MP2)*

Dance was also a popular activity cited by seven parents and the young people generally showed enthusiasm and excitement when dance was mentioned. Parents of P7 and P8 noted that their child enjoyed music and dancing particularly within unstructured and perhaps somewhat unplanned settings, i.e. at social events such as parties or weddings (Figure 1). For example:

*“She does seem to tire quickly like that but if she's dancing she can dance from 8 o'clock to midnight without even sitting down.” (MP7)*

Ten pin bowling in an alley/venue or using the Nintendo Wii video game console (via Wii Sports games) were cited by 4 parents (P – 1, 2, 3, & 4). This was an activity that generally involved socializing playing with friends or family and was an activity that the participants enjoyed to do and chose if given choice (Figure 1). For example:

*“You like ten pin bowling as well don’t you... (No reply from child.) You enjoy going bowling don’t you with Daniel (participants friend) when he is home from College”*  
(MP2)

The use of the trampoline in the garden (as opposed to any formal classes) was cited by 3 parents (P – 2, 4, & 8) as another popular activity. For example:

*“We’ve got a trampoline and for two years he wouldn’t go on it and then when he did go on it he sort of just sat on it but it’s only sort of in the last year or two that he will actually do jumps and stars...and rollovers and things.”* (MP4)

#### *Seasonal variation (Environment)*

Parents explained that certain activities that their child engaged in were weather dependent. Exercising on the trampoline performed outdoors and five parents noted the weather associated with PA without prompt. For example:

*“We haven’t done much of that (PA outdoors, walking) recently because the weather’s been bad”* (MP3)

### *Transport/Independence (Access)*

All eight of the participants' parents cited how they were the only means of transport for their child to and from any activity. Therefore in combination with other areas such as developing independence transportation is an important factor to consider when planning an PA intervention. Linked to the YPAP model (Welk 1999) transport is a significant enabling factor, without the transport from parents (Figure 1) and family this could prevent engagement with PA. For example:

*“We normally take her (their daughter), her mum and dad” (MP2).*

*“I think the barriers are that she (daughter) can't get herself there and she needs an extra eye” (MP7).*

### *Developing independence (Skills)*

Parents who expressed a need for developing their child's independence skills were parents of older children (19 – 20 yrs old). Independence was noted as a concern for parents in the general context of their child's future. Also, for three parents a lack of independence was described as a barrier to their child's PA participation. The development of independence and help from care providers was seen by parent as important as in the future their child's PA levels/participation would not always involve them as parents. For example:

*“I also hope that it (physical activity) wouldn't always involve us as parents given that she is now 19” (MP2).*

*“We’re at the point where like the other kids would be doing their own health and fitness and both the boys (P7 siblings) go to the gym things like that that opportunities for P7 it obviously depends on me or her dad taking her...But the barriers as far as P7 is concerned is she needs someone to sort it out and get her there, know how much to pay, when it is and bring her home” (MP7)*

Two parents noted the use of college as a means to develop independence skills such as using public transport and to become more active within college. It was felt that independence was fostered positively through college attendance thus not involving the parents all the time (Figure 1). For example:

*“She’s benefiting from college that she started in September from a point of view of doing things that encourage her to be more independent like using public transport” (MP2).*

*“or have an opportunity to do something a bit more active, so I would of said opportunities at college to do things” (MP1).*

One mother gave somewhat unprompted advice for other parents of younger children with DS with regards to independence.

*“So I think it is something that perhaps for parents of younger children with Down’s would be advised that it’s a good thing to start getting your children into activities and keep it going” (MP7)*

[Figure 2 near here]

***Predisposing (Am I able?) (Figure 2)***

*Dislikes*

Walking and running were issues noted by five parents (P – 1, 2, 3, 6, & 7) in respect of their child disliking the activity or found them difficult and tiring noting walking in particular. However, when these activities were components within a fun game the children would be more inclined to participate. For example:

*“Walking from when she was very young because she didn’t walk till she was two...She’s got too much movement in her hips knees and ankles and also her muscle tone is weak in the lower part of her body, so that’s probably why she doesn’t enjoy walking as much because she’s got problems with how her feet are placed, so she enjoys swimming because she’s got upper body strength that she has not always had in her lower body”*  
(MP2)

*“I was going to say you’re not keen on running are you but you will run for fun when we make it fun but then you’ve had enough so you don’t really like running do you? No”*  
(MP1)

Two parents (MP1 & MP4) in particular cited the dislike of their child trying new things MP4 found it very frustrating and a big problem for her child in relation to exploring apparatus and getting involved within PA. Conversely, P1 noted this was less significant but still expressed some concern.

*“He can’t ride a bike... I don’t know he can be quite scared of things he doesn’t know...I think he could do it but he won’t do it...he won’t go on anything, anything at all like rides like say at light water valley he will...do like a little baby one but won’t do anything else...and he he’ll go on a slide but if it is too tall he won’t go up it, he stays on the baby one” (MP4)*

*“He (personal trainer) finds it difficult to do something different. She likes her routine which obviously isn’t the best thing either” (MP1)*

#### *Following Instructions*

Five parents explained that their child struggled when following instructions within different situations, i.e. football (rules), swimming lessons (strokes), gymnastics and dance (being directly told what to do). This was observed across the age range from the youngest participant aged 6 yrs 2 months to the eldest participant 21 yrs 10 months. For example:

*“You don’t really like being told what to do (at the gym) either do you and I think that’s the problem.” (MP1).*

*“He loves the swimming aspect but doesn’t take instruction” (MP8).*

Linked to the principle of following instructions, general understanding of the task at hand and PA as a concept were issues discussed by two parents though in different ways 1) Principles of

working out (in the gym), and 2) understanding the rules to games (football) and instructions given (dance) (Figure 2).

*“I have took him to football but he didn’t understand what was going on...he couldn’t follow the instructions...and I took him to dancing...Because he likes music but again he couldn’t follow the instructions so what happens when he can’t follow the instructions...he starts acting up” (MP6 (youngest participant))*

*“She doesn’t quite understand where as we would go and to the gym and really work hard she doesn’t quite understand that principle...so he (personal trainer) does battle with her a bit to get her to work hard.” (MP1 (oldest participant)).*

### ***Predisposing (Is it worth it?) (Figure 2)***

#### *Enjoyment*

When discussing the whether participants enjoyed engaging in PA seven participants cited that in fact they did. ‘Happy’ was a term used by participants (n = 3) to describe how it made them feel. For example:

*“I do yes (enjoy PA)...Well actually I am happy all the time” (P7)*

*“Yeah I think it breaks the day up you see and I love going somewhere where I can walk slow pace or something like that it just breaks the day up things like that... I think...I think might be happy” (P3)*

### *Social interaction*

A key facilitator to participation in PA for children and young people with DS was that of social interaction cited by all (n=8) participants. For the participants social interaction involved activities with friends, youth clubs, and family members.

*“Yes he likes to be involved in things he likes to be around other children” (MP6)*

*“He really loves dancing you know disco and music and at family weddings what he really loves is getting his kilt on and then he gets up to every Scottish country dance.”  
(MP8)*

[Figure 3 near here]

### ***Reinforcing factors to PA (Figure 3)***

#### *Support and opportunities*

Parents were deemed the main influence for the child to engage in PA, and this links conceptually to the YPAP model (Welk 1999) construct of ‘reinforcing’. Reinforcing PA support and influences are necessary from different sources, i.e. coaches, peers, parents, etc and in special populations (i.e. children with DS) care providers and schools can also play an important role. Amongst parents there was a sense of both negativity and frustration from the parents as regards to support not only for their child but also for themselves.

Practical difficulties with organising swimming (either a school or local swimming pool) were noted by three parents (P – 1, 5, & 8) MP8 specifically could not understand why the SEN swimming sessions were so limited. Parents noted this as frustrating as the consequences were

they themselves had to get involved to resolve the situation, taking up more time within their already perceived as busy lifestyles.

*“Swimming started when she was at school the teacher she had used to take her as part of her peer group...and wanted her to go with children a lot younger... so we said no we felt there was no need for this and to cut a long story short they called it a health and safety risk and we had to threaten them with taking them to tribunal for disabled discrimination, however it was sorted out within about 4 weeks and she did swim with her peer group in the mean time we managed to get her one to one swimming lessons” (MP5)*

A common issue that the parents expressed was that at some point within their child's life they have felt there has been a lack of information about the PA opportunities that are available and suitable for people with DS. Resulting, that they themselves have to make enquiries about what is available. For example.

*“I think that there's a lack of information (about PA opportunities for children with DS) the information that we (parents) got was mainly as a younger child through Leeds Mencap up to the age of five and then when she (P2) went to school there was a lack of input of information really from anywhere, until we became heavily involved with the youth club...you've got to enquire yourself and sometimes they erm groups don't cope well with integrating into a normal sport or dance group” (MP2)*

Educating the young people as to the importance of PA is particularly important, but also in some cases perhaps extending this to the college staff about the importance of PA is also needed (Figure 3) when considering older age groups. Also, when prompted to consider their child's future two parents were apprehensive about the care that's provided for people with special needs, particularly whether their child's 'healthy life style' (PA & diet) and how this would be sustained into adulthood.

*“The people that provide care if they appreciated the need for activity whether it's walking or whatever but not just sitting around letting them watch television...so to get to a gym, get to classes where there is dancing” (MP1).*

*“I would hope that whoever she was in the care of whether it is us or someone else that they would keep up the PA levels” (MP2).*

[Figure 4 near here]

#### ***Barriers to PA (Figure 4)***

To enable and reinforce an individual to be active and informed by the YPAP model (Welk 1999) the barriers preventing the individual from engaging must be overcome and therefore this information is crucial.

#### ***Ear Problems***

Ear problems are a barrier to PA engagement affecting balance when dancing and walking (P7), and the level of participation in swimming (P - 1, 2, 4). Ear problems were cited by four parents

(P – 1, 2, 4 & 7) with ear infections specifically were noted by three parents. This was a concern as ear infections in particular hindered their child from any water based activities yet this was the most popular activity participated in by children and young people. For example:

*“He’s had extra swimming with a one to one teacher... but unfortunately we had to give that up because he has got problems with his ear and he’s got a hole and he kept getting infections so we had to stop that, but he was doing quite well with that...I mean definitely his ears have hindered him from doing swimming” (MP4)*

Balance can affect the completion of everyday tasks for those with DS, such as walking up the stairs. For P7 both the mother and participant showed similar concern P7 had hearing problems and her mother noted that she struggled with balance and that the two could be related.

## **Discussion**

The discussion has been structured around the YPAP Model (Welk 1999), including additional sub-headings. The headings are not presented in any particular hierarchical order.

### ***Physical activity enabling factors***

When considering the types of PA the participants engaged in, the majority were of an unstructured and casual nature with no defined rules and with enjoyment and fun being key facilitators to PA participation. Swimming was the most popular PA engaged in by the participants. This corroborates with an earlier study which noted that 69% of the participants (young people with DS) engaged in swimming on a regular basis (Jobling and Cuskelly 2006).

Other popular activities included trampolining (though garden based not formal classes), dancing, and bowling. With regards to the intensity of the activities, only one participant (P5) reported engaging in vigorous PA on a regular basis, with the remaining participants engaging in low-moderate intensity PA. These findings are in agreement with Whitt-Glover, O'Neill and Stettler (2006) who reported that children with DS accumulate a reduced amount of total vigorous PA in comparison to those without DS.

Within the current study ten pin bowling was cited by 4 participants with 2 participants used the Nintendo Wii video game console (via Wii sports version) to engage in the activity. Graves et al. (2008) compared the energy expenditure (EE) of adolescent girls and boys when participating in four computer games; three were classed as 'active' games using the Nintendo Wii sports game (bowling, tennis and boxing) and one game was classed as a traditional, sedentary video game, on the XBOX 360 (car racing). Results showed that the participant's EE was significantly greater when playing the active computer games in comparison to participating in traditional sedentary computer games. Despite this, EE when participating in active gaming was not as great as the EE associated with playing the authentic sports (Graves et al. 2008). With regards to the current study, children and young people with DS should be encouraged to take part in active gaming rather than engaging in sedentary activities. However, if given the opportunity authentic physical activities and sports would be preferable.

Five parents noted the decline in PA levels during the winter months. If seasonal variation does affect children's PA levels then different activities should be introduced that can be performed indoors to replace the outdoor activities that are less favourable during winter months. These activities may include; dance sessions, indoor trampolining, gymnastics, soft ball games etc. Previous research has described the influence of seasonal variation in physical

activity in non-DS children and young people, for example Rich, Griffiths and Dezateux (2012) completed a review article investigating seasonal variation in accelerometer-determined sedentary behaviour and PA in children. The authors concluded that, all the studies conducted within the UK showed seasonal variation in PA with the highest PA levels in summer months and lowest PA levels in winter months. Interventions should be appreciative of this influence and strategies put into place for UK children, to increase PA levels during winter months (Rich, Griffiths and Dezateux 2012).

Parents of older children with DS expressed a need to develop their child's independence skills in order to reduce the amount of reliance their child had on them. Maaskant et al. (1996) found that there was an increased level of care dependence from people with DS in later adulthood (40+ yrs), with results describing considerable reductions in daily living skill activities. Therefore the need to reach optimal independence at a young age is vital for long-term independence. Parents were the main means of transport for their child to get to and from the activities. Parents of the older participants noted that this was a clear barrier to their child's PA engagement, expressing that if their child had both the ability and skills to use public transport that this would potentially increase their child's total PA levels. At present, the PA participation of children and young people with DS is typically arranged around the whole family's busy schedule, and as a result it may not always be a practical to accomplish. Also, in the current study there seemed to be an identified need for parents to build PA into their child's life through other means such as through care workers, colleges, PA opportunities, leisure facilities and their staff. It is therefore important that care providers understand the importance of PA and the need for positive encouragement for people with DS, ensuring that important influences upon the participant's PA provide consistent messages and facilitate/reinforce PA.

### ***Predisposing (Am I able? Is it worth it?)***

In relation to the activities the participants disliked, common themes appeared including: walking (especially long distances), running, and apprehension with trying new activities. Difficulties with walking was perceived to be linked with to poor muscle tone in the lower body or because participants tire easily. MP7 also mentioned that her daughter suffered with silica disease which caused her to tire quickly. Two earlier studies (Stanish 2004; Temple and Stanish 2009) found that adults with DS accumulated fewer steps per day in comparison to peers with ID (without DS). The current study suggests that such reasons may be was because people with DS prefer not to walk as they disliked the activity, or that physiological factors mentioned above made the activity more difficult to complete and, as a result, individuals were reluctant to participate. These findings support Maye et al's. (2010) findings that barriers to PA include, not wanting to participate and medical and physiological factors and, Phillips and Holland (2011) proposal as to physiological limitations can explain why individuals with DS have low PA levels that decrease with age.

Maye et al. (2010) also found reasons to participate include physical activities that are fun or have an interesting purpose, and activities that integrate into a routine and are familiar. This aligns with previously noted findings from the present study that of, running and apprehension associated with trying new things. For some participants running on a treadmill was disliked. However, when incorporated into a fun game, participants were happy to engage. Routine and familiarity, according to Maye et al. (2010) could also explain why participants in the present study disliked using new apparatus or trying any new activities. Furthermore, activities that were frequently and enthusiastically engaged in by participants with DS were performed individually but generally occur within a social environment, and were informal

rather than formal activities. For example P2 enjoyed bowling with her friend, and P8 enjoyed dancing with guests at family weddings. Menear (2007) also found that parents described social reasons as the main motive for their child with DS to participate in PA.

Data from P1 indicated they didn't understand the principle of PA or exercise. This supports an earlier study, which reported that young people with DS didn't understand the frequency of exercise needed to benefit health (Jobling and Cuskelly 2006). Lack of understanding may explain why children and young people with DS tend to prefer activities of an informal nature. It is suggested that there is a need for further education concerning the benefits of PA and the amount necessary to benefit health for young people with DS. Indeed Jobling and Cuskelly's (2006) suggested that prolonged and more explicit teaching methods are needed for individuals with DS, in order to help guide the young people to make healthy choices and as a result take responsibility for their own health.

### ***Reinforcing factors to PA***

It is clear from the study's findings that support people, particularly parents of children and young people with DS, play an important role for PA engagement. Family support was also highlighted as an important aspect for PA participation for children with DS within Barr and Shields (2011) study. Heller, Hsieh and Rimmer (2002) reported that key barriers to PA for adults with DS included: lack of support and supervision and inadequate access to transportation. These barriers were also reported to increase with age (Heller, Hsieh and Rimmer 2002).

Support is not only important for the individuals with DS but also for their parents and carers, especially with regards to providing suitable information about different PA opportunities that are available to individuals with DS. Many of the parents from the current study commented

that there had been an overall lack of support for PA throughout their child's life. A number of the parents stated the support when their child was younger (up to 5 years) was very good. However MP2 described that as soon as her daughter began primary school this support declined, and she explained that the connection and communication between health services and that of education was very poor at the time. Menear, (2007) also reported similar findings regarding professional support, as all the parents felt that they personally needed specialist help from professionals, particularly with regards to educating the parents about different methods available to increase PA opportunities, within both their community and at home (Menear 2007). MP8 also explained that support came in essence too late for them as their son was 16 years old at the time of data collection and they had only received information in the previous 12 months about different activities taking place. It is suggested therefore that existing clubs, leisure centres and organisations that methods for advertisement are re-evaluated, as currently the target population seems unaware of opportunities available.

A number of parents had experiences difficulties when organising swimming lessons for their child. MP5 attributed this to other people's pre-conceptions of what a child with DS can and cannot do, essentially discriminating against people with DS. This links into the YPAP Model (Welk 1999) in two areas under predisposing factors and also under reinforcing related to support. MP8 spoke about the restricted places available within the special needs swimming classes resulting in a long and unacceptable waiting list. As a result children who were confident in the water but not necessarily experienced were expected to leave. As swimming was the most popular activity amongst the participants it is an issue of relevance that needs to be raised with practitioners responsible for swimming, and secondly, to future researchers.

### ***Barriers to PA***

Barriers to PA participation that were not associated with the YPAP Model (Welk 1999) were related to other factors, in particular, ear infections which directly affected the participants' engagement in swimming yet was the most popular PA based activity. If ear problems are a common issue for the Down syndrome population as a whole, information should be provided for parents and carers of children with DS with regards to methods of prevention.

### ***Limitations and future research***

There are a number of limitations with this study. The main limitations are the small sample size and a broad age range amongst the young people as participants. The effect of this sample has not been examined, and may limit the generalizability of findings. The sample size was small for this study due to difficulties in recruitment, as a result of these difficulties the age criteria was extended to include the youngest and eldest participants. Phillips and Holland (2011) also noted difficulties with recruitment of people with intellectual disabilities; although the sample size was much larger (152 participants of which 79 participants had DS) the age range included participants aged 12 – 70 years. In order to gain a large sample of participants whom are of a similar age and have the same disability, it may be beneficial to recruit entire schools to participate in research and build research networks through collaborations with other institutions such as universities within Europe. Within this study there was a lack of objective methods to accurately assess the participants' PA levels. This was a result of the limited time available to carry out and complete the study. As a result of not measuring total PA, levels of intensity were not assessed either. This may have limited the accuracy of data gained from questions related to the FITT (Frequency, Intensity, Time, Type) principles and should be considered in future

research. The study failed to consider some components of the YPAP Model (Welk 1999) including the effects of peer and coaches influence however, in this research the roles of care workers were more appropriate with regards to reinforcing PA participation. For some participant interviews only one parent was present and may have restricted the amount of information collected and should be considered for future research. Communication presented as a barrier between the participants and researcher, particularly with younger participants, and future studies should consider using other methods to gain rich data from participants, for example write and draw techniques. Knowles et al. (2012) used the write and draw technique for exploring into the insight of mainstream children's (aged 7 – 11) PA opportunities during playtime. It was concluded that the write and draw technique gathered rich data and suggest that this technique is appropriate for collection of children's perceptions of PA during school (Knowles et al. 2012). The write and draw technique would also gain rich data representing the 'child's voice'. Coates and Vickerman (2010) emphasize the importance of representation of the voice of children with SEN which would allow a deeper insight of children with SEN experiences in Physical Education for schools, teachers and policy makers.

It appears that there is a need for further education for people with DS with regards to the importance of PA and the amount necessary to benefit health. Future research is needed to outline the methods for the education that would be most effective within the DS population. Also, more research is needed to accurately estimate levels of habitual physical activity within DS children and young people. From the limited evidence available it appears that DS children and young people are not sufficiently active to benefit health and as such, intervention is required. From the findings of the current study it is suggested that future interventions include fun and unstructured activities housed within a social setting (i.e. with peers, friends or siblings),

and that integrate vigorous-intensity activity. These may be based within or around activities commonly engaged in people with DS, such as swimming and dancing. Within this study seasonal variation appeared to be a barrier to PA mentioned by a number of parents. Future research should assess whether seasonal variation is indeed a factor within a representative DS sample, and further assess the potential of indoor activities to minimise seasonal effects. Finally it is suggested when assessing PA in the DS population that their parents' or siblings' PA histories are also referenced, to gain an insight into the family environment.

## **Conclusion**

Interviews were designed to consider aspects around the YPAP model (Welk, 1999), including facilitators and barriers. The data presented within this study shows that children and young people with DS engaged in a range of activities. In general participants enjoyed being active and prefer to engage in fun, unstructured activities that involve socializing. Parent and carer support appears to be a key facilitator for participation in PA for people with DS. The findings suggest that further education is needed for parents, care providers and people with DS about the quantity of PA needed to benefit health. Finally, developing independence skills for individuals with DS throughout adolescence is vital to increase and maintain appropriate levels of PA performed in later life.

## Reference list

- Anderson, L., L. Sardinha, K. Froberg, C. Riddoch, A. Page, et al., 2008. Fitness, fatness and clustering of cardiovascular risk factors in children from Denmark, Estonia and Portugal: The European Youth Heart Study. *International Journal of Pediatric Obesity* 3, 58 - 66.
- Barr, M., and N. Shields. 2011. Identifying the barriers and facilitators to participation in physical activity for children with Down syndrome. *Journal of Intellectual Disability Research* 55, 1020 – 1033.
- Carmelj, E., S. Kessel, R. Coleman, and M. Ayalon. 2002. Effects of a treadmill walking program on muscle strength and balance in elderly people with Down syndrome. *Journals of Gerontology Series A: Biological Sciences and Medical Sciences* 57, 106 – 110.
- Chief Medical Officer. 2011. Start active, Stay active – A report on physical activity for health from the four home countries'. Retrieved June 27, 2011, from [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_128209](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_128209)
- Coates, J., and P. Vickerman. 2010. Empowering children with special educational needs to speak up: experiences of inclusive physical education. *Disability and Rehabilitation* 32, 1517 – 1526.
- Croce, R.V., K. H. Pitetti, M. Horvat, and J. Miller. 1996. Peak torque, average power, and hamstrings/quadriceps ratios in nondisabled adults and adults with mental retardation. *Archives of Physical Medicine and Rehabilitation* 77, 369–372.
- Department of Health. 2005. Choosing activity: A physical activity action plan. London: DH.
- Down's Syndrome Association. 2002. *Promoting Health in People - with Down's Syndrome*. Retrieved March 10, 2010, from [http://www.downs-syndrome.org.uk/images/stories/DSA-documents/Publications/health/promoting\\_health.pdf](http://www.downs-syndrome.org.uk/images/stories/DSA-documents/Publications/health/promoting_health.pdf)
- Down's Syndrome Association 2012. *Key Facts*. Retrieved June 6, 2012, from <http://www.downs-syndrome.org.uk/about-us/key-facts-and-faqs.html>
- Frey, G. C., H. I. Standish, and V. A. Temple. 2008. Physical activity of youth with intellectual disability: review and research agenda. *Adapted Physical Activity Quarterly* 25, 95 - 117.
- Graves, L., G. Stratton, N. D. Ridgers, and T. N. Cable. 2008. Energy expenditure in adolescents playing new generation computer games. *British Journal of Sports Medicine* 42, 592 – 594.
- Heller, T., K. Hsieh, and J. Rimmer. 2002. Barriers and supports for exercise participation among adults with Down syndrome. *Journal of Gerontological Social Work* 38, 161 – 78.
- Jobling, A., and M. Cuskelly. 2006. Young people with Down syndrome: A Preliminary investigation of health knowledge and associated behaviours. *Journal of Intellectual & Developmental Disability* 31, 210 – 218.
- Knowles, Z. R., D. Parnell, G. Stratton, and N. D. Ridgers. 2012. Learning from the Experts: Exploring Playground Experience and Activities Using a Write and Draw Technique. *Journal of Physical Activity & Health*. Retrieved August 8, 2012, from <http://journals.humankinetics.com/jpah-in-press/jpah-in-press/learning-from-the-experts-exploring-playground-experience-and-activities-using-a-write-and-draw-technique>
- Luke, A., J. N. Roizen, M. Sutton, and A. D. Schoeller. 1994. Energy expenditure in children with Down syndrome: Correcting metabolic rate for movement. *The journal of paediatrics* 94, 829 – 838.

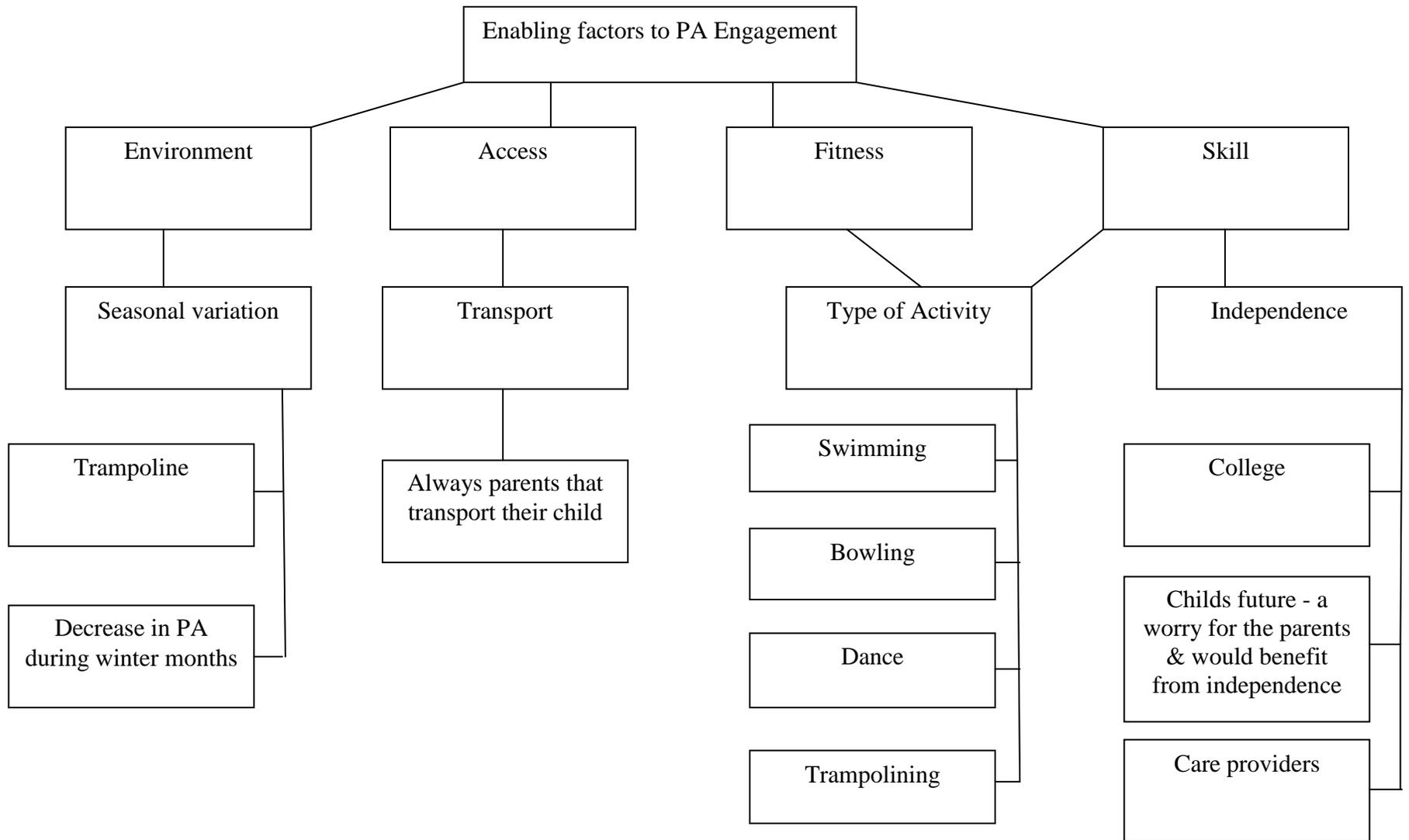
- Maaskant, M. A., M. Van Den Akker, A. G. Kessels, M. J. Haveman, H. M. Van Schrojenstein Lantman-de Valk, and H. F. Urlings. 1996. Care dependence and activities of daily living in relation to ageing: results of a longitudinal study. *Journal of Intellectual Disability Research* 40, 535 – 543.
- Mahy, J., N. Shields, N. F. Taylor, and K. J. Dobb. 2010. Identifying facilitators and barriers to physical activity for adults with Down syndrome. *Journal of Intellectual Disability Researcher* 54, 795 – 805.
- Meneer, K. S. 2007. Parents' perceptions of health and physical activity needs of children with Down syndrome. *Down Syndrome Research and Practice* 1, 60 – 68.
- NHS. 2010. *Medical advice: Down's syndrome*. Retrieved October 4, 2010, from <http://www.nhs.uk/conditions/Downs-syndrome/Pages/Introduction.aspx>
- Ortega, F. B., J. R. Ruiz, M. J. Castillo, and M. Sjostrom. 2008. Physical fitness in childhood and adolescence: a powerful marker of health. *International Journal of Obesity* 32, 1–11.
- Phillips, A. C., and A. J. Holland. 2011. Assessment of Objectively Measured Physical Activity Levels in Individuals with Intellectual Disabilities with and without Down's Syndrome. *PLoS ONE* 6, doi:10.1371/journal.pone.0028618
- Rich, C., L. J. Griffiths, and C. Dezaux. 2012. Seasonal variation in accelerometer-determined sedentary behaviour and physical activity in children: a review. *International Journal of Behavioural Nutrition and Physical Activity*. doi:10.1186/1479-5868-9-49. Retrieved August 8, 2012, from <http://www.ijbnpa.org/content/9/1/49/abstract>.
- Stanish, H. I. 2004. Accuracy of Pedometers and Walking Activity in Adults With Mental Retardation. *Adapted Physical Activity Quarterly* 21, 167–179.
- Temple, V. A., and H. I. Stanish. 2009. Pedometer-measured physical activity of adults with intellectual disability: predicting weekly step counts. *American Journal on Intellectual and Developmental Disabilities* 114, 15–22.
- Welk, J. G. 1999. The Youth Physical Activity Promotion Model: A Conceptual Bridge Between Theory and Practice. *Quest* 51, 5 – 23.
- Whitt-Glover, M. C., K. L. O'Neill, and N. Stettler. 2006. Physical activity patterns in children with and without Down syndrome. *Pediatric Rehabilitation* 9, 158 – 164.

**Table 1:** Participant information for Participants 1, 2, 3, & 4

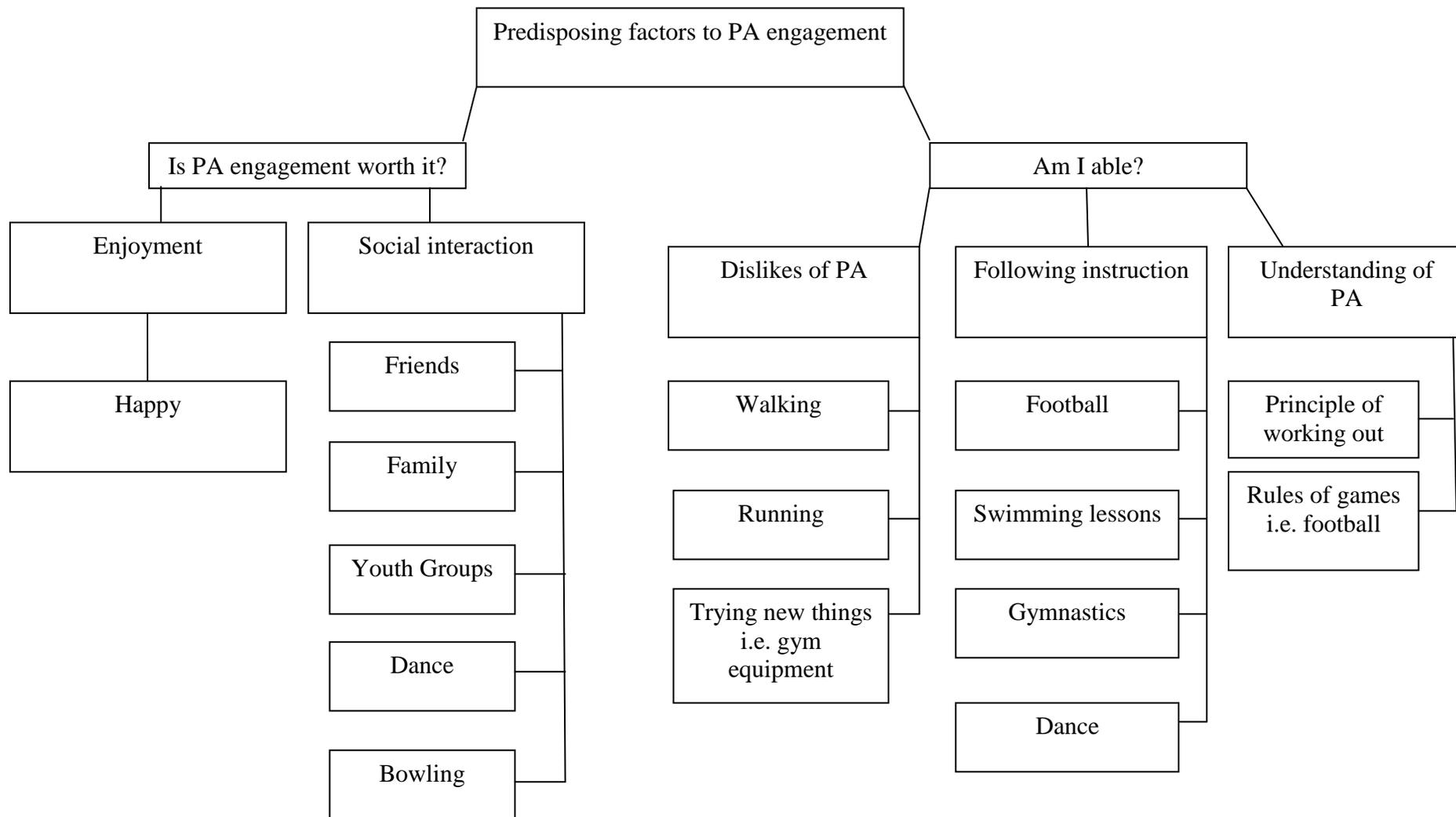
	P1	P2	P3	P4
Sex	Female	Female	Female	Male
Age	21	19	19	12
Type of DS	Regular Trisomy 21	Regular Trisomy 21	Translocation	Regular Trisomy 21
No of parents in interview	1	2	2	1
Place of study	SEN college	SEN college	Mainstream college	SEN school
Participant in interview	Yes	Yes	Yes	Yes

**Table 2:** Participant information for participants 5, 6, 7, & 8

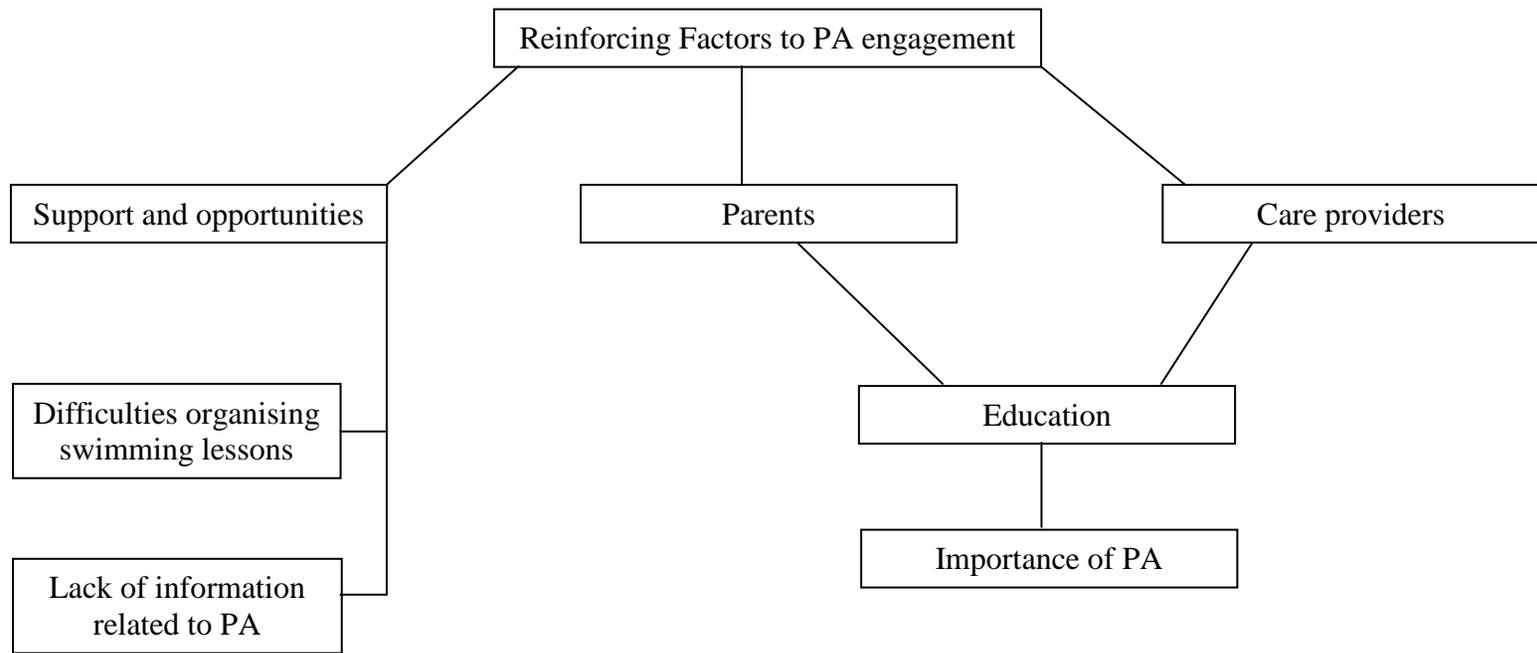
	P5	P6	P7	P8
Sex	Female	Male	Female	Male
Age	18	6	18	16
Type of DS	Regular Trisomy 21	Regular Trisomy 21	Regular Trisomy 21	Regular Trisomy 21
No of parents in interview	2	1	1	1
Place of study	Mainstream school	Mainstream school	SEN day centre	Residential SEN school
Participant in interview	Yes	Yes	Yes	No



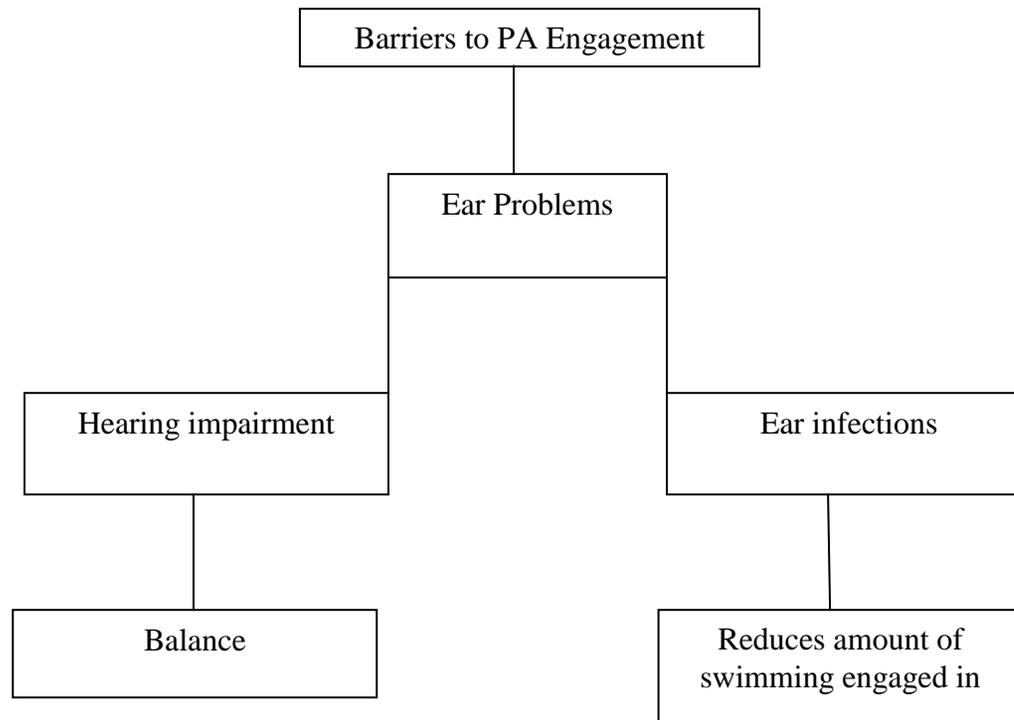
**Figure 1** Enabling factors to PA engagement for children with DS



**Figure 2** Predisposing factors to PA engagement for children with DS



**Figure 3** Reinforcing factors to PA engagement for children with DS



**Figure 4** Barriers to PA engagement for children with DS