Deakin, K., Moore, D. G. and Jahoda, A. (2018) Children and young people with Down syndrome: their awareness of Down syndrome and developing self-perceptions. *Journal of Applied Research in Intellectual Disabilities*, 31(6), pp. 1197-1208.

There may be differences between this version and the published version. You are advised to consult the publisher's version if you wish to cite from it.

This is the peer reviewed version of the following article Deakin, K., Moore, D. G. and Jahoda, A. (2018) Children and young people with Down syndrome: their awareness of Down syndrome and developing self-perceptions. *Journal of Applied Research in Intellectual Disabilities,* 31(6), pp. 1197-1208. http://dx.doi.org/10.1111/jar.12494 This article may be used for non-commercial purposes in accordance with Wiley Terms and Conditions for Self-Archiving.

http://eprints.gla.ac.uk/165003/

Deposited on: 15 August 2018

Title: Children and young people with Down Syndrome: their awareness of Down Syndrome and developing self-perceptions

ABSTRACT

Background: Past research suggests children with Down syndrome often lack awareness of their disability despite the visibility of their condition.

Method: This study used novel tasks to investigate their insight. Twenty-eight young people with Down syndrome (aged 8-17 years) were recruited, along with control groups of 67 typically developing young people. Three tasks explored the children's awareness of Down syndrome: i) choice of partner for social activities, ii) sorting photographs, and iii) attributing positive or negative descriptors to photographs.

Results: All participants expressed a preference to engage in social activities with typically developing peers. Most participants with Down syndrome identified with the typically developing person. Even though all participants attributed more positive descriptors to the photographs of the typically developing individuals, they remained positive about themselves.

Conclusion: The early awareness of difference shown by young people with Down Syndrome suggests this may play an important role in their developing identities.

Key words: Down syndrome, self-perception, attitudes, stigma

INTRODUCTION

Stigmatised people possess or display a characteristic or characteristics which are negatively perceived in society (Goffman, 1973). Consequently they are seen as lesser persons (Crocker, Major and Steele, 1998). Being stigmatised can lead to a variety of detrimental social experiences for the individual. Blatant stigmatisation can take the form of verbal or physical abuse. More subtle forms of stigma can also have far-reaching effects. For example, discriminatory treatment in education and denial of employment opportunities can lead to social marginalisation or exclusion (Link and Phelan, 2001). People with intellectual disabilities have long been represented and treated negatively (Jahoda, 1995). In Goffman's original writings about stigma, he distinguished between visible and hidden stigma. Those with visibly stigmatising characteristics face other people's immediate responses. While other people may not know that someone has a hidden stigma, the individual themselves is likely to be accutely aware of the negative social attitudes regarding their stigma. Down Syndrome is the most common genetic condition causing intellectual disabilities (Sherman et al., 2007). People with Down syndrome have singular physical characteristics, most notably the epicanthic fold that gives them a distinctive eye shape. They are easily identifiable, making them particularly vulnerable to stigmatised treatment. However, relatively little is known about how children and young people with Down syndrome develop an awareness of their disability and linked societal attitudes.

Symbolic Interactionist theories of the development of self (Mead, 1934; Gergen, 2009), propose that children's objective sense of self is shaped by others' responses to them. While this process continues across the lifespan, significant others in young people's lives are thought to play a key role in children and young people's emerging sense of self and social identities. This includes helping to shape the content of their beliefs, attitudes that make up their objective sense of self (Damon and Hart, 1991), as well as how they act in the world.

Significant others may include family members, peers and teachers. There has been particular interest in exploring the influence of school, with the widespread introduction of mainstreaming for those with intellectual disabilities in the UK. Kelly and Norwich (2004) carried out in-depth semi-structured interviews with mainstream and special school UK pupils with moderate intellectual disabilities. Most participants, aged between 10 and 14 years old, recognised negative terms used about people with intellectual disabilities, such as 'thick' and disliked these labels. Norwich and Kelly (2004) found both special school and mainstream pupils reported having experienced bullying and other stigmatised treatment due to their intellectual disability.

Cooney, Jahoda, Knott and Gumley (2006) found that adolescents with mild intellectual disabilities reported facing stigmatised treatment. Pupils in mainstream schools reported more abusive treatment, such as name calling, than those in specialist provision. However, both groups experienced stigmatised treatment in the wider community. The special school environment did not seem to protect the children from awareness of their stigmatised status. More positively, the young people's awareness of stigma did not affect their future aspirations. While stigma has been shown to have an emotional impact on people with intellectual disabilities and to be associated with lower self-esteem (Dagnan and Waring, 2004), it does not necessarily mean that they internalise a stigmatised identity or believe that negative social stereotypes apply to themselves (self stigma). People may reject dehumanising attitudes and treatment, distance themselves from others with disabilities or define themselves by other characteristics they positively value (Jahoda, Wilson and Stalker, 2010; Finlay and Lyons, 2000).

The way families manage the information children with Down Syndrome receive about their disability has been investigated. Cunningham, Glenn and Fitzpatrick (2000) examined the relationship between young people's awareness of their disability and parents'

disclosure of Down syndrome. They found that many young people appeared unaware of having Down syndrome and apparently this was not due to their parents' unwillingness to talk to children about their disability. Rather, it seemed these young people had not reached the cognitive developmental level required to grasp that people with Down syndrome might be considered a distinctive social group. Cunningham et al. argued that parents' disclosures to their offspring with Down syndrome were responsive to the needs and abilities of their child. Consistent findings emerged in a subsequent study, showing that young people with Down syndrome's understanding of their disability increased with their verbal understanding (Cunningham and Glenn, 2004).

What distinguished Cunningham et al.'s study from previous work in the area was the use of a non-verbal method to help determine whether participants were aware of the physical characteristics of Down syndrome. This was achieved by establishing whether participants could reliably sort photographs of children with Down syndrome and typically developing children, and then place a photograph of themselves onto the correct pile. Experimental approaches that are less reliant on verbal communication have potential advantages over interviewing. Researchers can begin to examine views of younger individuals with intellectual disabilities and others who have difficulty verbalising. Furthermore, experimental techniques may be helpful in examining children's ability to discriminate between physical characteristics and to explore their preferences and biases. The use of experimental techniques to investigate children's awareness of individual characteristics began with the innovative work of Horowitz and Horowitz (1936, 1939) and Clark and Clark (1939, 1947).

Non-verbal forced choice techniques can be used to distinguish between the ability to discriminate different categories versus showing specific preferences between them. The Horowitzs (1936) showed children pictures of black and white children and asked them to select who they would prefer as companions (e.g. show those you want in your class at

school). Horowitz and Horowitz found that both black and white children, aged 2-5 years old, chose interaction with white children. Clark and Clark (1939, 1947) used dolls rather than photographs. They found children aged 3-5 years old could identify dolls according to colour but when asked to choose which doll resembled themselves, both white and black children picked a white doll. The children also attached more positive attributes to White dolls than Black dolls. This suggests young children are sensitive to physical characteristics and the differential social value afforded to groups. However, these responses alone do not necessarily indicate children have low self-esteem. Spencer and Markstrom-Adams (1990), argued that children may grasp the relative value afforded members of different ethnic groups and align themselves with a higher status group, without fully considering their own ethnic identity and corresponding status.

A recent study by Saha et al. (2014), drew on Clark and Clark's (1939, 1947) ethnicity studies using a semi-structured free play paradigm with dolls representing a typically developing child and a child with Down syndrome. Participants with Down syndrome, aged between 4 and 17 years old, were given these two dolls. Patterns of play with each of the dolls were analysed and participants were then asked about the qualities of the dolls. Most preferred to play with the typical doll and expressed more positive views about the typical doll. When asked, 58% chose the typically developing doll as looking most like them. Saha et al. suggested that young children with Down syndrome are aware of Down syndrome, and of the accompanying negative social attitudes. However, there was no control group of typically developing children. No validity checks were carried out on the dolls to ensure they adequately represented the two social categories, nor did the study control for the attractiveness of the faces. Saha et al.'s findings contradict those of Cunningham et al. (2000) and suggest that children may develop early awareness of their Down syndrome and related negative social attitudes. However, methodological limitations mean the findings need a

cautious response. It is unclear whether factors such as perceived physical attractiveness affected the children's preferences.

Studies concerning people with Down syndrome's self-awareness have been limited by reliance on verbal responses and lack of systematic exploration of whether children's particular choices reflect their self-awareness or are due to other biases. Reliance on verbal responses also makes it difficult to explore these issues in less able and younger people. In the current study, three novel tasks were delivered to children with and without Down syndrome across the broad age range of 8 to 17 years. Participants with Down syndrome were split into younger and older age groups to explore changing insight into social views held about Down syndrome with age, reflecting increasing language abilities and more exposure to negative societal attitudes.

Three tasks were designed to explore social biases in young people with Down syndrome. These tasks were called 1) the Preference for Social Partners task, 2) the Person Sorting and Self-categorisation task and 3) the Attribution task. All tasks used forced choice non-verbal measures. Following Saha et al.'s tentative findings it was hypothesised that children with and without Down syndrome would demonstrate an awareness of Down syndrome from an early age and hold negative attitudes towards people with Down syndrome. We hypothesised that while children with Down syndrome may sort according to facial characteristics, they may not identify themselves with the category, and may match their own face with that of the typically developing child. We further hypothesised that the attributions of both groups of children about people with Down syndrome would reflect wider social stereotypes, and such beliefs would influence the self-perceptions of those with Down syndrome.

METHOD

Participants

Twenty-eight children with Down syndrome and 67 typically developing children were recruited for the study. The sample of children with Down syndrome comprised 18 girls and 10 boys. The ages of participants in the Down syndrome group ranged from 8 years and 8 months to 17 years and 9 months, and their mean verbal mental age, generated by their score on the BPVS-II, was 5.05 (SD= 1.77). Children with Down syndrome were recruited from schools for pupils with Moderate Learning Needs and one mainstream school in the West of Scotland. A small number were contacted through voluntary sector organisations. The typically developing children were recruited from mainstream schools in the West of Scotland.

A control group of typically developing children of a comparable age were recruited. In addition, we included a small group of younger children. The younger typically developing group represented children at an earlier developmental stage with less social experience than all other participants and were closer to those in the Down syndrome group in terms of cognitive development. The socio-demographic details of the different age groups are shown in table 1 below.

_____

Table 1 about here

_____

Development of materials

Photographs

Tasks one to three described below required pairs of colour photographs of children with Down syndrome and typically developing children. It proved challenging to collect sufficient numbers of suitable high quality photographs.

Photographs were collected from two sources; an online photograph library and a social group for young people with Down syndrome and their siblings. The social group was held in a different region of the country from where the participants were recruited and the individuals in the photographs were not known to the study participants. The photographs had to show the heads and shoulders of young people facing the camera with nothing obscuring their faces. The photographs were edited to the same size with background details deleted and replaced with neutral-beige. Each photograph measured 12 cm x 10 cm. In total, 17 pairs of male and female photographs were produced. For each task, the photographs used were the same gender as the participant.

Validation

Validity checks were carried out with 15 adult volunteers, to ensure young people depicted in the photographs were i) identifiable as having Down syndrome or not, ii) their facial expressions were neutral, iii) their gender was readily apparent, and iv) that they appeared to be between the ages of 8 to 17 years old. This age group was chosen because it was reasoned the participants would relate to other young people of a similar age to themselves. To control for attractiveness the adult volunteers also rated the photographs on attractiveness using a 5-point Likert scale. These ratings were used to match each photograph of a child with Down syndrome with a photograph of a typically developing child according to rank order attractiveness.

Illustrations for tasks one and three (the Preference for Social Partners Task and Attribution task)

A graphic artist produced the illustrations for tasks one and three, described below. The process of producing the illustrations involved the following steps: i) a focus group of young people helped to explore how children conceptualised words and phrases to be illustrated, ii) following piloting, illustrations were refined to ensure they had a lifelike quality, depicted scenes relevant to the age range of participants and included sufficient context to ensure the participants could interpret what was happening, iii) cartoon characters were used without detailed features, to allow both groups of participants to identify with the characters.

Procedure

Having obtained the consent of the children's parents, the researcher paid an initial visit to the children at school to introduce the study. The researcher met and spoke to the children on an individual basis at the school, telling them what the study entailed and then having a broader social conversation. This enabled the researcher to build a rapport with children and to become accustomed to their speech, in instances where the children had speech difficulties.

Approximately one week later, the researcher returned to carry out the study. Children were invited to leave their class and join the researcher in a room that was quiet and free of distractions. The researcher engaged in light conversation with the children before asking if they would like to take part, making clear they could choose to stop at any time. Where appropriate, children provided written consent. Otherwise children's assent was collected. None of the children declined to participate.

Sitting next to the child, the researcher then led participants through three tasks in the following order, 1) the Preference for Social Partners task, 2) the Person Sorting and Self-Categorisation task, 3) the Attribution task, and then all participants were administered the British Picture Vocabulary Scale (BPVS-II; Dunn et al., 1998). The entire procedure took no longer than 30 minutes.

Preference for Social Partners Task

This task was designed to investigate whether children would show a preference for engaging in six different social activities with children who have Down syndrome or children who are typically developing. The task used a 'post box' format. Participants were presented with a cardboard box (H 13 cm x W 15.5 cm x D 15.5 cm) that had a posting slot on top with a colour illustrated social activity attached to the front.

Participants were presented with a pair of photographs placed in front of the box, side by side; one of a child with Down syndrome and the other a typically developing child. Participants were first invited to talk about each pictured activity to establish they understood what was depicted. The activities are shown in Figure 1. Participants were asked to choose which of the photographed children they would rather undertake the activity with and post the corresponding photograph into the box.

_____

Figure about 1 here

_____

For the first activity, the researcher said: "*I have some pictures showing different things you do everyday, look. What do you think this one shows? Yes, that's right it shows young people in the playground (illustration placed on the posting box) Now, look carefully at the young people in these photos (showed two photographs; one of a child with Down syndrome and one of a typically developing child), if you could choose, which person would you pick to play with in the playground? Thank you, now could you put his/her picture in the box?"*

This process was repeated for six activities, in the following order: play with in the playground, sit next to in class, sit next to for lunch, pick for your team in a game, help with

school work and invite home to play. Each activity was assigned a different photograph pair, which remained the same for all participants. For each activity, the position of the Down syndrome photograph (left or right hand side relative to the child) was randomised. The task took approximately 10-15 minutes to complete.

Person Sorting and Self-Categorisation task

The Person Sorting task addressed children's developing awareness of Down syndrome. A 'post box' format was also used for this task and the children were asked to sort photographs of children with Down syndrome and typically developing children.

The first step was to check children had adequate sorting skills for the task. This ensured that any bias children showed was not due to a poor ability to sort. Two boxes were placed in front of the participant. On the front of each box a picture was attached; one portraying a red object the other a blue one. The child was asked to notice how these two pictures differed. Next, the child was presented with 8 pictures of everyday objects, 4 red and 4 blue, one at a time. Participants were asked to post each one through the slot of the appropriate box, 'to go with' the corresponding picture. All participants achieved the required success rate of sorting 7 out of 8 pictures into the correct box.

The Person Sorting task followed the same procedure using photographs of children with and without Down syndrome. A photograph of a child with Down syndrome was attached to the front of one box and a photograph of a typically developing child attached to the other. Participants were invited to look at each photograph and introduced to a selection of similar photographs of children (four with Down syndrome and four without). They were told some of the photographs belonged with the photograph on one box and some with that on the other. Participants were then handed the eight photographs one at a time in random order and asked if they could *"put each picture with the one it goes with"*.

After they had finished sorting the photographs, participants were shown a self-portrait photograph. The participant's self-portrait photograph was taken at the beginning of the session and printed immediately using a portable printer. Self-recognition was checked and then the participant was asked to put their photograph into one of the boxes. This last part of the procedure comprised the Self-Categorisation task.

Attribution task

Participants' beliefs about people with Down syndrome and themselves were investigated using the *Attribution* task. The task involved the same two 'posting' boxes used in previous tasks. Colour pictorial illustrations were provided of simple words or phrases used to describe people, and their polar opposites. There were seven descriptor pairs; Friendly/ Not friendly, Good/Naughty, Happy/ Sad, Clever/Stupid, Can do lots of things alone/Needs help to do things, Doesn't get called names/Gets called names, Has lots of friends/Doesn't have many friends. The descriptors were chosen to reflect cultural ideas about intellectual disability, the likely lived experiences of young people with intellectual disability and social stereotypes associated with Down syndrome (Enea-Drapeau, Carlier and Huguet, 2012). Examples of the illustrations are shown in Figure 2.

_____

Figure 2 here

_____

The illustrations were presented consecutively on the fronts of the boxes, one pair at a time. The experimenter asked participants what they thought the illustrations depicted, in order to ensure comprehension. Then, for each pair of illustrations, participants were shown three photographs in succession: one photograph of a child with Down syndrome, another of a typically developing child and finally, a self-portrait. A different pair of matched

photographs of children with Down syndrome and typically developing children was used for each descriptor pair.

As each photograph was presented, the participant was invited to look at it and asked to post it into one of the two boxes, according to which illustration described the photographed child best. For example, for the 'can do things alone vs. needs help to do things' illustration pair, participants were first reminded *"There is no right way or wrong way; I just want to know what you think, okay"*. Then, they were introduced to the illustrations on the boxes. *"Here are two pictures, what do you think this one shows? This boy is in class doing work and this boy is looking for a book in the library. What do you think this one shows" Prompt* if response is not about being helped. *"This boy is getting help doing school work and this boy is being helped to find a book"*. The participant's understanding was then assessed by asking them to point to the picture showing a boy/girl who needs help and a boy/girl who does not. Participants were then shown a photograph and told: *"Here is a picture of a boy/girl Do you think he/she needs help or does not need help?"* and then, *"Ok, put her into the needs help box/ does not need help box. Thank you"*. This process was repeated for each photograph and each descriptor pair.

Ethical approval

Ethical approval was granted by the University of Glasgow College of Medical, Veterinary and Life Sciences (MVLS) Ethics Panel.

RESULTS

Preference for Social Partners Task

As the participants were given a forced choice between the two photograph types and we were using non-independent counts we have conducted analyses on the preference shown for

the typically developing (TD) photograph only. Exploratory analyses revealed that the preference scores did not meet the assumptions of normal distribution and homogeneity of variance required for the use of parametric statistics. Consequently, non-parametric statistics were used in the following analyses. Table 2 reports the median number of times out of six trials that participants from each group chose the TD photograph to share social activities with.

_____

Table 2 about here

_____

Preference for TD photographs

The median values in table 2 show that participants in all groups were more likely to choose the photographs of TD children to share activities with.

Participants were regarded as indicating a preference for one type of photograph if they chose it four or more times out of six trials. Using this criterion, 23 of 28 participants with Down syndrome were considered to have shown a preference for the TD photographs. A binomial test indicated that this distribution was significantly different from chance (p=.001, 2-tailed).

Typically developing participants of the same chronological age were also significantly more likely to prefer the TD photographs (39 out of 53 participants chose the TD photograph on 4 or more trials, Binomial test, p=.001, 2 tailed). Furthermore all of the younger typically developing participants preferred the TD photographs (13/13 participants).

Age group differences in participants' preference for the TD photographs: No difference was found between the preference scores of younger and older children with Down syndrome (U (n=10, n= 18) = 73.5, p=.215, 1 tailed, r= -.16). However a significant difference was found between the preference scores for the three age groups of typically developing participants (H (df =2) = 7.53, p = .021). Mann-Whitney U tests showed that the youngest of these

participants (5- 7 years old) had a greater preference for the TD photographs than the 8-12 years old age group (U (n=13, n=27) = 89.5, p=.005, 1 tailed) and the 13-17 years old age group (U (n=13, n=26) = 92, p=.01, 1 tailed).

Person sorting and Self-Categorisation task

Person sorting

Table 3 shows the frequency with which participants in each disability and age group sorted the photographs according to Down syndrome above chance level (≥5/8 times). It is clear that most participants with Down syndrome, across age groups, performed poorly on this task. Typically developing participants of the same age did tend to sort the pictures correctly. Younger typically developing participants were less likely to sort the photographs according to Down syndrome than those in the older age groups, but performed better than those with Down syndrome.

_____

Table 3 about here

_____

Based on the fact that greater than chance sorting was defined as a sorting score ≥ 5, it was found that 15 of 28 participants with Down syndrome sorted according to whether or not the photographs depicted children with Down syndrome, and the remaining 13 participants did not sort the photographs according to Down syndrome. The binomial test confirmed that their ability to sort the photographs was not significantly above chance level (p=.851, 2 tailed).

Fifty-one out of 53 typically developing participants, who were the same chronological age as those with Down syndrome, sorted the photographs at above chance

level (≥5/8), and this was statistically significant (binomial P= .001, 2 tailed). Eleven of 14 participants in the youngest age group of non-disabled participants sorted above chance level, this trend was close to significance (binomial, p= .057, 2 tailed). Therefore, participants with Down syndrome did not sort the photographs accurately, while typically developing participants did appear to use Down syndrome as a sorting criterion.

Age group differences in participants' sorting

The sorting data for each age group violated assumptions of normality and homogeneity of variance. Comparisons of the responses produced by different age groups used nonparametric Kruskall Wallis and Mann Whitney U tests.

With regards to differences between the sorting scores of participants according to age group, the analysis showed there was no difference between the sorting scores of younger and older children with Down syndrome (U (n=10, n=18) = 75, p= .243, 1 tailed). However, a significant difference was found between the sorting scores of the three age groups of typically developing participants (H (df=2) = 5.13, p=.02). Mann-Whitney tests showed that this difference lay between the sorting scores of the youngest participants (5 to 7 years old) and the two other age groups, those aged 8 to 12 years old (U (n=14, n=26) = 113.5, p=.022, 1 tailed) and those aged 13 to 17 years old (U (n=14, n=27) = 119.5, p=.022, 1 tailed). Thus, the non-disabled group participants' ability to sort the pictures increased with age.

Self-Categorisation

The finding that 22 out of 27 participants with Down Syndrome chose to identify themselves with the TD photograph was significant (binomial, p= .002, 2 tailed). While 52 out of the 53 typically developing participants correctly self-identified with the TD photograph (binomial, p= .001, 2 tailed). Of the 14 younger typically developing participants,

13 self-identified with the TD photograph (binomial, p= .002, 2 tailed). Therefore, almost all participants, regardless of group, identified with the TD photographs.

Attribution task

Between group analysis/ attributions made two photograph types

Data for each group of participants did not meet the assumptions of normality and homogeneity of variance for parametric analysis. Therefore, non-parametric Wilcoxon tests were used to compare the number of positive traits participants attributed to the two photographs.

Wilcoxon tests confirmed that participants in the Down syndrome group and participants in the typically developing chronological age matched group were more likely to attribute positive traits to the non-disabled photographs than the Down syndrome photographs (T =56.5, p=.001, r=-.57, 1 tailed and T= 6, p=.001, r=-.82, 1 tailed, respectively). Similarly, typically developing participants who were younger than those in the Down syndrome group attributed more positive traits to TD children than children with Down syndrome (T = 0, p=.001, r=-.79, 1 tailed). There were minimal differences in the responses of participants in either group, according to age.

The overall descriptive data for the two groups are shown in table 4. The data reveal a slightly different pattern of responses at the level of individual items across the groups of participants. Most participants with Down syndrome viewed the photographs of individuals with Down syndrome as *not friendly*, *naughty*, *doesn't have many friends*, was *stupid* and *gets called names*. However, more than half of the participants with Down syndrome also thought that the photographs of individuals with Down syndrome was *happy* and *can do a lot of things alone*. On balance, the typically developing participants were more positive about

the individuals with Down syndrome, with a majority regarding them as *friendly*, *good*, *happy* and *clever*.

_____

Table 4 about here

_____

Self-attributions

Table 4 shows that the typically developing participants were almost all positive about themselves across all descriptors. While the participants with Down syndrome were generally positive about themselves too, a small number of participants expressed a different view on some descriptors and a majority thought they *need help to do things*. Moreover, almost a third said that they *get called names*. Care has to be taken to avoid assuming that attribution of some of these descriptors necessarily represent a negative evaluation of self, as they may simply reflect accurate descriptions of negative personal experience.

The self-attributions made by participants in each group were compared to the attributions they made to the photographs of children with and without Down syndrome, using the Wilcoxon test.

The median number of positive descriptors participants attributed to their own photograph was compared with the number of positive descriptors they attributed to the photographs of others of the same disability status. Participants with Down syndrome were significantly more positive about themselves than they were about photographs of other individuals with Down syndrome (T =23.50, p=.001, r=-.698, 2 tailed). Those with Down syndrome were also more positive about themselves than they were about the photographs of typically developing individuals (T =43.50, p=.037, 2 tailed, r=-.402).

The typically developing participants in the chronological-age matched group were more positive about themselves than they were about the photographs of typically developing others (T =-2.950, p=.003, 2 tailed, r=0.405). Although there was a notable trend towards being more positive about themselves, the younger typically developing group did not attribute significantly more positive traits to themselves compared to the photographs of the other typically developing children (T =-2.11, p=.063, r=-.564, 2 tailed).

As in previous tasks, there was minimal difference between the responses of participants in different age groups. Younger and older participants were equally positive about themselves.

DISCUSSION

All participants and age groups expressed a preference to socialise with typically developing children. The youngest participants with Down syndrome were aged eight and the typically developing children were aged five. However, many participants with Down syndrome did not sort photographs according to whether they depicted children with Down syndrome. In contrast, typically developing participants of the same age sorted the photographs almost perfectly. The fact that participants with Down syndrome all successfully completed the control sorting task and given that the younger typically developing participants sorted the photographs with greater accuracy, suggests that cognitive developmental level did not account for the performance of the participants with Down syndrome. Instead, those with Down syndrome seemed to show a disinclination to distinguish between the pictures of the young people with and without Down syndrome, whilst most identified themselves with the pictures of typically developing children.

In the Attribution task, participants with Down syndrome were generally more negative about the photographs of individuals with Down syndrome than the photographs of typically developing individuals. The typically developing participants were also more negative about the photographs of individuals with Down syndrome. Despite this, it was noteworthy that participants with Down syndrome remained largely positive about themselves, although the typically developing participants held even more favourable self-perceptions. As already stated, caution is needed when interpreting the self-attributions of the participants with Down Syndrome, because choosing a descriptor like being 'called names' might reflect real life experience and not necessarily lead to a negative evaluation of self.

When looking at the findings from across the different tasks, it is unclear why participants with Down syndrome did not sort photographs according to whether they depicted an individual with Down syndrome, since they showed themselves to be cognizant of Down syndrome and could discriminate between the photographs in the other tasks. Perhaps being forced to address Down syndrome as a distinct social category caused some participants unease, motivating them to deliberately refute such a classification. Thus, at least some participants may have been capable of sorting the photographs but chose not to.

The results from the present study, showing participants with Down syndrome's preference for typically developing peers, are consistent with those of Norwich and Kelly (2004) and Cooney et al. (2006), who found that young people with intellectual disabilities were aware of the stigma associated with having an intellectual disability. However, this is the first study to show an awareness of the negative social stereotypes linked to Down syndrome or intellectual disability more generally, at such a young age. Research by Cunningham and Glenn (2004) concluded that the insight of young people with Down syndrome into their disability did not emerge until later, due to their difficulties with verbal

understanding. However Cunningham and Glenn relied on a picture sorting task alone, to make this interpretation.

The present findings also contradict the ethnographic research by Todd and Shearn (1997), who documented family and care staff beliefs that adults with intellectual disability were successfully sheltered from awareness of stigma associated with their disability. Todd (2000) also believed that students in his study were unaware of the negative views associated with their special school. These different conclusions perhaps reflect a failure to consider how children with intellectual disabilities develop insight into prevailing social attitudes. Children with intellectual disabilities are socialised into the same world as their peers, developing a picture of social relationships and hierarchies. Children's tacit socio-emotional awareness may exceed what they can communicate (Matheson and Jahoda, 2005). This is also true of children with Down syndrome, who may not be able or willing to articulate their views about relatively abstract social constructs concerning their disability and related social attitudes. The methods used in the present study may have allowed children to express their awareness of Down syndrome and associated social attitudes, even if it was at a rudimentary level.

The participants' awareness of social stereotypes associated with Down syndrome was apparent in the Attribution task. All participants attributed fewer positive characteristics to the photographs of children with Down syndrome. However, the pattern of descriptors attributed by the groups differed. While those with Down syndrome were generally negative about children with Down syndrome, the typically developing participants appeared to be more selective in the negative descriptors they chose to attribute to individuals with Down syndrome. For example, many typically developing participants thought individuals with Down syndrome were 'friendly' and 'good', but believed they would be likely to 'need help' and 'get called names'. This pattern of responses from the typically developing participants

may indicate quite a nuanced perception of Down syndrome, with some awareness of the practical implications of having a cognitive impairment and the associated negative social consequences.

The encouraging finding that the participants with Down syndrome were able to retain a positive sense of self, despite holding apparently negative views about others with Down syndrome, may be testimony to these children's resilience or a strategy of identifying with what they regard as a higher status group. The latter explanation could be in line with Spencer and Markstrom-Adams (1990) argument that children may align themselves to higher status group without giving proper consideration to their own social identities. However, it is hard to believe that children with Down syndrome would be able to completely separate their negative views of Down syndrome from their views of self. While those with Down syndrome did hold slightly less positive views of self than the typically developing participants, not all of the descriptors necessarily meant the same to the different groups of participants. In particular, needing help or being called names may have reflected the reality of the lives of the young people with Down syndrome.

Goffman (1963) thought that some ambivalence towards the self was inevitable for an individual with a stigmatised identity. In social constructionist theories of the development of self, the objective self is shaped by others' responses (Gergen, 2009). However, the stereotypical or negative views internalised about the general category of Down syndrome may contrast with the nurturing and supportive relationships people with Down syndrome enjoy with significant others in their everyday lives. Furthermore, as actors, these young people are not simply shaped by the world but may wish to influence how they are seen. Hence, those with Down syndrome may have wished to present a positive view of themselves to the researcher, when completing the study tasks.

There are now important attempts to develop interventions to tackle what is described as internalised or self-stigma (Scior and Werner, 2016). However, the findings from this study are consistent with previous research suggesting that the concept of internalised stigma may oversimplify a complex process (Jahoda, Wilson and Stalker, 2010; Finlay and Lyons, 2000). For example, young people may play an active role in shaping their own identities and the complex nature of social identity allows for the possibility of different social selves. However, given their negative attitudes towards Down syndrome, it would be wrong to suggest that stigma did not have an emotional impact on the young people in this study. Obtaining greater insight into the impact of stigma on young people with Down syndrome's developing sense of self and the ways they cope with stigma, could help to develop more sensitive and timely support to promote resilience and wellbeing.

There were a number of limitations with the present study, including the relatively small sample size of children with Down syndrome, even if the findings for most of the tasks were significant. However, recruiting a sample of this nature is a labour intensive exercise. A larger sample would allow other important factors, such as gender and nature of schooling, to be considered in more detail. It would also have been useful to have a control group for key aspects of developmental level, such as verbal understanding. Another potential drawback to the current study was the possible impact of social desirability, particularly in responses of older typically developing children. The more positive responses of the older children may have reflected a growing social awareness and sensitivity in later adolescence, and more empathy for young people with Down syndrome or a recognition that certain views were socially unacceptable.

It would also have been helpful to know whether the typically developing participants knew anyone with Down syndrome as previous research has shown that familiarity can help foster more positive attitudes towards individuals with intellectual disabilities (Scior, 2011).

When considering future research on this topic and the methods to be used, it may also be necessary to take into account the changing cultural context, in terms of young people's use of images. Social media is an everyday part of many young people's lives. The images they exchange with each other may play an important role in their presentation of self and, in turn, others' reactions can influence their sense of self.

Conclusions

The results of this study have implications for policy and practice. The finding regarding the young people with Down syndrome's self-perceptions are encouraging and suggests that significant others in these young people's lives are helping to foster a positive identity. However, families and professionals can find it difficult to know when and how to talk to children about their disability, for fear of causing distress (Ali et al., 2012). The findings suggest children with Down syndrome have insight into their condition and related social attitudes from a young age. Failure of family or professionals to talk openly about this topic could be misunderstood by young people with Down syndrome as tacit support for prevailing negative attitudes. More fundamentally, there is a continuing need to tackle the prevailing negative attitudes towards people with Down syndrome and this should start with children at school.

REFERENCES

Ali, A., Hassiotis, A., Strydon, A. & King, M. (2012). Self stigma in people with intellectual disabilities and courtesy stigma in family carers: A systematic review. Research in Developmental Disabilities, 33 (6), 2122-2140. doi: 10.1016/j.ridd.2012.06.013

Clark, K. B., & Clark, M. K. (1939). The development of consciousness of self and the emergence of racial identification in Negro preschool children. *The Journal of Social Psychology, 10*(4), 591-599. doi: 10.1080/00224545.1939.9713394

Clark, K. B., & Clark, M. P. (1947). Racial identification and preference in Negro children. *Readings in social psychology*, 169-178. doi: 10.2307/2966491

Cooney, G., Jahoda, A., Gumley, A., & Knott, F. (2006). Young people with intellectual disabilities attending mainstream and segregated schooling: perceived stigma, social comparison and future aspirations. *Journal of Intellectual Disability Research, 50*(6), 432-444. doi: 10.1111/j.1365-2788.2006.00789.x

Crocker, J., Major, B., & Steele, C. (1998). Social stigma. In S. Fiske, D. Gilbert & G. Lindzey (Eds.), *Handbook of Social Psychology* (pp. 504-553). Boston, MA: McGraw-Hill.

Cunningham, C., & Glenn, S. (2004). Self-awareness in young adults with Down syndrome: I. Awareness of Down syndrome and disability. *International Journal of Disability, Development and Education, 51*(4), 335-361. doi: 10.1080/1034912042000295017

Cunningham, C. C., Glenn, S., & Fitzpatrick, H. (2000). Parents telling their offspring about Down Syndrome and disability. *Journal of Applied Research in Intellectual Disabilities, 13*(2), 47-61. doi: 10.1046/j.1468-3148.2000.00012.x

Dagnan, D., & Waring, M. (2004). Linking stigma to psychological distress: Testing a social–cognitive model of the experience of people with intellectual disabilities. *Clinical Psychology & Psychotherapy*, *11*(4), 247-254.

Damon, W., & Hart, D. (1991). *Self-understanding in childhood and adolescence* **(No. 7). CUP Archive.**

Enea-Drapeau, C., Carlier, M., and Huguet, P. (2012) Tracking Subtle Stereotypes pf Chldren with Trisomy 21: From Facial-Feature-Based to Implicit Stereityping. Plos One, 7(4)

Finlay, W. M., & Lyons, E. (2000). Social categorizations, social comparisons and stigma: Presentations of self in people with learning difficulties. *British Journal of Social Psychology*, *39*(1), 129-146.

Gergen, K., (2009). *Relational Being: Beyond self and community*. New York: Oxford University Press. doi: 10.1093/acprof:osobl/9780199846269.001.0001

Goffman, E. (1963; 1990). *Stigma: notes on the management of spoiled identity*. England; Penguin.

Horowitz, E. L. (1936). Development of attitudes towards Negros. *Archives of Psychology, 194*, 4-48.

Horowitz, E. L., & Horowitz, R. E. (1939). Development of social attitudes in children. *Sociometry, 1*, 307-338. doi: 10.2307/2785586

Jahoda, A. (1995) Quality of Life: Hope for the future or an echo from a distant past? In Markova, I. and Farr, N.M. (eds.) *Representations of Health Illness and Handicap*. Harwood: Great Britain.

Jahoda, A. , Wilson, A., Stalker, K. and Cairney, A. (2010) Living with stigma and the self-perceptions of people with mild intellectual disabilities. Journal of Social Issues, 66 (3), 521-534. doi: 10.1111/j.1540-4560.2010.01660.x

Kelly, N., Norwich, B. (2004). Pupils' perceptions of self and of labels: Moderate learning difficulties in mainstream and special schools. British Journal of Educational Psychology, 74, 411-435. doi: 10.1348/0007099041552297

Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual review of Sociology*, 363-385. doi: 10.1146/annurev.soc.27.1.363

Matheson, E., & Jahoda, A. (2005). Emotional Understanding in Aggressive and Nonaggressive Individuals with Mild or Moderate Mental Retardation. *American Journal on Mental Retardation, 110*, 57-67.

Mead, G. H. (1934). *Mind, self, and society from the standpoint of a social behaviorist*. Chicago: University of Chicago Press.

Norwich, B., & Kelly, N. (2004). Pupils' views on inclusion: moderate learning difficulties and bullying in mainstream and special schools. *British Educational Research Journal, 30*(1), 43-65. doi. 10.1080/01411920310001629965

Saha, S., Doran, E., Osann, K. E., Hom, C., Movsesyan, N., Rosa, D. D., Tournay, A., Lott, I. T. (2014). Self-concept in children with Down syndrome. American Journal of Genetics, Part A, 164A: 1891-1898. doi: 10.1002/ajmg.a.36597

Scior, K. (2011). Public awareness, attitdes and beliefs regarding intellectual disability: A systematic review. *Research in Developmental Disabilities*, 32(6), 2164-2182, doi:10.1016/j.ridd.2011.07.005

Scior, K., & Werner, S. (2016). *Intellectual Disability and Stigma*. Palgrave Macmillan.

Sherman, S., L., Allen, E., G., Bean, L., H. and Freeman, S., B. (2007). Epidemiology of Down syndrome. Mental Retardation and Developmental Disabilities Research Reviews, 13(3), 221-227. doi: 10.1002/mrdd.20157

Spencer, M. B., & Markstrom‐Adams, C. (1990). Identity processes among racial and ethnic minority children in America. *Child Development, 61*(2), 290-310. doi: 10.2307/1131095

Todd, S. (2000). Working in the public and private domains: Staff management of community activities for and the identities of people with intellectual disability. *Journal of Intellectual Disability Research, 44*(5), 600-620. doi: 10.1046/j.1365-2788.2000.00281.x

Todd, S., & Shearn, J. (1997). Family dilemmas and secrets: Parents' disclosure of information to their adult offspring with learning disabilities. *Disability and Society, 12*(3), 341-366. doi: 10.1080/09687599727218

TABLES AND FIGURES

Table 1: Participant numbers and age means (and standard deviations)

Participant group	Age group	N (girls)	Chronological age M (S.D.)	Verbal Mental Age M (S.D.)
DS	8.00-12.12	10 (4)	10.55 (1.34)	4.53 (1.65)
	13.00-17.12	18 (14)	15.03 (1.23)	5.35 (1.83)
	All	28 (18)	13.43 (2.52)	5.05 (1.78)
TD younger in age	5.00-7.12	14 (6)	6.21 (.96)	7.26 (1.42)
TD same age	8.00-12.12	27 (14)	10.24 (1.29)	10.17 (2.31)
	13.00-17.12	26 (14)	14.29 (1.27)	12.05 (1.58)
	All	53 (28)	12.23 (2.41)	11.09 (2.18)

DS= Down syndrome; TD= Typically developing

Table 2: Frequency of above chance level (≥ 4) preference for TD photographs and median (range) preference score, by participant and age group

Participant group	Age group	N	Chose TD photograph ≥4 times out of six trials	Did not choose TD photograph ≥4 times out of six trials	Median (range) number of times TD photograph chosen out of 6 trials
DS	8.00-12.12	10	8	2	5 (2-6)
	13.00-17.12	18	15	3	5.5 (3-6)
	All	28	23	5	5 (2-6)
TD	5.00-7.12	13	13	0	6 (4-6)
TD	8.00-12.12	27	17	10	4 (0-6)
	13.00-17.12	26	22	4	4.5 (1-6)
	All	53	52	14	4 (0-6)

DS= Down syndrome; TD= Typically developing

Table 3: Frequency of above chance level (≥5) photograph sorting and median (range) sorting scores by participant group and age group

Participant group	Age group	N	Did sort photographs ≥5 times out of 8 trials	Did not sort photographs ≥5 times out of 8 trials	Median (range) sorting score
DS	8.00-12.12	10	6	4	5 (1-8)
	13.00-17.12	18	9	9	4.5 (2-8)
	All	28	15	13	5 (1-8)
TD	5.00-7.12	14	11	3	6 (4-8)
TD	8.00-12.12	27	26	1	8 (3-8)
	13.00-17.12	26	25	1	7.5 (4-8)
	All	53	51	2	8 (3-8)

DS= Down syndrome; TD= Typically developing

Table 4: Frequency of characteristics attributed by participants with Down syndrome and typically developing participants

Trait	Down syndrome group (n=28)			Typically developing group (n=67)		
	DS photo	TD photo	self photo*	DS photo	TD photo	Self photo
Friendly	13	19	24	57	60	67
Not friendly	15	9	3	10	7	0
Good	9	22	22	54	55	66
Naughty	19	6	5	13	12	1
Lots of friends	8	19	23	21	65	67
Not many friends	20	9	4	46	2	0
Happy	15	21	21	41	60	64
Sad	13	7	6	26	7	3
Clever	10	19	25	37	55	63
Stupid	18	9	2	30	12	4
Can do things	17	12	13	12	63	61
Needs help	11	16	14	55	4	6
Called names	17	12	8	57	6	3
Not called names	11	16	19	10	61	64
Median no. positive descriptors	3 (0-7)	5 (1-7)	6 (1-7)	3 (0-7)	7 (3-7)	7 (5-7)

*1 missing participant (n=27)

Figure 1: Illustrations for Social Preference task

Figure 2: Examples of Illustrations for the Attribution of Person Characteristics task.