

**SELF-CONCEPTS IN ADOLESCENTS WITH AUTISM SPECTRUM  
CONDITIONS AND WILLIAMS SYNDROME**

A thesis submitted to The University of Manchester for the degree of  
Master of Philosophy  
in the Faculty of Medical and Human Sciences

**2012**

**HELENA TUCKER**

**School of Psychological Sciences**

## LIST OF CONTENTS

<b>ABSTRACT .....</b>	<b>7</b>
<b>DECLARATION .....</b>	<b>8</b>
<b>COPYRIGHT STATEMENT .....</b>	<b>8</b>
<b>ACKNOWLEDGEMENTS.....</b>	<b>9</b>
<b>CHAPTER 1: UNDERSTANDING SELF-CONCEPT - DEVELOPMENT IN CHILDHOOD AND ADOLESCENCE .....</b>	<b>11</b>
<b>Aims and Objectives of Chapter One.....</b>	<b>11</b>
<b>Introduction .....</b>	<b>11</b>
<b>Jamesian Theory .....</b>	<b>12</b>
<b>Symbolic Interactionist Perspective on Self-Concept.....</b>	<b>13</b>
<b>The Developmental Model of Self-Understanding.....</b>	<b>14</b>
<b>Developmental and Organisational Model of Self .....</b>	<b>15</b>
Development of Self-Concept in Early to Late Childhood .....	15
Development of Self-Concept in Adolescence.....	16
<b>Personal Construct Psychology .....</b>	<b>17</b>
Constructs in Children and Adolescents .....	18
PCT and Self-Construing .....	19
Core Construing.....	19
Clusters of Core Construing .....	20
<b>Self-Esteem.....</b>	<b>22</b>
Distinction of Self-esteem from Self-Image.....	23
Components of Self-Esteem .....	23
Development of Self-Esteem.....	24
Self-Esteem and Life Outcomes .....	25
<b>Comparison with Others.....</b>	<b>25</b>
<b>Conclusion.....</b>	<b>26</b>
<b>CHAPTER 2: SELF-CONCEPT IN CHILDREN AND ADOLESCENTS WITH ASC AND WILLIAMS SYNDROME .....</b>	<b>27</b>
<b>Aims and Objectives of Chapter Two .....</b>	<b>27</b>
<b>Introduction .....</b>	<b>27</b>

<b>AUTISM SPECTRUM CONDITIONS.....</b>	<b>28</b>
<b>Triad of Impairment.....</b>	<b>31</b>
<b>Emotional Difficulties in ASC .....</b>	<b>32</b>
<b>Psychological Explanation of ASC .....</b>	<b>32</b>
<b>Social Functioning in ASC.....</b>	<b>33</b>
<b>ASC and Self-Concept .....</b>	<b>34</b>
<b>WILLIAMS SYNDROME .....</b>	<b>36</b>
<b>Emotional Difficulties in WS .....</b>	<b>37</b>
<b>Social Functioning and Positive Interpersonal Bias in WS .....</b>	<b>37</b>
<b>WS and Self-Concept .....</b>	<b>39</b>
<b>Conclusion.....</b>	<b>39</b>
<b>CHAPTER 3: METHODOLOGY .....</b>	<b>41</b>
<b>Aims and Objectives of Chapter Three.....</b>	<b>41</b>
<b>Ethical Considerations.....</b>	<b>41</b>
<b>Recruitment .....</b>	<b>41</b>
<b>Participants .....</b>	<b>42</b>
Exclusion Criteria .....	43
Sample Size .....	43
Participant Response Rate .....	44
<b>Measures.....</b>	<b>45</b>
The British Picture Vocabulary Scale-II .....	45
Wechsler Abbreviated Scale of Intelligence .....	46
Measure of Theory of Mind – The Smarties Test.....	46
The Self-Image Profile for Adolescents.....	47
The SIP-A Follow-up Interview .....	48
<b>Assessment Procedure .....</b>	<b>49</b>
<b>Data Storage and Confidentiality .....</b>	<b>51</b>
<b>CHAPTER 4: RESULTS AND DATA ANALYSIS .....</b>	<b>52</b>
<b>Aims and Objectives of Chapter Four .....</b>	<b>52</b>
<b>Demographic Characteristics .....</b>	<b>52</b>

**Exploration of Data.....53**

**ASC and WS Group Comparisons.....53**

**How did adolescents with autism and WS perceive themselves and how did perception of self differ in the two conditions? .....55**

    SIP-A Self-description Scores ..... 55

    SIP-A Scale Scores ..... 58

    SIP-A Aspects of Self-scores ..... 61

**Is awareness and attitude to condition (ASC or WS) related to self-image and/or self-esteem?.....66**

**CHAPTER 5: DISCUSSION AND CONCLUSIONS .....70**

**Aims and Objectives of Chapter Five.....70**

**How do adolescents with autism and WS perceive themselves and how does perception of self differ in the two conditions? .....70**

    SIP-A Self-descriptions ..... 70

    SIP-A Scale Scores ..... 71

    Sense of Difference ..... 72

    SIP-A Aspects of Self-scores ..... 74

    The Role of Cognitive Functioning ..... 75

**Implications on Existing Theory .....75**

**Applied Implications.....76**

**Critical Analysis of Study .....77**

    Generalisability ..... 77

    Depth of Information Gained in Interviews ..... 78

**Further Research .....79**

**Conclusions .....80**

**REFERENCES: .....81**

**APPENDICES: .....99**

## LIST OF TABLES AND FIGURES

### CHAPTER 3: METHODOLOGY

<b>Table 1:</b> Participant Response Rate – ASC Group	45
<b>Table 2:</b> Participant Response Rate – WS Group	45
<b>Table 3:</b> Students Unable to Participate	45

### CHAPTER 4: RESULTS AND DATA ANALYSIS

<b>Table 1:</b> Sample Characteristics	52
<b>Table 2:</b> Summary of Between-Group Comparison	53
<b>Table 3:</b> Theory of Mind Scores Comparison	53
<b>Table 4:</b> SIP-A Self-description Scores	56
<b>Table 5:</b> SIP-A Scale Scores	60
<b>Table 6:</b> SIP-A Aspect of Self-scores	62
<b>Table 7:</b> ASC Correlational Analysis Scale Scores and Aspects of Self-scores	64
<b>Table 8:</b> WS Correlational Analysis Scale Scores and Aspects of Self-scores	65
<b>Table 9:</b> Awareness and Reaction to Awareness Scores	67
<b>Table 10:</b> Summary of Awareness and Reaction to Awareness Collapsed Scores	68

### CHAPTER 5: DISCUSSION

<b>Figure 1:</b> Relationships Between Sense of Difference, Self-esteem and Negative Self-image	73
---	----

## **LIST OF APPENDICIES**

<b>APPENDIX 1</b>	Ethics Committee Approval Letter	99
<b>APPENDIX 2</b>	Research Information – Letter to Parents	100
<b>APPENDIX 3</b>	Participant Information Sheet (Parents)	101
<b>APPENDIX 4</b>	Participant Information Sheet (Adolescents)	104
<b>APPENDIX 5</b>	Consent Form	105
<b>APPENDIX 6</b>	The Smarties Test Administration and Scoring Guidelines	106
<b>APPENDIX 7</b>	SIP- A Follow up Interview Schedule	108
<b>APPENDIX 8</b>	Interview transcripts	109

**Total Word Count: 21, 340**

## **ABSTRACT**

### **Self-Concepts in Adolescents with Autism Spectrum Conditions and Williams Syndrome**

**BACKGROUND:** Self-concept, defined as a set of self-attitudes that describe behaviour and characteristics of self (Piers, 1994), is of central importance in one's psychological functioning and fundamental to psychological well-being. The present study explored self-concepts in adolescents with autism spectrum conditions and Williams syndrome, conditions that present with distinct social phenotypes. The aim was to investigate whether perceptions of self differ in the two conditions and whether awareness and attitude to condition is related to self-image and/or self-esteem.

**METHOD:** The Self-Image Profile for Adolescents (Butler, 2001), interviews and standardised tests were used to explore self-concepts and awareness of condition in 16 adolescents with ASC and 18 adolescents with WS.

**RESULTS:** No significant differences were found on positive and negative self-image, sense of difference and self-esteem between the two groups, however results suggest trends of more positive construing of self in adolescents with WS. No association was found between awareness and attitude to condition and self-image and/or self-esteem.

**CONCLUSIONS:** A likely positive social reaction towards individuals with WS coupled with positive social bias may be attributed to a more positive perception of self. The need for tailored interventions to promote positive self-concept was highlighted in the light of evidence that behavioural and emotional problems change with increasing age in the two conditions.

**Helena Tucker**  
**Degree of Master of Philosophy**  
**School of Psychological Sciences**  
**The University of Manchester**

## DECLARATION

I declare that no portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning.

## COPYRIGHT STATEMENT

- i. The author of this thesis (including any appendices and/or schedules to this thesis) owns certain copyright or related rights in it (the “Copyright”) and she has given The University of Manchester certain rights to use such Copyright, including for administrative purposes.
- ii. Copies of this thesis, either in full or in extracts and whether in hard or electronic copy, may be made **only** in accordance with the Copyright, Designs and Patents Act 1988 (as amended) and regulations issued under it or, where appropriate, in accordance with licensing agreements which the University has from time to time. This page must form part of any such copies made.
- iii. The ownership of certain Copyright, patents, designs, trade marks and other intellectual property (the “Intellectual Property”) and any reproductions of copyright works in the thesis, for example graphs and tables (“Reproductions”), which may be described in this thesis, may not be owned by the author and may be owned by third parties. Such Intellectual Property and Reproductions cannot and must not be made available for use without the prior written permission of the owner(s) of the relevant Intellectual Property and/or Reproductions.
- iv. Further information on the conditions under which disclosure, publication and commercialisation of this thesis, the Copyright and any Intellectual Property and/or Reproductions described in it may take place is available in the University IP Policy (see <http://www.campus.manchester.ac.uk/medialibrary/policies/intellectual-property.pdf>), in any relevant Thesis restriction declarations deposited in the University Library, The University Library’s regulations (see <http://www.manchester.ac.uk/library/aboutus/regulations>) and in The University’s policy on presentation of Theses



## ACKNOWLEDGEMENTS

This research would not have been possible without the help of a number of people, to only some of whom it is possible to give particular mention here.

First, I would like to express my great gratitude to Dr Dougal Hare, my research supervisor, for his patient guidance, continued encouragement and support which allowed me to achieve more than I ever expected. His anecdotes, pearls of wisdom and milky cups of tea were always worth the long train journey. I also wish to thank Dr Penny Bunton for her support, helpful feedback and ever positive encouragement. Her willingness to give her time has been very much appreciated.

My grateful thanks are extended to all the young people and parents who generously gave their time to participate in the study. Special thanks goes to the Williams Syndrome Foundation for their generous financial contribution and help with participant recruitment. Their support to WS families and commitment to research is truly exemplary. I would like to thank the staff at Peterhouse School for their support over the past five years. Through their tireless work they make a real difference in the lives of young people with autism and their families. Many thanks also go to Redbridge High School for their invaluable help with participant recruitment.

I wish to thank Jenny for all her help with this project and her wonderful map reading skills on our long travels to see participants. I am also very grateful to Jasmin, Kerri, Rachel, and Sarah for giving up their time to help with the data collection process.

I am thankful for my friends who were there for me along the way. Thanks go to Kate for her friendship and believing in me from the very beginning; Vicki, a friend I admire for her determination, for her support and honesty; to Mary for well needed holidays and opportunities to escape from work with a great friend; Mary A. for many encouraging words and her famous pancakes; and Vicki W. for her prayers and love.

This work could have not been completed without the help of my loving family who always believed in me and supported me on every step of the way. Thanks to mum and dad who are my inspiration; my brother who I admire for going after his dreams; my loving grandparents who provided me with much missed Czech food; and my parents-in-law whose support and love have been such a blessing.

To my husband Jermie, I am eternally grateful for his patience, love and the sacrifices he continues to make for me. I could not have done this without you.

Finally, I would like to dedicate this work to my Granddad, who died on the 19th June 2011, a brave man who was determined to enjoy every moment in life until the very end.

## **CHAPTER 1: UNDERSTANDING SELF-CONCEPT - DEVELOPMENT IN CHILDHOOD AND ADOLESCENCE**

### **Aims and Objectives of Chapter One**

The aim of chapter one is to highlight the importance of self-concept in psychological functioning and its association with life outcomes. Literature on the development of self-concept in childhood and adolescence will be reviewed to set the scene for enquiry in self-concept in adolescent with ASC and WS.

### **Introduction**

For the purpose of this study, it is important to clarify the use of 'self' terms. There has been some confusion in the frequent and interchangeable use of 'self' terms including self-esteem, self-concept and self-image (Butler & Gasson, 2006). Shavelson & Bolus (1982) provided some clarification and described self-concept as an overall global term for the perception of self, with self-esteem as its evaluating component highlighting the discrepancy between the real and ideal self (Butler & Green, 2007). Self-image refers to how one perceives descriptive characteristics of self (Butler & Gasson, 2005). The terms 'self-perceptions', 'self-description' and 'self-representations' have been used interchangeably referring to how one describes oneself through the use of language (Harter, 1999).

Self-concept is of central importance in one's psychological functioning (Elmer, 2001; Glick, Bybee, & Zigler, 1997) and fundamental to psychological well-being. Positive self-belief is associated with happiness, motivation and positive life outcomes such as academic achievement. On the other hand, negative self-belief is related to negative life outcomes, depression and anxiety (Craven & Marsh, 2008). A variety of settings such as education, child development, social services, mental and physical health, etc. identify self-concept as a crucial construct and focus on its enhancement (Craven & Marsh, 2008).

The purpose of this study is to explore self-concepts in adolescents with ASC and WS. Before reviewing literature relevant to these two conditions, it is appropriate

to focus on understanding the development of self-concepts in childhood and adolescence. The Jamesian theory will be briefly introduced to in order to provide background of conceptualisation and formulation of self-concept. The 'symbolic interactionist' view will then be considered, demonstrating the importance of interpersonal relationships and how these affect the development of self. A review of the developmental model of self-understanding by Hart & Damon (1988) and the significant work of Harter (1999) on the development of self-understanding will follow. Subsequently, personal construct perspective (Kelly, 1955) and its implications for understanding the development of self-concept will be discussed. Finally, attention will be given to self-esteem, the evaluative component of self.

### **Jamesian Theory**

In the classic analysis of self-concept, James (1892/1961, p.44) distinguished two components of the self. 'Me' is the sum of all personal attributes, with its primary elements including material (body, possessions), social (relations, roles, personality) and spiritual (consciousness, thoughts, psychological mechanisms) constituents. In the Jamesian theory, as suggested by Hart & Damon (1988), self-concept is constituted in the hierarchical organization of 'me' constituents, whereby one becomes aware of all aspects of the self through observation and feedback from others, which are then placed in order of importance. 'I' is the abstract component of self, categorised into four types of experience: agency (autonomy of self), distinctness (how one is different to others), continuity (stability of the 'I') and reflection (self-consciousness). James interjects the indeterminate nature of the 'I' and the difficulty with its investigation. In Mead's (1934) modification of James' theory, he suggests accessing the 'I' through the 'me' by understanding the subjective and objective knowledge of self. Understanding of the 'I' experiences is provided through one's knowledge of what one is experiencing, rather than the experience itself. Much more could be written about James' work on self-concept, however, for the purpose of this study, his theory is briefly described to provide a background for conceptualising the self, which influenced much of later work in this area.

## **Symbolic Interactionist Perspective on Self-Concept**

The symbolic interactionist perspective, conversely to the Jamesian theory, emphasises the importance of interpersonal relationships and how these affect the development of self (Harter, 1999). The self is viewed as a 'social construction' established by symbolic interactions, i.e. social interactions and verbal exchanges with others (Baldwin, 1902; Cooley, 1902; Mead, 1934). Cooley's (1902) concept of the 'looking glass self' lays emphasis on one's interpersonal relationships and interactions, wherein one is influenced by the perception of others, and in turn reinforces their perceptions on self. Cooley's (1902, p.152) words: 'I am not what I think I am and I am not what you think I am; I am what I think that you think I am' encapsulates the notion that we perceive ourselves as a reflection of how we *believe* others see us.

Common themes emerging from the symbolic interactionist literature are children's imitation of significant others, seeking approval and regulating behaviour accordingly and taking on the views and values of significant others. It is suggested that children's perception of self is shaped by how they believe significant others perceive them (Harter, 1999). Research that is congruent with the above formulations stresses the importance of interactions with caregivers and significant others and how these affect the developing concept of self (e.g. Bretheron, 1991; Case, 1991; Harter, 1998). In particular, the link between approval or disapproval and global self-worth, the overall perception of self-domains, is highlighted as parental validation and approval are significant in childhood and adolescence and are highly correlated with self-worth. As a child progresses to adolescence, the approval of self by peers also becomes important, but Harter (1999) suggests that peer approval *per se* does not diminish the significance of support and approval by parents in adolescents. There is evidence to suggest the positive effect of social inclusion and peer acceptance (Altermatt & Pomerantz, 2003; Dubois et al., 2002; Pijl & Frostad, 2010), while the lack of peer acceptance is associated with lower academic self-concept (Asher & Coie, 1990; Flook, Repetti, & Ullman, 2005). Furthermore, social acceptance and global self worth has been shown to be associated with the severity of depression in adolescents (King, Naylor, Segal, Evans, & Shain, 1993) and feelings of not being accepted by relevant others as

related to psychotic symptoms (Lincoln et al., 2010). The symbolic interactionist perspective offers important insight into the development of self-concept, which is viewed as the result of active interpersonal process rather than a trait that is manifested over time. As noted by Harter (1999), both the Jamesian and the symbolic interactionist formulations add to the overall understanding of self-worth in children and adolescents. Having discussed the symbolic interactionist perspective, attention will now be given to the developmental model of self-understanding.

### **The Developmental Model of Self-Understanding**

In their integrative account, Hart & Damon (1988) describe the multi-faceted developmental model of self-understanding following on the work of James (1890/1950) and Mead (1934). They address the lack of a developmental component in James' version of self-concept and describe a comprehensive account of how self-understanding develops across multiple domains that interact with one another (Damon & Hart, 1982, 1988). They point to the behavioural evidence that children from a very young age attributing characteristics to themselves (Kegan, 1982) and talk about themselves in psychological and social terms and in terms of actions, i.e. what the child does (Keller, Ford, & Meacham, 1978).

Describing the developmental model of self-understanding, Hart & Damon (1988) organised the self-as-object, the Jamesian 'Me', into four constituents of physical, active, social and psychological self. Through the course of development the child moves through four developmental levels described as 'categorical identifications', 'comparative assessment', 'inter-personal implications' and 'systematic beliefs and plans' (Hart & Damon, 1988, p.10). At the first level of development - categorical identifications (early childhood), one would simply describe oneself as belonging to a specific group/category without implication of a meaning. At the 'comparative assessment' level (middle to late childhood), children describe themselves using relational statements as a result comparing self to others. This comparison is focused on abilities and performances. As the name of the third developmental level suggests - interpersonal implications (early adolescence), one moves on from

simple comparison to focus on one's interaction with others and its implications on one's position in a group. At developmental level number 4 - systematic beliefs and plans (late adolescence), one's perception and understanding of self becomes systematic and includes belief systems, personal and moral standards and personal philosophy. The 'I', the self-as-subject, is divided into three concepts of continuity, distinctiveness and agency and according to the developmental model, it goes through the same developmental stages at the above described 'self-as-object' yet each concept has its own development trajectory. The concept of 'reflection' is not included in the model due to it being inaccessible to the researcher.

Following the necessarily brief description of this model, it shall be noted that it has been fundamental in further research investigating self-understanding in various groups, including typically developing children (Malti, 2006), children with autism and adolescents with Asperger syndrome (Jackson, Skirrow, & Hare, 2012; Lee & Hobson, 1998) and in adolescents with specific psychopathology, e.g. eating disorders (Levitt & Hart, 1991).

### **Developmental and Organisational Model of Self**

The work of Harter (1999) has been fundamental to our understanding of the development of self. Similarly to Damon and Hart (1988) and Shavelson, Hubner, & Stanton (1976), Harter (1999) advocates that self-concept is multidimensional and hierarchical, contrary to the one-dimensional views attempting to measure and conceptualise the self as a whole (Coopersmith, 1967). The hierarchical structure of self-concept is also supported in more recent reviews (Byrne, 1996; Marsh, 2007; Marsh, Craven, & Martin, 2006). Harter categorised self-perceptions into domains – 'academic', 'athletic competence', 'physical appearance', 'social', 'behavioural' and an overall global construction 'self worth'. In her influential work, Harter illustrates a strong developmental component of self-concept from early childhood through adolescence to adulthood described in more detail in the following sections.

#### *Development of Self-Concept in Early to Late Childhood*

According to Harter (1999), children in *very early childhood* (3-4 years old)

describe themselves by concrete accounts and characteristics that can be observed by others (e.g. I live with my mum and sister, I like to watch TV). As children at this age are unable to synthesize elements of self, their descriptions are discontinuous and fragmented. They also tend to be unrealistically positive about themselves and see themselves in terms of 'absolutes' (all good or all bad) as they lack the ability to realistically compare self to others and distinguish between various domains of self. In *early to middle childhood* (5-7 years old) some of these elements are still present, however children become more able at de-fragmenting the concrete descriptions of self into a more coherent whole and making 'temporal' comparisons, i.e. appreciating that characteristics and abilities change over time. *Middle to late childhood* (8-11 years old) is a key developmental stage where increased cognitive ability impacts on the formation of global evaluation of self. Unlike in early childhood where attributes of self are fragmented, children's perceptions of self become more balanced demonstrating the ability to integrate positive and negative self-representations. Children also begin to compare themselves to their peers and distinguish between the various domains of self and form a more realistic view of self. Their perception of self is dependent upon how adept they feel they are in domains that they consider to be important (Harter, 1999).

#### *Development of Self-Concept in Adolescence*

Harter (1999) described three developmental stages of self-concept in adolescence. Interpersonal attributes play a central role in *early adolescence*. Increased cognitive ability contributes to the formation of abstract self-attributes, which at this stage of development are perceived as separate characteristics. Furthermore, the adolescent does not seem concerned by separate presentations of self that may be contradictory (e.g. happy and sad). With the increasing levels of social pressure one may feel forced to present oneself differently in different situations and a distorted perception of self may be observed due to the inability to distinguish between multiple portraits of self (Brewer & Cutting, 1976; Harter, 1999). In *middle adolescence*, we see a manifestation of a conflict and confusion with the increasing emergence of contradictory attributes that the adolescent struggles to integrate. As a result, adolescent at this developmental stage may display mood swings, changes



in behaviour and evaluations of self. A strong link emerges between self-worth and perceived validation of self by important others. If one is preoccupied with the gap between the real and ideal self this may result in low self-worth (Harter, 1999).

During *late adolescence*, one develops the ability to synthesize the multiple components and domains of self into a unified entity (Erickson, 1968) and self perceptions and standards undergo a process of internalisation (Harter, 1999). Adolescents' ability to make realistic comparisons with others leads to a more realistic view of self, however this makes them at risk of negative self-esteem if they perceive themselves as not adept in domains that are important to them (Harter, 1999). Where there is a large discrepancy between the real and ideal self, the adolescent may experience depressive affect (Courtney, Gamboz, & Johnson, 2008; Evans, 1998). Furthermore, Harrop & Trower (2001) postulated a link between incomplete self-development in adolescence and the subsequent development of psychosis. They propose that vulnerable adolescents face self-construction difficulties and that such 'blocked adolescence' may result in the emergence of psychosis. Physical appearance also plays an important role in self-perception of adolescents (Erickson, 1959; Harter, 1999; Haugen, Säfvenbom, & Ommundsen, 2011; Kroger, 2007) and it is exaggerated by the desire and perceived pressure to be attractive (Evans, Brody, & Noam, 1995).

Harter's detailed description of developmental differences in the perception of self across the developmental levels in childhood and adolescence has been fundamental in understanding of the cognitive-developmental framework and liabilities associated with each stage of the child's development.

### **Personal Construct Psychology**

The perspective of personal construct psychology (PCP) has been important in further understanding of self-concept. In his significant pioneering work, Kelly (1955) details the theory of personal constructs where 'a person's processes are psychologically channelised by the way in which he [sic] anticipates events' (Kelly, 1955, p.46). According to Kelly, the individual is seeking to understand the self and his/her world and through this process identifies similarities and themes

and creates so called 'constructs', which will unable him/her to anticipate and predict future events. Thus, he/she develops unique and subjective perception and understanding of reality shaped by his/her interpretations of events (Dalton & Dunnnett, 1999). Constructs are fluid and considered to have contrasting poles (e.g. active - lazy), which are sought to enhance the understanding of one's construing (Butler & Green, 2007). Furthermore, it is proposed that children have a low level of awareness of their construing (Ravenette, 1997), whereby they do not consciously access their constructs before they act.

Personal construct theory (PCT) does not seek to categorise or predict one's behaviour, but its aim is to assist the individual in understanding him/herself, what is important to him/her and becoming aware of his/her means of construing (Dalton & Dunnnett, 1999; Kelly, 1955). In describing the structure of constructs, Kelly proposed that constructs are interrelated and subsuming and presented in terms of *superordinacy* and *subordinacy*. One of PCT techniques to elicit constructs is called laddering. It uses questions to elaborate on superordinate constructs such as "what life is all about" (Fransella & Dalton, 1990). A way to elicit more concrete subordinate constructs may be achieved by asking what a construct means to the individual. Kelly called this method pyramiding.

#### *Constructs in Children and Adolescents*

Kelly's detailed description of PCT is based on his work with adults and he writes very little about the use of PCT with children. He suggested that the child's earliest constructs are bodily states. Later on, significant others function as constructs and later still they are represented by verbal symbols (Ravenette, 1999). Ravenette points out Kelly's omission to identify that children's 'own actions and the actions of others in relation to children' (p.43) are a significant source of children's expectations. He illustrates the complexity of children's constructs and explains that unlike in adulthood, when the base of expectation is relatively stable, children's verbal representations are still developing and the base of expectations is only becoming more established as children progress through development. According to Ravenette, development of the sense of self is closely connected to the process of our constructs being confirmed or disconfirmed, which establishes a

certain level of consistency in one's responses to events. As children develop and interact with their environment, they encounter and make sense of various events or 'elements' and their construing becomes more detailed (Damon & Hart, 1982). In early childhood children often construe events widely (e.g. 'all good or 'all bad' and 'happy' or 'sad'). As they develop they become more skilled in conceiving constructs that are more narrow and complex (Butler & Green, 2007).

### *PCT and Self-Construing*

PCT suggests hierarchical structure of the self. At the lowest level constructs include 'physical characteristics', 'social roles' and 'behavioural nature' (Butler & Green, 2007). Such descriptions of self are usually offered by young children between the ages of 4-7 years (Harter, 1990). At this stage, higher level constructs of social and psychological nature begin to emerge (Robinson, 2007) with the most superordinate level being core constructs, which are a foundation for the way one behaves and perceives oneself (Butler & Green, 2007). By the age of 8 years, constructs become more complex and abstract, comparisons with others become more reliable and social awareness more prominent. With transition to adolescence, one establishes their perception of the real and the ideal self. Adolescents experience incongruous aspects of self that may be demonstrated in different situations and with different people (e.g. easygoing with friends but moody at home). Experiencing so called 'multiple selves' can be difficult for the individual to deal with, yet as the adolescent progresses through this stage, this conflict is usually resolved (Harter, 1999).

It is important to note that there are researchers who suggest that developmental models are not sufficient to explain variation how the self develops (Zigler, 1999). Particularly, as detailed above, social interaction and interpersonal relationships play a significant role in establishing one's core constructs by the influence of construing others on our own perception of self (Kelly, 1955).

### *Core Construing*

Kelly (1995) suggests that core construing shapes maintenance of the self and regulates our behaviour and actions and unlike constructs at a more subordinate

level, core constructs are resistant to change. Core constructs lie at low level of awareness (Leitner & Thomas, 2003; Ravenette, 2003). If they were easily accessible, there is a higher possibility of invalidation, which may lead to what is called 'Kellyan hostility', which is a denial of invalidating evidence and persistence to maintain the core belief.

It is proposed that core constructs are unique to each individual (Butler & Green, 2007), yet there are views suggesting that core constructs are finite. Rowe (2003) conjectured that individuals' construing is underpinned by their interpersonal relationships and need for acceptance, or by their need for order and control and striving for achievement. Tafarodi & Swann (1995) affirm this view by suggesting that 'self-liking' and 'self-competence' are the two fundamental core constructs. Congruent with Cooley's social cognitive perspective, self-liking is dependent upon one's perception of others' views and reactions towards oneself leading to establishing constructs associated with approval by others and fear of rejection. Unlike self-liking, self-competence is represented by a view of self as competent and in control, evaluating internal qualities and principles, which may be independent of the view and approval of others. This focus on maintaining one's sense of self by the concept of motivation was challenged by Kelly's view of core constructs defining a person's identity by 'anticipatory actions' when one desires and anticipates validation (Butler and Green, 2007).

#### *Clusters of Core Construing*

In a survey with 419 adults, Butler (2006) found four clusters of core constructs, proposing that these begin to form in childhood and are characterised in terms of continuity. The four clusters are described as 'self-competence based on a need to make sense'; 'self-respect based on relatedness'; 'self-determination based on achievement'; and 'self-reliance based on individuality'.

In the first cluster, 'self-competence based on a need to make sense', the fundamental question of the young person is: 'Am I capable?' The individual seeks validation by engaging in activities he/she is good at to confirm his/her sense of feeling competent and capable. Conversely, we see children and young people not

wanting to engage in activities that would invalidate such notion. Using the framework of James (1890/1950) and more recently Harter (1999), individuals' achievements are perceived as judged against internal personal standards. Hence, a young person may be putting significant effort into a task he wants to succeed in.

The second cluster, 'self-respect based on relatedness', is reiterating Rowe's (2003) view of one's need for interpersonal relationships, sense of acceptance and being understood by others, whereby one may conform to others to avoid rejection. The fundamental question here is: 'How well liked am I?' Stager & Young (1982) found that the most important factor in children's construing was in fact relatedness, specifically how children felt to be liked or disliked by others. Leitner & Thomas (2003) suggest that the notion of self is best understood in a social context. Through core construing around self-respect, young people's actions are influenced by their anticipation of others' approval, therefore they are likely to build relationships where they feel valued and accepted, where they please others, demonstrate accomplishment and seek appraisal.

The third cluster, 'self-determination based on achievement', is related to Rowe's descriptions of striving for achievement, where one is seeking to gain success whilst avoiding failure. The central question is: 'Will I succeed?' Through utilising the core construct of self-determination, one seeks for validation of success by approval and recognition by others. This may be evidenced by young children eagerly wanting to demonstrate their new skills and their desire for others to recognise their achievements.

In the fourth cluster, 'self-reliance based on individuality', the important question is 'Am I being myself?' when one is looking for the sense of being different, independent and not conforming to one's surroundings. We see young people's various expressions of their search to be individual, which may be in their sense of fashion, humour, creativity, etc. (Butler & Green, 2007). In sum, it is suggested that constructs are interrelated and hierarchical in structure, with core construct being at the most superordinate level directing all behaviour and maintaining one's identity. The function of actions and behaviour displayed by the individual is to validate the core construct maintaining the sense of self.

### *The Use of PCT Principles with Children and Adolescents*

The principles of PCT are applied in educational and clinical settings with children and adolescents to gain a better understanding of their reality and to offer help with various difficulties (Butler & Green, 2007; Ravenette, 1999, 2003). PCT has been used with typically developing children (Butler, Redfern, & Forsythe, 1990; Butler, Redfern, & Holland, 1994). Personal construct elicitation methods have also been successfully employed to explore self-image in children and adolescents with learning disabilities (Maxwell, 2006; Oliver, 1986; Thomas, Butler, Hare, & Green, 2011).

Having reviewed multiple perspectives on self-concept and its development, attention will now be given to self-esteem, the evaluating components of self-concept, and self-image, being the descriptive component of self.

#### **Self-Esteem**

Self-concept and self-esteem have often been used interchangeably. There have been some attempts to characterise self-esteem as the affective component and self-concept as the cognitive component of self. However, Shavelson et al., (1976) argued that there is little empirical evidence for this distinction and proposed that domains of self-concept such as academic, social and physical are evaluative in their nature, which was supported by Marsh, Craven, & Debus (2000) and Swann, Chang-Schneider, & Larsen McClarty (2007). Craven & Marsh (2008) describe self-esteem as the global component of self-concept, being 'operationalised as a higher-order factor in a multidimensional model of self-concept' (p.106), separate from self-concept domains such as physical, social, and academic.

Similarly, Harter (2003) described self-esteem as the evaluating component of self-concept, whereby one assesses their value as a person and detailed domains of self-esteem as scholastic competence, athletic competence, peer likeability, physical appearance and behavioural conduct, with global self-esteem being the overarching construct. According to Harter (1999), with increasing age children become more skilled at evaluating themselves in comparison with others. Young children evaluate their skills or characteristics in specific domains and it is not until middle

childhood when children begin to make overall evaluations about their worth as a person and their view of self is shaped by how adept they feel in domains that they perceive important. In similar fashion, (Butler & Green, 1998, 2007) describe self-esteem as one's perceived difference between 'where I am' and 'where I want to be', and their 'affective reflection' on this discrepancy. Therefore, where such discrepancy is high, one feels far from the ideal self and his/her self-esteem is low, whereas one would have a high self-esteem when he/she feels the real self is not distant to the ideal self.

#### *Distinction of Self-Esteem from Self-Image*

Although self-esteem and self-image are often used interchangeably, self-image is considered to be a descriptive component of self – 'the constructs, dimensions or characteristics by which the self is identified' (Butler, 2001, p.3). It reflects how one thinks about oneself, in PCT terminology, how one construes oneself (e.g. good looking, happy, kind, lazy, boring, etc.) (Butler, 2001). As detailed above, such constructs are hierarchical and become more complex over the course of development. Similarly to Harter (1999), Bybee & Zigler (1991) suggest that that self-image follows cognitive-developmental framework.

#### *Components of Self-Esteem*

In the last decade researchers identified important components self-esteem (Harter, 2003; Kernis, 2002). Kernis & Goldman (2003) described *self-esteem stability* as an important aspect of self-esteem. As self-esteem fluctuates, it affects the feelings of self-worth and therefore makes them unstable. More fluctuation of self-esteem is present in childhood with stabilisation increasing in adolescence (Trzesniewski, Donnellan, & Robins, 2003).

Another important aspect of self-esteem is *contingency*. Self-esteem is contingent upon outcomes and achievements (Kernis, 2002) and individuals with contingent self-esteem seek approval of others. Their self-esteem is fragile and fluctuates depending on perceived success and performance. A distinction is made between domain-specific and global contingent self-esteem. Domain-specific contingent self-esteem fluctuates in accordance with perceived success or failure in domains

of importance such as appearance, approval of significant others or sport (Crocker & Wolfe, 2001). Bos, Muris, Mulkens, & Schaalma, (2006) suggest that domain-specific contingent self-esteem can be related to psychopathology in adolescent, e.g. contingency on appearance and eating disorders (Björck, Clinton, Sohlberg, Hällström, & Norring, 2007; Björck, Clinton, Sohlberg, Hällström, & Norring, 2003).

A distinction is also made between *implicit and explicit self-esteem*. Implicit self-esteem lies at a low level of awareness and is related to automatic self-evaluation, whilst in contrast explicit self-esteem is easily accessible to awareness and relatively controlled (Baccus, Baldwin, & Packer, 2004; Dijksterhuis, 2004). Low correlation of implicit and explicit self-esteem suggests that these are two separated processes (Baccus et al., 2004; Hofmann, Gawronski, Gschwendner, Le, & Schmitt, 2005).

#### *Development of Self-Esteem*

Leary & MacDonald (2003) proposed that children take on the views that their parents or significant others have about them. Therefore, children with parents who are supportive, approving and nurturing are likely to develop positive self-esteem. In adolescence, approval of peers begins to play an important role in addition to parental acceptance.

Children's global self-esteem is initially rather positive, yet tends to decline dramatically in adolescence (Major, Barr, Zubek, & Babey, 1999; Robins, Trzesniewski, Tracy, Gosling, & Potter, 2002). This can be attributed to the important biological, cognitive, social, psychological and academic changes at this stage of development (Finkenauer, Engels, Meeus, & Oosterwegel, 2002; Robins et al., 2002). Contrary to these assertions, Erol & Orth (2011) in their longitudinal study found that self-esteem increases during adolescence and continues to increase more slowly in young adulthood. With regard to gender differences in childhood, Robins et al., (2002) and Erol & Ulrich (2011) found no difference in gender, however other studies propose that boys have higher self-esteem than girls (Kling, Hyde, Showers, & Buswell, 1999). As for adolescence, there is evidence to suggest that self-esteem declines more significantly in adolescent girls than boys (Robins et



al., 2002).

### *Self-Esteem and Life Outcomes*

Self-esteem is associated with a wide range of life outcomes in children and adolescents such as academic achievement and social functioning, and plays an important role in developing children's feelings of competence (Gurney, 1988). Positive view of self impacts on one's feelings, behaviours and thoughts (Jerome, Fujiki, Brinton, & James, 2002). Self-esteem has been shown to be related to academic achievement (Booth & Gerard, 2011; Mohammad, 2010; Rahmani, 2011) and improved health and behaviour (Dalgas-Pelish, 2006; Johnson, 2011; Paradise & Kernis, 2002). With respect to social functioning, self-esteem is related to peer acceptance (Thomaes et al., 2010). Elmer (2001) conjectured that negative self-esteem is related to negative behaviour towards oneself as well as allowing others to treat oneself negatively.

There is also evidence to suggest that low self-esteem is related to psychopathology, including anxiety (Coudevylle, Gernigon, & Martin Ginis, 2011; Fathi-Ashtiani, Ejei, Khodapanahi, & Tarkhorani, 2007), eating problems and depression (e.g. Courtney et al., 2008; Harter, 1993; Renouf & Harter, 1990) and increased risk-taking, self-harm and suicide attempts (Rhodes & Wood, 1992).

Bos, Huijding, Muris, Vogel, & Biesheuvel, (2010) found that global and contingent components of self-esteem had a unique effects on symptoms of depression, anxiety and eating problems in adolescents. Yet, recent study by Michalak, Teismann, Heidenreich, Ströhle, & Vocks, (2010) challenges the view that self-esteem is a prerequisite for healthy functioning providing evidence that non-judgemental mindful acceptance moderates the relationship between self-esteem and depression.

### **Comparison with Others**

We know that one's comparison to those around him/her has direct link to happiness and self-esteem (Festinger, 1954). Sociometric status can be described as respect and admiration one receives from individuals in their social group, e.g. classmates, peers, neighbours (Anderson, John, Keltner, & Kring, 2001). Social

acceptances and feelings of admiration, belongingness and respect from peers are important predictors of psychological well being (Baumeister & Leary, 1995; Keltner, Gruenfeld, & Anderson, 2003) supporting Tajfel and Turner's social identity theory (Tajfel & Turner, 1979) suggesting a direct link between one's social identity and self-esteem, belonging and purpose (Anderson, Kraus, Galinsky, & Keltner, 2012; Haslam, Jetten, Postmes, & Haslam, 2009).

## **Conclusion**

Self-concept is a psychological construct of great significance that affects one's potential and facilitates important life outcomes (Craven & Marsh, 2008; Marsh, 2007). The notion of self-concept and self-esteem and its development was reviewed in this chapter using cognitive-developmental and social-cognitive frameworks. A particular emphasis was placed on personal construct perspective as it provides an evidence-based framework and its elicitation techniques have been successfully used in research and clinical practice with individuals with intellectual disabilities (Maxwell, 2006; Oliver, 1986; Thomas, Butler, Hare, & Green, 2011). Both, the formulations of self with roots in the Jamesian theory and those of symbolic interactionist perspective are important in the overall understanding of self-concept in children and adolescents. In addition, significant associations were proposed between self-concept and self-esteem, and child and adolescent psychopathology and life outcomes such as academic achievement and peer acceptance.

## **CHAPTER 2: SELF-CONCEPT IN CHILDREN AND ADOLESCENTS WITH ASC AND WILLIAMS SYNDROME**

### **Aims and Objectives of Chapter Two**

The previous chapter focused on the development of self-concept in typically developing children and adolescents setting a scene for further enquiry into self-concepts in adolescents with autism spectrum conditions and Williams syndrome. The goal of chapter two is to review the work on self-concept in children and adolescents with these conditions with focus on the role of social functioning.

### **Introduction**

ASC and WS are both genetically based neurodevelopmental disorders. It is conjectured that typical brain development is affected by specific genetic abnormalities resulting into discrete phenotypes, which are characteristic of these disorders (Tager-Flusberg, Skwerer, & Joseph, 2006). ASC and WS present with distinct social phenotypes. Although both of these groups demonstrate impairment in social understanding, such as understanding the emotional expressions of others (Gagliardi et al., 2003), discriminating social cues, forming social relationships and performance on Theory of Mind tasks (Tager-Flusberg et al., 2006), there are contrasting differences in their social and communication profiles. Individuals with ASC are characterised by impairment in social interactions manifested by ‘lack of social or emotional reciprocity’ (DSM-IV-TR, American Psychiatric Association, 2000, p.75) and often described as socially withdrawn (Green, Gilchrist, Burton, & Cox, 2000). Unlike ASC, WS is characterised by hypersociability, high empathy for others and being socially fearless (Meyer-Lindenberg, Mervis, & Berman, 2006) and individuals with WS are often described as more friendly than other individuals with developmental disorders (Frigerio et al., 2006). The aim of this study is to explore and compare how adolescents with these two conditions construe their sense of self.

## **AUTISM SPECTRUM CONDITIONS**

Autism Spectrum Conditions (ASCs) are neurodevelopmental disorders characterised by social and communication impairment accompanied by narrow interest and/or repetitive and stereotyped behaviour (ICD-10, World Health Organisation, 1992). There is growing evidence that ASC presentation can be accounted for by abnormal brain development as a result of genetic origin (Bailey, Phillips, & Rutter, 1996; Happe & Frith, 1996) with prevalence estimated to be 157 per 10, 000 (Simon Baron-Cohen et al., 2009). The term ‘autism’ was first used by Bleuler (1911) to describe a marked social withdrawal in patients with schizophrenia. Kanner (1943) used the term to refer to a social withdrawal of a group of children he observed in his clinical practice, described in his seminal paper *Autistic Disturbances of Affective Contact* (1943). These children shared characteristic features, which are now referred to as ‘classic’ or ‘Kanner’s’ autism, including: failure to relate to people from early life while demonstrating fascination for objects; good cognitive potential; obsessive desire for maintenance of sameness and insistence on routines; atypical speech including muteness and echolalia; and limitations in the variety of spontaneous activity and play.

In 1944, Asperger (Asperger, 1944) used the term ‘autistic psychopathy’ to describe children who demonstrated difficulty with social interaction and integration. His work only became widely known in the 1980’s after the publication of ‘Asperger’s syndrome’ by Wing (1981). Key characteristics of Asperger syndrome (AS) from Wing’s account include: typical language development; impaired non-verbal communication; limitations in reciprocal interaction; lack of empathy; repetitive activities and intense absorption in certain interests; poor motor coordination; and a higher prevalence in boys.

According to the ICD-10 classification, ASCs subgroups include child autism, Asperger syndrome, pervasive developmental disorder ‘other’ (PDD other) and atypical autism. In childhood autism, language delay is a typical feature accompanied by cognitive ability, which may be below the average range. To receive a diagnosis of ‘childhood autism’, the following criteria in the ICD-10 (WHO, 1992) must be fulfilled:

A. Abnormal or impaired development is evident before the age of 3 years in at least one of the following areas:

1. receptive or expressive language as used in social communication;
2. the development of selective social attachments or of reciprocal social interaction;
3. functional or symbolic play.

B. A total of at least six symptoms from (1), (2) and (3) must be present, with at least two from (1) and at least one from each of (2) and (3)

1. Qualitative impairment in social interaction are manifest in at least two of the following areas:

a. failure adequately to use eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction;

b. failure to develop (in a manner appropriate to mental age, and despite ample opportunities) peer relationships that involve a mutual sharing of interests, activities and emotions;

c. lack of socio-emotional reciprocity as shown by an impaired or deviant response to other people's emotions; or lack of modulation of behaviour according to social context; or a weak integration of social, emotional, and communicative behaviours;

d. lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g. a lack of showing, bringing, or pointing out to other people objects of interest to the individual).

2. Qualitative abnormalities in communication as manifest in at least one of the following areas:

a. delay in or total lack of, development of spoken language that is not accompanied by an attempt to compensate through the use of gestures or mime as an alternative mode of communication (often preceded by a lack of communicative babbling);

b. relative failure to initiate or sustain conversational interchange (at whatever level of language skill is present), in which there is reciprocal responsiveness to the communications of the other person;

c. stereotyped and repetitive use of language or idiosyncratic use of words or phrases;

d. lack of varied spontaneous make-believe play or (when young) social imitative play

3. Restricted, repetitive, and stereotyped patterns of behaviour, interests, and activities are manifested in at least one of the following:

a. An encompassing preoccupation with one or more stereotyped and restricted patterns of interest that are abnormal in content or focus; or one or more interests that are abnormal in their intensity and circumscribed nature though not in their content or focus;

b. Apparently compulsive adherence to specific, nonfunctional routines or rituals;

c. Stereotyped and repetitive motor mannerisms that involve either hand or finger flapping or twisting or complex whole body movements;

d. Preoccupations with part-objects of non-functional elements of play materials (such as their order, the feel of their surface, or the noise or vibration they generate).

C. The clinical picture is not attributable to the other varieties of pervasive developmental disorders; specific development disorder of receptive language (F80.2) with secondary socio-emotional problems, reactive attachment disorder (F94.1) or disinhibited attachment disorder (F94.2); mental retardation (F70-F72) with some associated emotional or behavioural disorders; schizophrenia (F20.-) of unusually early onset; and Rett's Syndrome (F84.12).

According to ICD-10 criteria for AS, language follows typical development and cognitive ability is in the average range or above. There has been much debate

whether AS is synonymous with high-functioning autism (HFA) with some suggesting that AS and HFA are ‘not distinct conditions’ (Wing, 1998, p.23), while others studies, criticised for being confounded by differing diagnostic criteria, report differences in AS and HFA (Szatmari, Archer, Fisman, Streiner, & Wilson, 1995). Atypical autism include features such as late age at onset and atypical symptoms, while in PDD other, autistic features are present, yet criteria for autism, AS and atypical autism are not met.

### **Triad of Impairment**

In their seminal epidemiological study, Wing and Gould (1979) demonstrated the range of features of the syndrome that can be manifested and established the broader spectrum concept. They described the term ‘triad of impairment’ suggesting clusters of core impairments in communication; symbolic, imaginative activities; and social interaction that are perceived as core features of ASC.

Impairment in communication was described in the form of four types of abnormalities: absence of speech; abnormal speech including echolalia; reversal of pronouns; and idiosyncratic use of words and phrases. Abnormalities of symbolic, imaginative activities included complete absence including pretend play; and repetitive, stereotyped symbolic activities. Impairment of social interaction was subdivided into the socially aloof group, where individuals demonstrated aloofness and indifference to others around them; passive group where individuals made no spontaneous contact; active but odd group where spontaneous social contact was made however behaviour was inappropriate; and appropriate interaction group, where individuals’ behaviour was classed as appropriate in relation to their mental age (Wing & Gould, 1979, p.15).

Volkmar, Cohen, Bregman, Hooks, & Stevenson (1989) provide some support of the validity of social subtypes. In their study, children in the ‘aloof’ category had lower intellectual functioning and were younger compared to the passive group, with the ‘active-but-odd’ children on the other pole of the continuum.

## **Emotional Difficulties in ASC**

Emotional difficulties are common in individuals with ASC and rates of anxiety and depression problems are greater than in typically developing peers (Kim, Szarmari, Bryson, Streiner, & Wilson, 2000). Although its exact prevalence is not known, there is evidence to suggest that depression is the most common psychiatric disorder in ASC with rates of 2-37% (Ghaziuddin, Ghaziuddin, & Greden, 2002). White and colleagues (2009) review (White, Oswald, Ollendick, & Scahill, 2009) indicated that between 11% and 84% of children with ASC experience some degree of impairing anxiety. A recent meta-analytic study (van Steensel, Bögels, & Perrin, 2011) revealed that 39.6% of young people with ASC meet DSM-IV-TR (APA, 2000) criteria for at least one comorbid anxiety disorder, including specific phobia (29.8%), OCD (17.4%) and social anxiety disorder (16.6%). There is also evidence to suggest that anxiety is associated with deficits in social interaction (White et al., 2009).

## **Psychological Explanation of ASC**

Although there is much evidence to suggest that ASC has a biological origin, consistent genetic markers have not been defined across individuals with ASC and there is a prominent psychological line of enquiry. This enquiry includes research on Theory of Mind (ToM) (Baron-Cohen, Leslie, & Frith, 1985), i.e. the ability to attribute mental states to others and predict behaviour (Premack & Woodruff, 1978), which is suggested to be at the centre of social and communication difficulties in ASC. Bowler (2007) conjectures that ToM should not be used to explain the impairment but it should rather have a descriptive use. Other theories attempting to explain behaviour in ASC focus on executive function (Pennington & Ozonoff, 1996) and weak central coherence (Hoy, Hatton, & Hare, 2005). Also, a specific deficit in autobiographical memory has been reported (Powell & Jordan, 1992), e.g. individuals with ASC demonstrated better recall of observed events compared to self-experienced events (Hare, Mellor, & Azmi, 2007). It is suggested that autobiographical memory impairment has a developmental association with mentalization abilities (Abell & Hare, 2005; Tager-Flusberg, 1991) and that the combination of impaired autobiographical memory and difficulty to recall personally experienced events has an affect on self-awareness (Verhoeven et al.,



2012).

### **Social Functioning in ASC**

Research focusing on social functioning in ASC provides evidence of social abilities that are impaired in ASC as well as some 'islets of spared social ability' (Rosset et al., 2011, p.954). Deficits in social cognition are present even in individuals with high functioning autism and include difficulties in recognising and expressing thoughts and emotions and using such knowledge to predict behaviour (Baron-Cohen, Wheelwright, Hill, Raste, & Plumb, 2001), which is strongly linked to impairment in communication (Sigman & Ruskin, 1999; Tager-Flusberg & Sullivan, 2000). ASC is associated with a notable impairment in social attention and processing of social cues (Dalton et al., 2005; Gervais et al., 2004). A recent neuroimaging study provides further evidence that social cues in ASC are not assigned the same priority status as in typically developing controls (Greene et al., 2011).

Difficulties with the concept of inter-personal self is demonstrated (Capps, Sigman, & Yirmiya, 1995; Lee & Hobson, 1998) as well as impaired understanding of relationship between self and others (Stern, 1985) and seeing oneself as a part of a social context (Lombardo & Baron-Cohen, 2010). Lee & Hobson's (1998) study also points to a specific abnormality in the sense of self in relation to others. Their participants with ASC did not place their self-descriptions in the context of relationships or social activities, unlike their typically developing peers. Similarly, Hobson (1990) conjectured that children with autism are limited in 'self to other' experience and unable to differentiate their own attitudes from the attitudes of others. He argued that social-relational limitations could result in difficulties in forming a concept of interpersonal relationships by the inability to form and maintain friendships and actually understanding the concept of 'friend' (Hobson, 1993, p.5).

The difficulty with forming and maintaining friendships causes concern in regards to its implications. Kanner describes 'basic desire for aloneness' in individuals with ASC (1943, p. 249), where it may be assumed that aloneness is a desirable and

positive situation for the individual. However it is important to distinguish one's desire to be alone and one feeling alone as a result of lacking the required social skills. Loneliness is the perceived discrepancy between perception of the quality and quantity of actual relationships and relationships one wishes to have (Cassidy & Asher, 1992) and feelings of loneliness have negative consequences on one's well-being (Margalit, 1994). Recent research indicates that adolescents with ASC report higher loneliness rates compared to typically developing peers (Bauminger & Casari, 2000; Bauminger, Shulman, & Agam, 2004; Bossaert, Colpin, Pijl, & Petry, 2012) and although they would like to have more friends they do not feel socially able to do so (Bauminger et al., 2004). Similarly, Attwood (2000) reports that many individuals with ASC are aware of their social disconnectedness and wish they could change their reality. The research of Jobe & Williams White, (2007) indicates that individuals with stronger autistic phenotype report significantly more loneliness and fewer and shorter duration friendships, linked to difficulty in social understanding and social skills. In turn, feelings of loneliness and social inadequacy can be expected to have a negative affect on one's self-concept. In reviewing the literature on social functioning in ASC, as already highlighted in Kanner's work (Kanner, 1943) implicating difficulty in relational relatedness, the impairment of social cognitive skills in ASC would suggest impaired development of self-concept (Bowler, 2007).

### **ASC and Self-Concept**

Studies focusing on perception of disability show negative perceptions of people with ASC (Gray, 2002). In a more recent study, individuals with no experience of ASC expressed negative views about people with the condition, e.g. people with ASC violate social norms, are mentally retarded, cannot live independently, and there are internal and external causes for their disability (Jones, Zahl, & Huws, 2010). Unique cognitive, social, sensory and behavioural impairments of individuals with ASC (Mesibov & Shea, 1996) and the way other perceive and react to these impairments may have a negative effect on their self-concept (Jerome et al., 2002). Common social reaction toward people with ASC may often be unfavourable, which carries a high risk of negative consequences for their self-concept and mental health (Cunningham & Glenn, 2004).

Huws & Jones (2008) describe the complex reaction to diagnosis in children and young people with ASC. Disclosure of a diagnosis is viewed in a positive light by some, allowing one to make sense of previous life experience and providing an explanation of why one behaves in a certain way. Yet in some cases, awareness of diagnosis was described as detrimental and stigmatising, and seen as interfering with one's plans for the future. Some participants demonstrated that they dislike the autism 'label' and wanted to distance themselves from it. It is suggested that disclosure of a diagnosis lead to all participants having to re-evaluate their self-identity and self-concept, similarly to the results of the study of Punshon and colleagues (Punshon, Skirrow, & Murhpy, 2009). Verhoeven's et al. (2012) study highlights difficulties with understanding ASC diagnosis and its implications. Participants know the 'fact' they have a diagnosis, yet lacked understanding of how this is evident in their everyday life. In the study of Jones, Zahl, & Huws (2010) individuals with HFA described predominant negative emotions including fear and apprehension about how others saw them and feelings of loneliness, frustration and depression. Kelly (2005) discussed the pressure individuals with ASC feel under to change and 'fix' their impairment being aware of their difference and negative attitudes from others. Similarly in the study of Ochs and colleagues (2001), adolescents with ASC report frustration as they feel marginalised by their peers who do not understand their condition (Ochs, Kremer-Sadlik, Solomon, & Sirota, 2001). Baines (2012) followed 2 young people with ASC in various social contexts over a period of 2 years to examine how they construe their identities through social interaction. She found that these students demonstrated tendencies to distance themselves from the label of being 'autistic'. Their experiences included being used to the perception of others that there is something 'wrong' with them and the pressure to appear 'normal'. It also highlighted that one is a part of multiple social contexts and how these contexts influence the way individuals construe their identity. Comparing children with ASC with typical developing peers, Capps et al. (1995) reported lower overall perception of self in children with ASC and highlighted the difficulties with interpersonal self-concept in ASC. Participants with higher cognitive ability, better social adaptive behaviours and ability to present emotional experiences viewed themselves as less socially adept.

Finally, there is evidence to suggest that social and interpersonal skills improve as

children with ASC progress through development (Dimitropoulos, Ho, Klaiman, Koenig, & Schultz, 2009; Mesibov & Handlan, 1997) which may facilitate development of positive self-concept. This highlights the importance of understanding self-concept in terms of development. In sum, social functioning ability, perception of sociometric status, awareness and perception of diagnosis all play an important role in the complex process of construing self-concept.

## **WILLIAMS SYNDROME**

WS is a neurodevelopmental disorder caused by a spontaneous microdeletion of a section of chromosome 7q11.23, which can be detected by the Fluorescent in-situ Hybridisation (FISH) test (Meyer-Lindenberg et al., 2006) with prevalence estimates of one in 7,500 births (Stromme, Bjornstad, & Ramstad, 2002). Williams and colleagues first described the syndrome in 1961 (Williams, Barratt-Boyes, & Lowe, 1961) focusing predominantly on distinct facial features, growth retardation and cardiovascular abnormalities, which are typical in WS (80% of individuals with WS). WS is associated with other somatic symptoms such as endocrine, gastrointestinal and orthopaedic problems and neurological problems including coordination difficulties and hypersensitivity to sound (Meyer-Lindenberg et al., 2006). Its distinct cognitive profile is associated with poor performance on intelligence measures and visuospatial deficits (Farran & Jarrold, 2003), and strengths in linguistic abilities (Fishman, Yam, Bellugi, Lincoln, & Mills, 2011) and verbal short-term memory (Mervis, Morris, Bertrand, & Robinson, 1999). A prominent social profile is characterised by high sociability and empathy (Doyle, Bellugi, Korenberg, & Graham, 2004). Even from young age, children with WS are very keen to interact with others (Mervis et al., 2003) and such behaviour even extends to strangers (Jones et al., 2000). While children with WS are very sociable and demonstrate empathy, there are aspects of social understanding that appear impaired. Individuals with WS demonstrate difficulty with their ability to attribute mental states (Sullivan & Tager-Flusberg, 1999), lack of understanding of emotional expressions (Gagliardi et al., 2003), difficulties with communication, social reciprocity and social inhibition (Stojanovik, 2006; Stojanovik & James, 2006), and social decision-making (Fidler, Hepburn, Most, Philofsky, & Rogers, 2007).

Unlike in ASC, individuals with WS demonstrated greater behavioural and emotional difficulties with increasing age and while friendliness and sociability remains a dominant feature, emotional elements such as anxiety or heightened arousal may result in disinhibition with negative affect on social interaction (Dykens, 2000). There is evidence to suggest that young people with WS present difficulties in forming and maintaining friendships (Klein-Tasman, Li-Barber, & Magargee, 2011). Research with adults with WS shows similar findings (Davies, Udwin, & Howlin, 1998; Udwin, 1990).

### **Emotional Difficulties in WS**

Despite the outward gregariousness, WS is associated with high anxiety. Individuals with WS report high rates of symptoms of generalised and anticipatory anxiety with up to 54% of participants meeting the DSM-IV-TR (2000)/ ICD-10 (1992) criteria for anxiety disorders (Kennedy, Kaye, & Sadler, 2006; Leyfer, Woodruff-Borden, Klein-Tasman, Fricke, & Mervis, 2006; Meyer-Lindenberg et al., 2006; Stinton, Elison, & Howlin, 2010; Stinton, Tomlinson, & Estes, 2012). There is research to suggest that individuals with WS report significantly higher rates of anxiety compared to those with ASC, Prader-Willi syndrome, Intellectual Disability of mixed/unknown aetiology and typically developing children (Dimitropoulos et al., 2009; Dykens, 2003). Some studies also reported affective disorders including bipolar disorder, depression and hypomania and psychotic disorders including schizophrenia with rates of 3-25% and 1-2%, respectively (Dodd & Ported, 2009; Kennedy et al., 2006; Stinton et al., 2010).

### **Social Functioning and Positive Interpersonal Bias in WS**

In contrast with ASC, WS is associated with high sociability (Asada & Itakura, 2012). In a study comparing sociability in individuals with WS, ASC, Down syndrome and typically developing individuals, participants with WS were most sociable and ASC were found to be least sociable (Jones et al., 2000). Studies focusing on sociable traits in WS report excessive eye contact, lower frequency of exhibiting negative facial expression (e.g. Jones et al., 2000), more willingness to approach others and initiation of interaction with strangers (Dodd, Porter, Peters, &

Rapee, 2010).

Research in the area of perception of facial expression and appraisal of social information in WS gained much attention in recent years. Faces of those we communicate with provide important information for social interaction and therefore the role of face processing skills is crucial in the development of interpersonal behaviour (Santos, Silva, Rosset, & Deruelle, 2010). There is evidence to suggest that brain activity related to face recognition is abnormally organised in WS. A specific impairment in recognising negative facial expressions is reported (Capitão et al., 2011) with increased activation to positive facial expressions (Haas et al., 2009). Significant hypoactivation of the amygdala when participants with WS are presented with negative facial affect may account for the pattern of decreased social fear (Meyer-Lindenberg et al., 2005). There is further supporting evidence demonstrating higher positive ratings of facial expressions (Frigerio et al., 2006; Porter, Coltheart, & Langdon, 2007), high approachability and trustworthiness ratings for unfamiliar faces (Martens, Wilson, Dudgeon, & Reutens, 2009; Porter et al., 2007) and reduced arousal to negative social images in adolescents and adults with WS (Plesa-Skwerer et al., 2011). Furthermore, there is evidence of absence of anger superiority effect in WS, i.e. angry and threatening faces are more prominent and identified more efficiently than other expressions (Hansen & Hansen, 1988). Interestingly, the anger superiority effect is intact in ASC and AS (Ashwin, Wheelwright, & Baron-Cohen, 2006; Krysko & Rutherford, 2009; Rosset et al., 2011). A recent review comparing ASC and WS reported that overall WS demonstrated higher preference to faces and eye, while findings regarding emotion recognition in the two syndromes are mixed and more research in this area would be beneficial (Asada & Itakura, 2012).

Research on facial expression abnormalities in WS suggests a positive social bias, a more optimistic social judgement, which in turn may have a positive affect on their perception of social self and self-concept. Furthermore, it can be assumed that the unusually friendly, affectionate and charming personality of persons with WS (Dilts, Morris, & Leonard, 1990) together with facial features often described as appealing and cute (Pober & Dykens, 1996) may positively contribute to successful social interactions (Dykens, 2000).

## **WS and Self-Concept**

It is suggested that common social reaction towards adolescents with WS may be influenced by their sociability and hence a sense of acceptance may affect perception of self in those concerned (Evans, 1998). The findings of Plesa-Skwerer and colleagues (Plesa-Skwerer, Sullivan, Joffre, & Tager-Flusberg, 2004) suggest that children and young people with WS view themselves in the context of their relationships with others as a result of their focus on social aspects of their environment. Therefore, they are more advanced in their understanding of self compared to other people with developmental disabilities. Furthermore, positive social reaction from their social group, coupled with positive interpersonal bias, may facilitate more positive construing of self-concept.

Research focusing on self-concept and awareness of WS in self is limited. In a study comparing adolescents and adults with WS and Prader-Willi Syndrome, participants with WS made significantly more positive references to their syndrome. They reported mixed attitudes towards their condition in the light of their social difficulties and health problems such as marginalisation, difficulties establishing long-term relationships, lack of respect from others and need for medical support. Some participants verbalised their wish to be 'normal' (Plesa-Skwerer, et al., 2004).

## **Conclusion**

There have been questions whether WS can be described as 'the other end of the spectrum' alluding to the contrasting ASC and WS phenotypes (Brock, Shiri, & Riby, 1999, p.1). Yet, although there are some distinct differences, considering the review of research in the two syndromes, it can be concluded that impaired social functioning in ASC and 'intact' functioning in WS is a very crude distinction (Brock et al., 1999). While there is much evidence for contrasting phenotypes in face processing and sociability, there are lines of enquiry pointing to similarities and shared characteristics. Similarly to ASC, individuals with WS demonstrate deficits in social cognition and communication skills (Asada & Itakura, 2012) and there is little evidence that mentalization, language ability and face processing are 'preserved' in WS (Brock et al., 1999).

Having reviewed the similarities and contrasting differences in social functioning in the two groups and the limited research on awareness of condition and implications of the above on self-concept, it is clear that our knowledge in this area is incomplete and better understanding of self-concepts and self-perceptions in adolescents with ASC and WS is needed. This study used methods derived from personal construct psychology as there is compelling evidence to support their usefulness in research and clinical practice with individuals with intellectual disability (Maxwell, 2006; Oliver, 1986; Thomas et al., 2011).

The following questions were addressed:

1. How do adolescents with autism and WS perceive themselves?
2. How does perception of self differ in the two conditions?
3. Is awareness and attitude to condition (ASC or WS) related to self-image and/or self-esteem?



## **CHAPTER 3: METHODOLOGY**

### **Aims and Objectives of Chapter Three**

This chapter will provide details of methodology employed in the study. Ethical considerations will be discussed as well as details of selected measures, design and procedure to allow accurate replication.

### **Ethical Considerations**

It is particularly important to consider the issues of informed consent in research with people with intellectual disability (Dye, Hare, & Hendy, 2005). In the present study, a clear focus was given to the process of ensuring each potential participant made an informed choice as to whether to take part. Parents were first approached due to the age of potential participants. Parents were then able to discuss the project with their child and give their consent if they and their child agreed to participate. After obtaining parental consent, the researcher presented the potential participant with the participant information sheet and assent from the adolescent was sought (Appendix 4). Participants in the WS group were usually seen in their home and majority of participants in the ASC group were seen in their school. Participants were informed that they could terminate the session and withdraw from the study at any time without providing an explanation. Participants were assured that all data is confidential and would be stored securely. Ethical approval was granted by the University of Manchester Research Ethics Committee (Appendix 1).

### **Recruitment**

#### *ASC Group*

Ten specialist schools in the North West of England were selected for recruitment on the basis of Specialist School Status and catering for pupils with ASC considering the required age category of 12-18 years of age. School contact details were obtained from the Office for Standards in Education website. One participant

in the ASC group was recruited from a different source. When recruiting WS participants, a parent informed the researcher that she had a son diagnosed with ASC and a daughter with WS. Both of these adolescents were also eligible to participate. The study was also advertised on the National Autistic Society website. There was no response to this advertisement.

#### *Response Rate*

The researcher contacted the Head Teachers by letter explaining the rationale of the study and requesting help in identifying and approaching potential participants. From the ten potential specialist schools approached, one school expressed interest in the project and one school declined participation on the basis of being involved in another study at the time. The remaining eight schools were contacted again via email or telephone, to which two schools responded expressing interest. Following conversations with head teachers of schools who expressed interest, the three schools agreed to participate.

#### *WS Group*

The Williams Syndrome Foundation (WSF) was approached requesting help in identifying and approaching potential participants (age category 12-18 years of age). The WSF provided the researcher with a list of its members in the specified age category who had previously consented to being contacted regarding research projects. Parents of potential participants were contacted by a letter informing them about the study, participant information sheet and a consent form. Information about the study was also published in the Williams News magazine, however no further participants were recruited as a result of this article.

### **Participants**

It was assumed that participants who did not demonstrate their verbal comprehension level to be above 5 years equivalent on the British Picture Vocabulary Scale-II (BPVS) would have difficulties with understanding the assent process and following instructions on the Self-image Profile measure. A score on the British Picture Vocabulary Scale above 5 years range was therefore a part of the inclusion criteria. There was 1 participant, who scored below the 5 years age

equivalent on the BPVS, however she demonstrated a good understanding of the assent process as well as a good understanding of the SIP-A, further supported by relevant details provided in the follow-up interview, where the participant was eloquent in the description of her condition and how she feels about this awareness. Therefore, the decision was made to include the participant in the sample.

Participants were recruited based on the following inclusion and exclusion criteria:

*Inclusion Criteria for Adolescents with ASC*

- Age between 12 and 18
- Formal ASC diagnosis
- Able to communicate in English
- A score on the British Picture Vocabulary Scale above 5 years range

*Inclusion Criteria for Adolescents with WS*

- Age between 12 and 18
- Formal WS diagnosis
- Able to communicate in English
- A score on the British Picture Vocabulary Scale above 5 years range

*Exclusion Criteria*

- Diagnosis of other intellectual disability syndrome (e.g. Downs syndrome)

*Sample Size*

An approximate sample size was established a priori on the basis of power calculations that were undertaken by an internal statistician. It was advised that for 80% power, effect sizes of 0.5, 0.6, 0.7, 0.8, 0.9 and 1 can be detected using a t-test with 5% significance level, and assuming equal group sizes, for groups of size 64, 45, 34, 26, 21 and 17 respectively. Furthermore, it was advised that for 80% power, correlations of 0.3, 0.4, 0.5 and 0.6 can be detected with 5% significance level, with sample sizes of 85, 47, 30 and 20 respectively.

### *Participant Response Rate*

School A, where the researcher was previously employed, provided the researcher with a list of 35 students who met the inclusion criteria. Parents were contacted via a letter and 6 consent forms were returned. Parents that did not respond to the initial letter were contacted via telephone and further 13 consent forms were obtained. Out of the total of 19 parents consenting, 18 students were approached and their assent was sought. One student was not approached, as advised by his teacher, due to behavioural difficulties. Three students declined participation and 1 student was unable to demonstrate due to limited verbal communication. Assent was received from 14 students. Two students completed part of the session with the researcher and then decided they did not want to continue and subsequently withdrew from the study.

Schools B and C took responsibility for distributing letters to parents including a participant information sheet and a consent form (Appendices 2, 3 and 5). Four parental consents were received from school B. Subsequently, consent was received from three students and one student was unable to participate due to limited verbal communication, as advised by a teacher. No parental consent forms were received from school C.

WSF provided the researcher with a list of 98 adolescents in the specified age category. Forty-two parents were chosen based on their geographical location, i.e. travel distance was for the researcher and research assistants was considered, and participants from the following areas were contacted via a letter: North West, North East, Midlands and East England. Eight consent forms were returned. Parents that did not respond to the initial letter were contacted via telephone and further 10 consents were obtained. Four parents preferred for their child to be seen by the researcher at their school. The relevant schools were contacted by the researcher and consent was obtained to conduct the session in the schools. Fourteen participants were seen in their family home. All of the young people with WS gave consent to participate. Thirty-four adolescents participated overall, 16 in the ASC group and 18 in the WS group.

**Table 1: Participant Response Rate – ASC Group**

Source	Information packs distributed	Parent consent given	Student assent given	Student assent declined	Unable to participate	Withdrew from study
School A	35	19	14	3	1	2
School B	20	4	3	0	1	0
School C	7	0	N/A	N/A	N/A	N/A
Other	1	1	1	0	0	0
<b>Total</b>	<b>63</b>	<b>24</b>	<b>18</b>	<b>3</b>	<b>3</b>	<b>2</b>

**Table 2: Participant Response Rate – WS Group**

	Information packs distributed	Parent consent given	Student consent given	Student consent declined	Unable to participate	Withdrew from study
<b>WSF</b>	<b>42</b>	<b>18</b>	<b>18</b>	<b>0</b>	<b>0</b>	<b>0</b>

**Table 3: Students Unable to Participate**

Reason	Frequency
Non-verbal or very limited verbal communication	3

**Measures**

A battery of measures was presented in the order as detailed below.

*The British Picture Vocabulary Scale-II*

The British Picture Vocabulary Scale-II (BPVS) is a widely used, normed-referenced measure with evidence of good validity and reliability (Dunn, Whetton, & Burley, 1997). It assesses receptive vocabulary by presenting participants with four black and white illustrations and asking them to select a picture that illustrates

the word spoken by the researcher. Words represent a range of content areas such as actions, animals, toys and emotions and parts of speech such as nouns, verbs or attributes, across all levels of difficulty. The BPVS-II contains 168 items in 14 sets and only items that cover the participants' critical range are administered.

#### *Wechsler Abbreviated Scale of Intelligence*

Wechsler Abbreviated Scale of Intelligence (WASI) (Wechsler, 1999) is a reliable, nationally standardized measure of intelligence normed with to the Wechsler Adult Intelligence Scale–Third Edition (WAIS-III) (Wechsler, 1997). The WASI has a four-subtest and two-subtest versions and full IQ scores on both of these versions correlate strongly with WAIS-III IQ scores (Strauss, Sherman & Spreen, 2006). The two-subtest format of the WASI was used to provide a brief measurement of participants' general level of cognitive functioning. The two-subtest format comprises of Vocabulary and Matrix Reasoning subtests. In addition to the overall summary score - full scale intelligence quotient (FSIQ), Verbal Intelligence Quotient (VIQ) and Performance Intelligence Quotient (PIQ) are generated.

#### *Measure of Theory of Mind – The Smarties Test*

Although individuals with ASC and WS display contrasting differences in their social and communication profiles, both groups demonstrate difficulties in the ability to infer a range of mental states to others (Tager-Flusberg et al., 2006). The Smarties test (Perner, Frith, Leslie, & Leekam, 1989), a widely used measure of theory of mind (ToM), was used to assess participants' the ability to attribute mental states to self and others (Premack & Woodruff, 1978). Results of the ToM measure were used as an additional descriptor of the sample (Bowler, 2007) and were particularly relevant in relation to participants' awareness of condition.

This enquiry includes research on Theory of Mind (ToM) (Baron-Cohen, Leslie, & Frith, 1985), i.e. the ability to attribute mental states to others and predict behaviour (Premack & Woodruff, 1978), which is suggested to be at the centre of social and communication difficulties in ASC. Bowler (2007) conjectures that ToM

should not be used to explain the impairment but it should rather have a descriptive use.

The Smarties test involves the researcher presenting a Smarties box to the participant, who is asked: "What do you think is in this box?" The participant usually responds: "Smarties or sweets". The researcher then opens the box and shows the participants that there is actually a pencil in the box instead. The researcher puts the pencil back in the box and the participant is then asked a reality prompt: "What's in this box?" and own response prompt: "When I first asked you, what did you say?" Reality prompt question answered 'pencil' and own response prompt answered 'Smarties' is scored as correct self response. A second part of the task includes the researcher asking the following: "Now let's say we are going to get your friend/mum/teacher and ask them the same question. S/he hasn't seen this box. When s/he comes in, I'll show her/him this box just like this and ask: [Name] what's in here? What will [Name] say?" The researcher usually referred to a parent or used the name of a friend or teacher. Reality check questions are then asked: "What is really in the box?" as well own-response check questions: "Do you remember, when I took the box out of my bag [researcher reenacts this] and asked you what was in it, what did you say?" Correct answers are then scored as self correct response plus correct attribution (Crain, 2005; Muris et al., 1999). See (Appendix 6) for order of questions and scoring. Flavell and colleagues (Flavell, Miller, & Miller, 1993) found that children with impaired ToM would assume that an individual who has not seen what is inside the box would share their knowledge and know what the actual contents [i.e. pencil] of the box was, rather than thinking there are Smarties in the box as first believed by the participant.

#### *The Self-Image Profile for Adolescents*

The Self-Image Profile for Adolescents (SIP-A) (Butler, 2001) is based on personal construct theory principles (Kelly, 1955) and Harter's (1999) developmental and organisational aspects of self. It is a self-report measure that investigates the individual's theory of self and provides a visual display of positive and negative self-image revealing how the participants construe themselves. The *SIP-A* also provides a measure of self-esteem, which is estimated by the discrepancy between

ratings of 'How I am' and 'How I would like to be', the real and ideal self. The measure is used in clinical and educational contexts. The SIP-A comprises of 25 self-descriptions e.g. kind, happy, annoying, lazy etc. and participants are asked to score themselves using a 0-6 scale, where 0 means 'not at all' like the description, up to 6 which means 'very much' like the description. Items 1-12 are positive self-descriptions and provide a positive self-image scale score (SI+ve) while items 14-25 are negative self-descriptions and provide negative self-image scale score (SI-ve). Measures of internal consistency were 0.69 and 0.79 for Cronbach's coefficient alpha, for positive and negative self-image respectively. Participants are asked to score themselves 'how they are now' and then 'how they would like to be'. The discrepancy between actual and ideal scores is calculated on all 25 items and the sum of discrepancy scores provides self-esteem (SE) scale score. Also, the SIP-A provides 10 aspects of self-scores (revealed by factorial validity): 'expressive', 'caring', 'outgoing', 'academic', 'emotional', 'hesitant', 'feel different', 'inactive', 'unease', and 'resourceful'. 'Feel different' aspect of self score is a score on item 13, also referred to as 'sense of difference' (SD) scale score. The SIP-A was developed using elicitation techniques as described by Ravenette (1997) and involves asking participants to describe themselves in three ways. A total of 892 pupils, between the ages of 12 and 16 years, from three secondary schools in the Leeds, UK area covering a range of socio-economic status participated in the development of the measure. The SIP-A provides normative data that was used to compare the results of the ASC and WS groups in the current study.

#### *The SIP-A Follow-up Interview*

The follow-up interview focused on exploring constructs such as friendly, confident, feeling different from others, worry a lot etc. by asking participants to elaborate on their self-description scores, e.g. "How come you gave yourself a rating of 'x' on 'friendly'?" Discrepancy between actual and ideal self was also explored by asking questions such as: "You said you would like to be more intelligent. Can you tell me a bit more about that?" The second part of the interview focused on awareness of participants' condition and reaction to this awareness, e.g. "What do you know about ASC/WS?" "How does having WS/ASC make you feel?" "Are there any advantages and disadvantages?" These questions



were previously used by Cunningham and Glenn (2004) in their research with persons with Down's syndrome.

Interviews were recorded on a digital audio device and transcribed verbatim. The following coding criteria, previously used in Cunningham and Glenn (2004), were applied for awareness of condition and reaction to this awareness.

*Awareness of condition* was coded as a) no apparent awareness – participant indicates no awareness by making no response or saying 'I don't know'; b) simple awareness – participant has heard the name of the condition, does not elaborate on his/her awareness, no emotional reaction is demonstrated; c) concrete awareness – participant recognises the term and describes using physical or psychological characteristics (e.g. heart problems, makes me happy, get anxious); e) social – participants demonstrated understanding of social and relational aspects of the condition, compared self to others. *Reaction to awareness* was coded as a) no response – participant did not respond to question or there was no demonstration of awareness; b) positive – participant notes positive aspects of the condition and is proud or glad to have the condition; c) negative – participant lists negative aspects of the condition, wishes to be able to change; and d) mixed – participant lists both positive and negative aspects of the condition.

### **Assessment Procedure**

The researcher and five honorary research assistants (RAs) employed by the University of Manchester were involved in the data collection process. All of the RAs had a BSc (Hons) in Psychology and previous experience of working in the health or social care sector. The researcher, who had previously used the measures employed in this study, provided a thorough training for the RAs. The training involved an initial session covering the background of the study including relevant information about ASC and WS, the notion of self-concept and rationale for the use of PCT elicitation techniques. At this point, the literature review for the project was completed and RAs were provided with this information to gain deeper understanding of relevant issues. The importance of ethical considerations in research with individuals with intellectual disabilities was discussed. The full

research procedure was demonstrated and discussed in detail, which included issues of seeking informed consent, demonstration of administration and scoring of all relevant measures.

Following the initial training, RAs observed the researcher in at least two sessions with a participant prior to them seeing participants on their own. It was ensured that the RAs observed the full assessment procedure including initial meeting with the participant, presenting the adolescent with a participant information sheet, answering any questions and seeking informed consent, and administration of all measures. In these sessions, only one RA was present at a time with the researcher, so that participants would not feel nervous or embarrassed with a group of researchers present. Subsequently, the scoring of all relevant measures was demonstrated and discussed. Following the RAs sessions with participants, supervision was provided in a form of a face-to-face meeting or a telephone conversation.

Participants were seen by the researcher or RA at school or in their family home. In schools, sessions took place in a quiet area that was easily accessible by staff for safety and security reasons. The majority of participants were seen on their own and two participants had a teaching assistant present for concerns regarding their behaviour. Parents were usually present in sessions carried out in family homes.

A set procedure was followed:

1. Introduction, opportunity to establish rapport
2. Reading and discussing the participant information sheet and obtaining consent
3. Completing measures in the following order:
  - a. The Smarties Test
  - b. The SIP-A
  - c. SIP-A follow-up interview
  - d. The BPVS-II
  - e. The WASI- two subtest format
4. Thanking the participant and the opportunity for questions from the participants

The researcher started by introducing themselves and establishing rapport with the participant (e.g. by asking about hobbies). Following the reading and discussion of the participant information sheet and obtaining consent, measures were administered in the above order with flexibility such that if a participant was apparently having difficulties in sustaining attention on a particular measure, the researcher could move on to the next task and complete the other one later on. Both parents and adolescents were asked for permission to record the SIP-A follow-up interview on a digital recorder. One parent did not consent and therefore the conversation with the adolescent was noted on paper. The researcher offered breaks when participants appeared tired or distracted or at their request. All participants with WS completed the assessment in one session. Some participants with ASC completed the assessment in two or three sessions, which was often dependant on their alertness and behaviour presentation, and what lesson was taking place at the time of assessment. The session was concluded by thanking the participant and giving an opportunity for questions. The time spent conducting the research procedure varied between 35 to 50 minutes.

### **Data Storage and Confidentiality**

All data was confidential and was anonymised when entered onto a database and stored on an encrypted CD ROM at the University of Manchester.

## CHAPTER 4: RESULTS AND DATA ANALYSIS

### **Aims and Objectives of Chapter Four**

This research was designed to explore how adolescents with ASC and WS perceive themselves, whether the perception of self differs in the two conditions and whether awareness and attitude to condition (ASC or WS) is related to self-image and/or self-esteem. The Self-image Profile for Adolescents (SIP-A) (Butler, 2001) based on personal construct theory, comprising of 25 self-descriptions, was used to explore the participants' self-concept and a follow-up interview explored awareness and attitude to their condition. This section will summarise demographic characteristics of the sample followed by exploration of the data. Inferential statistics will explore between-group differences and correlation analyses will explore associations between scores on the SIP-A and performance on additional measures. P level used for statistical significance will be  $p = .05$ .

### **Demographic Characteristics**

Thirty-four adolescents participated in the study (11 female, 23 male). There were 16 participants in the ASC group (3 female, 13 male) and 18 participants in the WS group (8 female, 10 male). The mean age of the whole sample was 16 years 4 months (SD = 1 years 11 months) with a mean verbal comprehension level (as assessed by the BPVS) of 9 years 2 months (SD= 2 years 8 months), 95% CI [8 years 5 months, 9 years 11 months]. Mean IQ level shown by the WASI was 64, 95% CI [59, 72]. The mean age of the ASC group sample was 15 years 9 months (SD= 2 years 3 months) with a mean verbal comprehension level of 10 years 2 months (SD= 2 years 6 months), 95% CI [9 years 4 months, 10 years 11 months]. Mean IQ score was 70, 95% CI [65, 78]. The mean age of the WS group sample was 16 years 10 months (SD= 1 year 6 months) with a mean verbal comprehension level of 8 years 4 months (SD= 2 years 6 months), 95% CI [7 years 7 months, 9 years 1 month]. Mean IQ level shown by the WASI was 59, 95% CI [54, 67]. Female participants had lower IQ scores than males in the sample as a whole (mean= 58, SD= 7; mean= 66, SD= 10), ( $U = 69.5$ ,  $p = .034$ ). Sample characteristics are summarised in Table 1.

**Table 1: Sample Characteristics**

Group	N	Gender F:M	IQ	IQ conf. levels	Chronol. age (SD)	BPVS verbal compreh. level (SD)	BPVS confidence levels
Whole sample	34	11:23	64	59 - 72	16:4 (1:11)	9:2 (2:8)	8:5 – 9:11
ASC	16	3:13	70	65 - 78	15:9 (2:3)	10:2 (2:6)	9:4 – 10:11
WS	18	8:10	59	54 - 67	16:10 (1:6)	8:4 (2:6)	7:7 – 9:1

**Exploration of Data**

To inform selection of statistical analyses it was initially examined whether parametric assumptions had been met. A two-sample Kolmogorov-Smirnov test revealed variables that did not meet the assumptions of normality. In the ASC group, assumptions were violated by self-esteem scores ( $p = .002$ ) and aspects of self-scores: ‘caring’ ( $p = .033$ ) and ‘academic’ ( $p = .027$ ). In the WS group, sense of difference ( $p = .02$ ), IQ scores ( $p = .001$ ) and aspects of self-scores: ‘caring’ ( $p = .033$ ), ‘outgoing’ ( $p = .002$ ), ‘academic’ ( $p = .005$ ), ‘hesitant’ ( $p = .001$ ), ‘inactive’ ( $p = .018$ ) and ‘unease’ ( $p = .001$ ) did not meet the assumptions of normality. Non-parametric tests were therefore indicated.

**ASC and WS Group Comparisons**

A two-tailed Mann-Whitney test revealed a significant difference between IQ scores in the two groups. IQ scores for the ASC group (mean= 70, SD= 9) were significantly higher than for the WS group (mean= 59, SD= 7), ( $U = 48$ ,  $p = .001$ ). This difference between Vocabulary task scores for the ASC group (mean= 23, SD= 4) and the WS group (mean= 21, SD= 3) was not significant ( $U = 89$ ,  $p = .059$ ). Matrix reasoning task scores for the ASC group (mean = 36, SD= 10) were significantly higher than for the WS group (mean= 23, SD= 7), ( $U = 53$ ,  $p = .001$ ). This difference between BPVS verbal comprehension level for the WS group (mean= 8 years 4 months, SD= 2 years 6 months) and the ASC group (mean= 10 years 2 months, SD= 2 years 6 months) was not significant ( $U = 87$ ,  $p = .050$ ). Summary of between-group comparison is show in Table 2.

**Table 2: Summary of Between-Group Comparison**

	Mean (SD)		Inferential Statistics	
	ASC	WS	Mann-Whitney's U	p-value (2-tailed)
IQ	70 (9)	59 (7)	48	.001
Vocabulary	23 (4)	21 (3)	89	.059
Matrix reasoning	36 (10)	23 (7)	53	.001
BPVS	10:2 (2:6)	8:4 (2:6)	87	.050

*Theory of Mind Scores Comparison*

The Smarties test is a measure of theory of mind (ToM). In the ASC group, 2 participants gave incorrect responses, 3 gave correct self responses and 11 gave correct self responses and correct attributions. In the WS group, 2 participants gave incorrect responses, 6 gave correct self responses and 10 gave correct self responses and correct attributions. The percentage of participants scoring incorrect, correct self response and correct self response plus correct attribution did not differ significantly in the two groups ( $\chi^2 (2) = .933, p = .627$ ). Summary of ToM scores comparison is shown in Table 3.

**Table 3: Theory of Mind Scores Comparison**

	Frequency (percent)	
	ASC	WS
Incorrect	2 (12.5%)	2 (11.1%)
Correct self response	3 (18.8%)	6 (33.3%)
Correct self response + correct attribution	11 (68.5%)	10 (55.6%)

Spearman's rho revealed a positive correlation between the BPVS scores and IQ ( $r = .557, p = .001$ ), and BPVS scores and scores on the ToM measure ( $r = .547, p = .001$ ). The correlation between IQ and ToM scores was not significant ( $r = .259, p = .139$ ). Also in the ASC group, BPVS scores correlated with IQ ( $r = .506, p = .046$ ) and ToM scores ( $r = .519, p = .039$ ). In the WS group, BPVS scores correlated with IQ ( $r = .528, p = .024$ ) and ToM scores ( $r = .538, p = .021$ ).

## **How did adolescents with autism and WS perceive themselves and how did perception of self differ in the two conditions?**

### *SIP-A Self-description Scores*

Participants scored themselves on the 25 self-descriptions on the SIP-A using a 0-6 scale, where 0 means 'not at all' like the description, up to 6 which means 'very much' like the description. Items 1-12 are positive self-descriptions. In the ASC group participants' means scores on these items varied from 3.81 (SD= 2.37) on 'sporty' to 5.00 (SD= 1.15) on 'happy' and in the WS group from 4.17 (SD= 2.36) on 'sporty' to 5.61 (SD= .85) on 'happy' and 5.61 (SD= .70) on 'fun to be with'. Both ASC and WS groups scored very closely on item 13 that reflects a sense of difference from others (mean= 2.88, SD= 2.78; mean= 2.89, SD= 2.37, respectively). Items 14-25 are negative self-descriptions. In the ASC group participants' means scores on these items varied from 1.56 (SD= 2.00) on 'annoying' to 2.94 (SD= 1.98) on 'worry a lot' and in the WS group from 1.50 (SD= 1.72) on 'mess about' to 4.28 (SD= 2.08) on 'worry a lot'. The 25 self-descriptions on the SIP-A were compared in the two groups and no significant differences were found except on 'funny' (U= 216, p= .012).

Normative data from the SIP-A was used and matched with participants on age and gender. Discrepancy between self-description scores in the ASC and WS groups and self-description normative scores was calculated. Mean discrepancy scores are detailed in Table 4. Positive scores on discrepancy from normative data indicate that ASC and WS group scored above the normative mean, negative scores indicated scores below the normative mean. On all positive self-descriptions, except 'sporty', participants in both groups reported higher mean scores compared to normative data. As for negative self-descriptions, participants in both groups reported lower scores compared to normative data, except for 'worry a lot' and 'short tempered'. Discrepancy scores were compared in the two groups and no significant differences were found except on 'funny' (U= 84.5, p= .039) and 'good looking' (U= 84.0, p= .039). Summary of SIP-A self-descriptions are show in Table 4

**Table 4: SIP-A Self-description Scores**

Constructs	Mean (SD)		Inferential Statistics	
	ASC	WS	Mann-Whitney's U	p-value (2-tailed)
Kind	4.94 (1.18)	4.89 (1.68)	158.5	.621
ND Discrepancy	1.01 (1.16)	.83 (1.65)	139.0	.878
Happy	5.00 (1.15)	5.61 (.85)	193.0	.095
ND Discrepancy	.89 (1.15)	1.47 (.86)	102.5	.154
Friendly	4.88 (1.26)	5.33 (.97)	173.5	.313
ND Discrepancy	.85 (1.25)	1.22 (.98)	123.5	.484
Funny	3.93 (1.77)	5.22 (1.44)	216.0	<b>.012</b>
ND Discrepancy	.11 (1.78)	1.35 (1.40)	84.5	<b>.039</b>
Helpful	4.56 (1.71)	5.50 (.85)	188.5	.126
ND Discrepancy	.88 (1.72)	1.70 (.86)	117.5	.365
Hard Working	4.06 (2.11)	5.17 (1.29)	184.0	.175
ND Discrepancy	.07 (2.17)	1.15 (1.41)	108.0	.224
Talkative	4.63 (1.93)	5.06 (1.39)	163.5	.506
ND Discrepancy	.58 (1.86)	.87 (1.48)	129.5	.621
Confident	4.44 (1.41)	5.00 (1.61)	188.5	.126
ND Discrepancy	.87 (1.48)	1.54 (1.75)	91.5	.070
Sporty	3.81 (2.37)	4.17 (2.36)	160.5	.574
ND Discrepancy	-.04 (2.46)	.79 (2.29)	115.5	.330
Intelligent	4.69 (1.08)	4.94 (1.63)	182.0	.198
ND Discrepancy	.67 (1.25)	.92 (1.68)	123.5	.484
Fun to be with	4.63 (1.82)	5.61 (.70)	186.0	.154
ND Discrepancy	.70 (1.85)	1.69 (.69)	108.0	.224
Good Looking	4.65 (1.50)	5.44 (.86)	193.5	.088
ND Discrepancy	1.47 (1.55)	2.56 (1.05)	84.0	<b>.039</b>

ND discrepancy – Discrepancy from normative data (age and gender matched)



Constructs	Mean (SD)		Inferential Statistics	
	ASC/ ND	WS/ ND	Mann-Whitney's U	p-value (2-tailed)
Feeling Different from others	2.88 (2.78)	2.89 (2.37)	142.5	.959
ND Discrepancy	.16 (2.11)	-.11 (2.33)	160.5	.574
Lazy	2.19 (2.14)	2.28 (2.35)	147.0	.932
ND Discrepancy	-.45 (2.18)	-.50 (2.35)	147.0	.932
Annoying	1.56 (2.00)	1.56 (2.01)	139.5	.878
ND Discrepancy	-.87 (2.03)	-1.02 (1.97)	159.0	.621
Moody	1.63 (1.89)	2.11 (2.25)	159.5	.597
ND Discrepancy	-.57 (1.93)	-.37 (2.28)	141.0	.932
Mess about	1.88 (1.89)	1.50 (1.72)	124.5	.506
ND Discrepancy	-1.18 (1.91)	-1.59 (1.72)	165.0	.484
Shy	2.13 (2.03)	1.22 (2.05)	99.5	.126
ND Discrepancy	-.16 (2.07)	-1.20 (2.07)	196.0	.075
Cheeky	2.50 (2.10)	1.72 (2.08)	110.0	.251
ND Discrepancy	-.23 (2.11)	-1.1 (2.09)	191.0	.109
Loud	2.56 (2.13)	2.72 (2.22)	150.5	.825
ND Discrepancy	-.22 (2.20)	-.20 (2.50)	141.5	.932
Sarcastic	2.44 (2.13)	2.11 (2.30)	127.0	.574
ND Discrepancy	-.15 (2.31)	-.78 (2.21)	168.0	.422
Worry a lot	2.94 (1.98)	4.28 (2.08)	199.0	.059
ND Discrepancy	.24 (2.07)	1.29 (2.04)	99.0	.126
Bossy	2.00 (1.93)	1.89 (2.37)	129.0	.621
ND Discrepancy	-.01 (1.92)	-.33 (2.48)	172.0	.374
Short Tempered	2.00 (2.03)	3.06 (2.41)	180.0	.224
ND Discrepancy	-.68 (2.02)	.30 (2.40)	109.5	.237
Get Bored	2.63 (2.09)	3.28 (2.24)	166.0	.463
ND Discrepancy	-1.16 (2.09)	-.48 (2.24)	120.5	.422

ND discrepancy – Discrepancy from normative data (age and gender matched)

### *SIP-A Scale Scores*

Positive self-image scores below the cut-off scores of 19 to 30 (depending on gender and age) would be a cause for concern. Mean positive self-image scores in the ASC group (mean= 54.87, SD= 12.75) and in the WS group (mean= 61.89, SD= 8.30) are significantly above the cut-off scores demonstrating high positive self-image. No participants scored below the cut-off score. Negative self-image scores above the cut-off scores of 54 to 59 (depending on gender and age) would be a cause of concern. Mean negative self-image scores in the ASC group (mean= 28.07, SD= 12.96) and in the WS group (mean= 27.83, SD= 13.63) are significantly below the cut-off scores. No participants scored above the cut-off score. Self-esteem scores above the cut-off scores of 62 to 79 (depending on gender and age) would be a cause of concern demonstrating a high discrepancy between 'How I am' and 'How I would like to be'. Mean self-esteem scores in the ASC group (mean= 19.27, SD= 19.62) and in the WS group (mean= 13.89, SD= 8.62) are significantly below the cut-off scores reflecting a positive self-esteem. No participants scored below the cut-off score. Discrepancy between mean scale scores in the two groups and normative data (age and gender matched) was calculated. Normative means scores and discrepancy mean scores are detailed in Table 5. Positive self-image scores in both the ASC and WS groups were higher than the normative data, however the discrepancy score on positive self-image in the ASC group (mean= 9.02, SD= 12.94) was significantly lower than in the WS group (mean= 16.32, SD= 8.68), ( $U = 202.5, p = .042$ ). Negative self-image score in both groups were lower than compared to normative data. Self-esteem scores were lower than normative data, indicating lower discrepancy between real and ideal self and therefore higher self-esteem. Sense of difference in the two groups was similar to the normative data. It is important to note that there were great differences in individual scores. Positive self-image scores varied from 26 to 72, negative self-image from 0 to 54 and self-esteem from 0 to 66.

There were no significant differences in positive self-image, negative self-image, sense of difference and self-esteem scores between the ASC and WS groups. The ASC group reported higher discrepancy between 'actual' and 'ideal' self (self-esteem score), (mean= 19.27; SD= 19.62) compared to the WS group (mean= 13.89; SD= 8.62). This difference was not significant ( $U = 126; p = .762$ ). The ASC

group reported lower positive self-image (mean= 54.87; SD= 12.75) compared to the WS group (mean= 61.89; SD = 8.30). This difference was not significant ( $U= 199$ ;  $p= .059$ ). The ASC and WS groups scored closely on negative self-image (mean= 28.07; SD= 12.96), (mean = 27.83; SD= 13.63), ( $U= 156.5$ ;  $p= .670$ ); and sense of difference (mean= 2.87; SD= 2.34), (mean= 2.89; SD= 2.37), ( $U= 142.5$ ;  $p= .762$ ) respectively. Both in the ASC and WS groups, related samples Wilcoxon signed rank test revealed a significant difference between positive and negative self-image scores ( $W(16)= -3.352$ ,  $p= .001$ ;  $W(18)= -3.682$ ,  $p= .001$ ). Kruskal-Wallis H test was used to explore differences in means in the ASC and WS groups and normative data. There was a significant effect of group for positive self-image ( $H(2)= 29.70$ ,  $p= .001$ ) with a mean rank of 40.00, 52.67 and 22.29; negative self-image ( $H(2)= 6.32$ ,  $p= .042$ ) with a mean rank of 26.53, 30.58 and 40.32; and self-esteem ( $H(2)= 38.01$ ,  $p= .001$ ) with a mean rank of 22.00, 16.72 and 47.88 for ASC, WS group and normative data respectively. Significant effect of group was not found for sense of difference ( $H(2)= .416$ ,  $p= .812$ ). Summary of SIP-A Scale Scores is show in Table 5.

**Table 5: SIP-A Scale Scores**

Scores	Mean (SD)		Inferential Statistics	
	ASC	WS	Mann-Whitney's U	p-value (2-tailed)
SI +ve	54.87 (12.75)	61.89 (8.30)	199.0	.059
ND SI +ve	45.85 (1.69)	45.56 (1.94)	-	-
SI +ve ND Discrepancy	9.02 (12.94)	16.32 (8.68)	202.5	<b>.042</b>
SI -ve	28.07 (12.96)	27.83 (13.63)	156.5	.670
ND SI -ve	31.79 (2.66)	33.55 (2.12)	-	-
SI -ve ND Discrepancy	-3.72 (13.49)	-5.72 (14.15)	141.00	.932
SE	19.27 (19.62)	13.89 (8.62)	126.0	.762
ND SE	34.24 (2.14)	35.17 (2.38)	-	-
SE ND Discrepancy	-14.98 (19.51)	-21.28 (8.22)	109.00	.361
SD	2.87 (2.34)	2.89 (2.37)	142.5	.959
ND SD	2.72 (.40)	3.00 (.27)	-	-
SD ND Discrepancy	.16 (2.11)	.11 (2.33)	160.5	.574

Positive self-image (SI+ve), Negative Self-image (SI-ve), Self-esteem (SE), Sense of difference (SD), Normative data (ND)

### *SIP-A Aspects of Self-Scores*

The SIP-A provides 9 aspects of self-scores. Both ASC and WS group mean scores were below normative data on 'expressive', 'emotional', 'hesitant', 'inactive' and 'resourceful' aspects of self-scores, and above normative data on 'caring', 'outgoing', 'academic' and 'unease'. There were no significant differences in aspects of self-scores between the ASC and WS group. There were no significant differences in the discrepancy from normative data scores in the ASC and WS group. Kruskal-Wallis H test was used to explore differences in means in the ASC and WS groups and normative data. There was a significant effect of group for the following aspects of self-scores: 'caring' ( $H(2)= 37.31, p= .001$ ) with mean ranks of 45.56, 51.81 and 20.13; 'outgoing' ( $H(2)= 18.47, p= .001$ ) with mean rank scores of 40.28, 48.03 and 24.62; 'academic' ( $H(2)= 11.36, p= .003$ ) with mean rank scores of 36.16, 46.53 and 27.35; 'hesitant' ( $H(2)= 12.60, p= .002$ ) with a mean rank of 29.78, 23.33 and 42.63; 'unease' ( $H(2)= 9.66, p= .008$ ) with a mean rank of 32.62, 46.58 and 28.99; and 'resourceful' ( $H(2)= 6.84, p=.003$ ) with a mean rank of 24.03, 34.17 and 39.60 for ASC group, WS group and normative data respectively. Summary of SIP-A aspects of self-scores are show in Table 6.

**Table 6: SIP-A Aspects of Self-Scores**

Scores	Mean (SD)		Inferential Statistics	
	ASC	WS	Mann-Whitney's U	p-value (2-tailed)
Expressive	2.69 (1.16)	2.43 (1.02)	126.5	.551
ND Discrepancy	-.12 (1.24)	-.522 (1.08)	172.0	.347
Caring	4.75 (.97)	5.33 (.83)	200.5	.050
ND Discrepancy	.81 (.95)	1.31 (.82)	91.0	.070
Outgoing	4.30 (1.33)	4.68 (1.31)	173.5	.313
ND Discrepancy	.64 (1.35)	1.17 (1.36)	98.5	.117
Academic	4.38 (1.43)	5.06 (1.11)	188.5	.126
ND Discrepancy	.37 (1.56)	1.10 (1.30)	102.5	.154
Emotional	1.84 (1.73)	2.53 (2.02)	170.0	.384
ND Discrepancy	-.60 (1.74)	-.12 (2.02)	123.5	.484
Hesitant	1.56 (1.22)	1.11 (1.41)	113.0	.297
ND Discrepancy	-.75 (1.26)	-1.30 (1.40)	176.5	.266
Inactive	2.19 (2.14)	2.28 (2.35)	147.0	.932
ND Discrepancy	-.45 (2.18)	-.54 (2.35)	148.0	.905
Unease	2.94 (1.98)	4.28 (2.08)	199.0	.059
ND Discrepancy	.24 (2.07)	1.33 (2.02)	97.5	.109
Resourceful	2.63 (2.16)	3.44 (2.09)	175.5	.281
ND Discrepancy	-1.16 (2.14)	-.33 (2.10)	114.5	.313

Correlational analyses were carried out to explore relationships between scale scores. Controlling for age, gender and IQ, there was a positive correlation between negative self-image and sense of difference ( $r = .871$ ,  $p = .001$ ); negative self-image and self-esteem ( $r = .736$ ,  $p = .006$ ); and self-esteem and sense of difference ( $r = .601$ ,  $p = .039$ ) in the ASC group. Controlling for age, gender and IQ, there was a positive correlation between negative self-image and sense of difference ( $r = .533$ ,  $p = .041$ ) in the WS group. There was no significant correlation between negative self-image and self-esteem ( $r = .096$ ,  $p = .733$ ); and self-esteem and sense of

difference ( $r = .359$ ,  $p = .188$ ) in the ASC group. There was a positive correlation between age and self-difference scores ( $r = .547$ ,  $p = .019$ ) in the WS group. Correlational analysis was also carried out to explore relationships between scale scores and aspects of self-scores. Summary of SIP-A scale scores and aspects of self-scores correlational analyses for ASC and WS groups are shown in Tables 7 and 8.

**Table 7: ASC Correlational Analysis Scale Scores and Aspects of Self-scores**

	SI+ve	SI-ve	SD	SE	Exp.	Car.	Out.	Acad.	Emot.	Hes.	Inac.	Uneas.	Res.
SI+ve	-	-.008 .979	-.112 .729	-.103 .749	.104 .748	.856 <b>.001</b>	.874 <b>.001</b>	.443 .149	-.006 .985	-.350 .265	-.046 .888	-.231 .470	-.122 .705
SI-ve	-.008 .979	-	.871 <b>.001</b>	.736 <b>.006</b>	.831 <b>.001</b>	-.087 .789	-.093 .773	-.064 .843	.855 <b>.001</b>	.503 .096	.592 <b>.042</b>	.558 .059	.552 .063
SD	-.112 .729	.871 <b>.001</b>	-	.601 <b>.039</b>	.863 <b>.001</b>	-.211 .511	-.096 .767	-.170 .598	.718 <b>.009</b>	.607 <b>.036</b>	.466 .127	.551 .064	.362 .248
SE	-.103 .749	.736 <b>.006</b>	.601 <b>.039</b>	-	.458 .134	-.211 .511	-.152 .636	-.004 .990	.669 <b>.017</b>	.513 .088	.622 <b>.031</b>	.610 <b>.035</b>	.537 .072
Expressive	.104 .748	.831 <b>.001</b>	.863 <b>.001</b>	.458 .134	-	-.144 .656	.177 .582	-.321 .309	.600 <b>.039</b>	.280 .378	.661 <b>.019</b>	.386 .215	.399 .198
Caring	.856 <b>.001</b>	-.087 .789	-.211 .511	-.211 .511	-.144 .656	-	.535 .073	.728 <b>.007</b>	-.079 .806	-.373 .232	-.466 .127	-.218 .497	-.188 .558
Outgoing	.874 <b>.001</b>	-.093 .773	-.096 .767	-.152 .636	.177 .582	.535 .073	-	.028 .930	-.116 .720	-.281 .376	.201 .532	-.294 .353	-.069 .832
Academic	.443 .149	-.064 .843	-.170 .598	-.004 .990	-.321 .309	.728 <b>.007</b>	.028 .930	-	.051 .876	-.113 .727	-.571 .052	.043 .895	-.416 .178
Emotional	-.006 .985	.855 <b>.001</b>	.718 <b>.009</b>	.669 <b>.017</b>	.600 <b>.039</b>	-.079 .806	-.116 .720	.051 .876	-	.611 <b>.035</b>	.520 .083	.531 .076	.318 .314
Hesitant	-.350 .265	.503 .096	.607 <b>.036</b>	.513 .088	.280 .378	-.373 .232	-.281 .376	-.113 .727	.611 <b>.035</b>	-	.272 .393	.423 .170	.201 .531
Inactive	-.046 .888	.592 <b>.042</b>	.466 .127	.622 <b>.031</b>	.611 <b>.019</b>	-.466 .127	.201 .532	-.571 .052	.520 .083	.272 .393	-	.243 .447	.560 .058
Unease	-.231 .470	.558 .059	.551 .064	.610 <b>.035</b>	.386 .215	-.218 .497	-.294 .353	.043 .895	.531 .076	.423 .170	.243 .447	-	-.018 .955
Resourceful	-.122 .705	.552 .063	.362 .248	.537 .072	.399 .198	-.188 .558	-.069 .832	-.416 .178	.318 .314	.201 .531	.560 .058	-.018 .995	-



**Table 8: WS Correlational Analysis Scale Scores and Aspects of Self-scores**

	SI+ve	SI-ve	SD	SE	Exp.	Car.	Out.	Acad.	Emot.	Hes.	Inac.	Uneas.	Res.
SI+ve	-	-.453 .090	-.436 .105	-.385 .157	-.072 .798	.826 <b>.001</b>	.068 .811	.685 <b>.005</b>	-.526 .004	-.572 <b>.026</b>	-.156 .579	-.292 .291	-.267 .335
SI-ve	-.453 .090	-	.533 <b>.041</b>	.096 .733	.750 <b>.001</b>	-.302 .274	-.498 .059	-.414 .125	.613 <b>.015</b>	.569 <b>.027</b>	<b>.780</b> <b>.001</b>	.604 <b>.017</b>	.725 <b>.002</b>
SD	-.436 .105	.533 <b>.041</b>	-	.359 .188	.545 <b>.036</b>	-.185 .509	-.382 .160	-.388 .153	.115 .684	.485 .067	.294 .287	.419 .120	.513 .051
SE	-.385 .157	.096 .733	.359 .188	-	-.016 .956	-.324 .239	-.348 .204	-.065 .819	.140 .619	.390 .150	.001 .997	.045 .873	.280 .313
Expressive	-.072 .798	.750 <b>.001</b>	.545 <b>.036</b>	-.016 .956	-	-.051 .856	-.258 .353	-.325 .273	.245 .378	.216 .440	.473 .075	.219 .434	.596 <b>.019</b>
Caring	.826 <b>.001</b>	-.302 .274	-.185 .509	-.324 .239	-.051 .856	-	-.112 .690	.582 <b>.023</b>	-.543 <b>.036</b>	-.361 .186	-.063 .823	.014 .961	-.092 .774
Outgoing	.068 .811	-.498 .059	-.382 .160	-.348 .204	-.258 .353	-.112 .690	-	-.098 .729	-.230 .410	-.205 .464	-.234 <b>.004</b>	-.423 .116	-.536 <b>.039</b>
Academic	.685 <b>.005</b>	-.414 .125	-.388 .153	-.065 .819	-.325 .273	.582 <b>.023</b>	-.098 .729	-	-.459 .085	-.039 .891	-.234 .401	-.083 .769	-.224 .422
Emotional	-.572 <b>.044</b>	.613 <b>.015</b>	.115 .684	.140 .619	.245 .378	-.543 <b>.036</b>	-.230 .410	-.459 .085	-	.313 .256	.404 .135	.244 .381	.295 .285
Hesitant	-.572 <b>.026</b>	.569 <b>.027</b>	.485 .067	.390 .150	.216 .440	-.361 .186	-.205 .464	-.039 .891	.313 .256	-	.254 .360	.473 .075	.327 .235
Inactive	-.156 .579	.780 <b>.001</b>	.294 .287	.001 .997	.473 .075	-.063 .823	-.697 <b>.004</b>	-.234 .401	.404 .135	.254 .360	-	.457 .087	.525 <b>.044</b>
Unease	-.292 .291	.604 <b>.017</b>	.419 .120	.045 .873	.219 .434	.014 .961	-.423 .116	-.083 .769	.244 .381	.473 .075	.457 .087	-	.578 <b>.024</b>
Resourceful	-.267 .335	.725 <b>.002</b>	.513 .051	.280 .313	.596 <b>.019</b>	-.092 .774	-.539 <b>.039</b>	-.224 .422	.295 .285	.327 .235	.525 <b>.004</b>	.578 .024	-

**Is awareness and attitude to condition (ASC or WS) related to self-image and/or self-esteem?**

In the ASC group, one parent did not want the researcher to ask their child about their condition (6.25%). One participant (6.25%) did not complete the interview due to expressive language difficulties. Six participants demonstrated no awareness of their condition (37.5%). One participant demonstrated simple awareness (6.3%). Three participants demonstrated concrete awareness (12.5%); e.g. *“It’s something like kids are different from the outside world because they act in different ways”*; *“It is for disabled people who go to special school”*. Four participants demonstrated social-relational awareness (25%); e.g. *“I sometimes don’t know what to say in conversation...for example when my dad is speaking with all of his friends I don’t know what to say but you know I do interact.”* Nine participants did not demonstrate a reaction to awareness to their condition (56.3%). One participant (6.3%) demonstrated a positive response: *“When my mum told me that I have autism, honestly now that I know about this autism, I really am getting a feel of kind of special, like a special jewel.”* Five participants (31.3%) demonstrated a negative response; e.g. *“I do get a bit jealous of mainstream, I would rather be mainstream...what I’d prefer is if everyone would like stop rubbing it into me that I’m like autistic ‘cause I don’t really like to know I am autistic.”* One participant demonstrated a neutral response (6.3%) to their awareness of condition.

In the WS group, one parent did not want the researcher to ask their child about their condition (5.6%). Six participants demonstrated no awareness of their condition (33.3%). No participants demonstrated simple awareness. Five participants (27.8%) demonstrated concrete awareness; e.g. *“When I was a little baby I got WS...I think I had heart problems”*. Six participants (33.3%) demonstrated social-relational awareness; e.g. *“People think you are special when you have it”*; *“I used to talk to a lot to strangers, that’s part of Williams Syndrome.”* Seven participants did not demonstrate a reaction to awareness to their condition (38.9%). Five participants (27.8%) demonstrated a positive response; e.g. *“It’s just that God made me with that...I know I was born with it and I know that I can’t change it but I know it makes me beautiful”*. Four participants (22.2%)

demonstrated a negative response; e.g. *“I feel quite embarrassed. I wish I didn’t happen. It’s not something I wanted...it makes me feel awful.”* Two participants (11.1%) demonstrated a mixed response to their awareness of condition; e.g. *“I’d just like to be like other people and go out with my friends and go to parties. I think I would be all right if I had a friend who was like me and could come to my house to play. They don’t, they are just nasty to me...I’m made up I’m not normal, so I don’t have to go to the party drinking”*. There were no significant differences in the distribution of awareness ( $H(1) = .716, p = .397$ ) and reaction to awareness ( $H(1) = .350, p = .554$ ) across the two groups. In the WS group 8 participants used physical characteristics when describing WS (e.g. heart problems, difficulties with walking etc.). There were no such descriptions in the ASC group. Both in the ASC and WS groups, there were no correlations between awareness of condition and self-image and/or self-esteem, nor between reaction to awareness and self-image and/or self-esteem. Summary of awareness and reaction to awareness scores are shown in Table 9.

**Table 9: Awareness and Reaction to Awareness Scores**

		Frequency (percent)	
		ASC	WS
Awareness	Did not complete interview task	2 (12.5)	1 (5.6)
	No apparent awareness	6 (37.5)	6 (33.3)
	Simple	1 (6.3)	0 (0)
	Concrete	3 (18.8)	5 (27.8)
	Social	4 (25)	6 (33.3)
Reaction to awareness	No response	9 (56.3)	7 (38.9)
	Positive	1 (6.3)	5 (27.8)
	Negative	5 (31.3)	4 (22.2)
	Mixed	1 (6.3)	2 (11.1)
Physical	Physical description	0 (0)	8 (44.4)

In order to carry out Fisher’s exact test to determine association between the awareness and reaction to awareness, ‘awareness’ scores were collapsed as follows:

‘Yes’ including simple, concrete and social awareness, and ‘No’ including ‘no apparent awareness’ and participants who did not complete the interview. ‘Reaction to awareness’ scores were collapsed as follows: ‘No’ including ‘no response’ and ‘Yes’ including ‘neutral’, ‘positive’, ‘negative’ and ‘mixed’ responses. The percentage of participants having awareness of their condition did not differ significantly in the ASC and WS groups ( $p = .730$ ). The percentage of participants demonstrating a reaction to awareness of their condition did not differ significantly in the ASC and WS groups ( $p = .492$ ). Summary of awareness and reaction to awareness collapsed scores are shown in Table 10.

**Table 10: Summary of Awareness and Reaction to Awareness Collapsed Scores**

		Frequency (percent)	
		ASC	WS
Awareness	No	8 (50)	7 (38.9)
	Yes	8 (50)	11 (61.1)
Reaction to awareness	No	9 (56.3)	7 (38.9)
	Yes	7 (43.8)	11 (61.1)

A correlational analysis was carried out to explore the relationship between awareness of condition and results on the Theory of Mind task. Controlling for age, gender and IQ, there was a positive correlation between awareness of condition and results on the Theory of Mind task ( $r = .400$ ,  $p = .026$ ) in the whole sample. Controlling for age, gender and IQ in the WS group, there was also a positive correlation ( $r = .697$ ,  $p = .004$ ). Awareness of condition and results on the Theory of Mind task did not correlate in the ASC group ( $r = .083$ ,  $p = .787$ ).

As a large number of analyses was conducted, it is important to note that the likelihood of Type I error is increased. Bonferroni correction commonly carried out to reduce this likelihood was considered, however it is suggested that there are limitations to its use that outweigh its benefits. Nakagawa (2004) argues against the

use of Bonferonni correction as it increases the probability of making a Type II error and reduces statistical power. This is predominantly the case with the standard Bonferonni procedure but also with the sequential procedure. Furthermore, there is no formal consensus of when Bonferonni correction should be used. In the light of these limitations it was decided that Bonferonni correction would not be used and that data would be interpreted with caution.

## CHAPTER 5: DISCUSSION AND CONCLUSIONS

### **Aims and Objectives of Chapter Five**

This section will focus on theoretical and clinical implications of the findings relating to each of the three research questions stated in the introduction, followed by consideration of the limitations of the study and a critically appraisal of the study. Finally, ideas for further research will be considered.

It is important to highlight that the results discussed in this chapter are preliminary and to bear in mind the risk of over-interpretation. Due to the small sample size and confounding variables, e.g. differences in age, gender and IQ scores between the two groups, further research would be required to explore self-concepts in adolescents with ASC and WS.

### **How do adolescents with autism and WS perceive themselves and how does perception of self differ in the two conditions?**

#### *SIP-A Self-descriptions*

SIP-A normative data (age and gender matched) was compared to ASC and WS scores. Participants in both groups reported higher scores than normative scores on all positive items, except on 'sporty', and lower scores on all negative items, except on 'worry a lot' in both groups and 'short tempered' in ASC group, demonstrating higher positive self-image and lower negative self-image than their typically developing peers. Although not statistically significant, all of the positive self-descriptions scores except 'kind' were higher in the WS group, suggesting that adolescents in this group construe their self-image very positively. Unlike in the case of positive self-descriptions where WS group reported higher scores on the majority of items, higher negative self-descriptions were spread more evenly across the two groups, suggesting that construing the self in negative terms is similar, although less negative when compared to normative data. Positive and negative self-image differences will be further discussed when considering SIP-A scale scores.

There were no significant differences in how participants construed themselves in the two groups other than on the item ‘funny’. Participants with WS reported themselves to be significantly more ‘funny’ than participants in the ASC group. When compared to the normative data, there were significant differences for the ‘funny’ and ‘good looking’ self-descriptions. Significantly higher scores on ‘funny’ in the WS group may be attributed to the notion that perceiving oneself as ‘funny’ requires an immediate reaction from other people. Possibly due to the extroverted and sociable nature of people with WS, they receive more positive response from social interactions and in turn construe themselves as significantly more ‘funny’ than those with ASC, who are known to experience difficulties with social interaction (Lee & Hobson, 1998; Capps et al. 1995). No significant differences on items such as ‘fun to be with’ and ‘friendly’ may support the notion that unlike ‘funny’, these descriptions may be understood as *not* requiring immediate reaction from others and therefore they are construed differently.

Participants in the WS group reported higher scores on ‘worry a lot’ self-description, supporting previous findings that individuals with WS report significantly higher rates of anxiety compared to those with ASC (Dimitropoulos et al., 2009; Dykens, 2003). It is important to note a possible gender bias (more male participants in the ASC group), as the normative scores on this item are higher for females than males (Butler, 2001).

#### *SIP-A Scale Scores*

There were no significant differences in the SIP-A scale scores (positive and negative self-image, sense of difference and self-esteem) between the two groups. However, although not statistically significant, the WS group reported higher self-esteem and higher positive self-image. Furthermore, the positive self-image discrepancy with regard to normative data was significantly higher for the WS group compared to the ASC group, thus reflecting a more positive self-image. Negative self-image was similar in the two groups, although lower WS group scores compared to normative data indicated a less negative construing of the self. Both groups scored very similarly with respect to sense of difference.

Higher self-esteem and positive self-image scores as well as significantly higher positive self-image discrepancy and lower negative self-image discrepancy from normative data in the WS group indicates that individuals with WS in the present study construed their sense of self in a more positive light. As previously discussed, high sociability and friendliness coupled with appealing facial features may facilitate successful social interactions. It can be postulated that this has a positive affect on self-construing. In addition, research focusing on appraisal of social information and perception of facial expression in WS provides evidence of reduced arousal to negative social images (Plesa-Skwerer et al., 2011), impairment in recognising negative facial expressions (Capitão et al., 2011) and increased activation to positive facial expressions (Haas et al., 2009). Such positive social bias may contribute to a more optimistic social judgement and perception of the self. The trend of more positive self-construing in the WS group may also be influenced by the fact that participants in the WS group had lower IQ and BPVS scores and therefore an overly positive perception of self may be affected by lack of self-awareness (Verhoeven et al., 2012), as is typically observed in earlier stages of development (Harter, 1999).

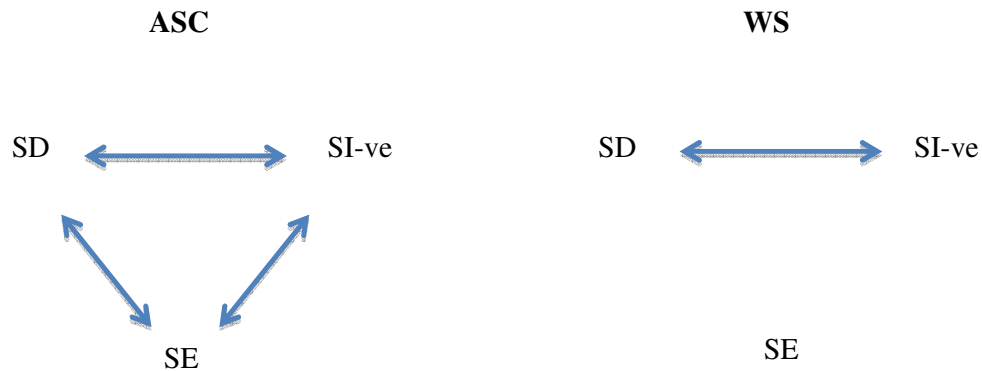
It is important to note that there were great differences in individual scores. Positive self-image scores varied from 26 to 72, negative self-image from 0 to 54 and self-esteem from 0 to 66. Therefore, caution is required when making definite distinctions between the groups as the varying scores highlight the uniqueness of construing the self in each individual.

#### *Sense of Difference*

There was a strong positive correlation between sense of difference and negative self-image and self-esteem in the ASC group. Compared to the WS group, there was only a moderate correlation between sense of difference and negative self-image, however no correlation with self-esteem, as demonstrated in Figure 1.



**Figure 1: Relationships between sense of difference (SD), self-esteem (SE) and negative self-image (SI-ve)**



Sense of difference from others on the SIP-A reflects the participant’s sense of uniqueness (Butler, 2001). The sense of uniqueness, or ‘separatedness’ or ‘distinctness’ to use James’ (1961) terminology, is one of the four types of ‘I’ experience, the abstract component of self. Scores on ‘sense of feeling different from others’ were almost identical in the two groups and were also very close to normative data. The results suggest that although the social phenotypes in the two conditions are very different, the sense of difference from others is not condition dependent, and it is similar to typically developing adolescents.

It is important to bear in mind whom the participants compare themselves to, as we know that sociometric status, i.e. comparison to those in one’s social group, plays an important role in one’s self-esteem and psychological well being (Anderson et al., 2012). The majority of participants attended a school with a special education status. In the interviews, some participants disclosed that they previously attended a mainstream school and their experience of feeling accepted was very different to being around those with the same condition or other disability. In the ASC group, 75% participants attended a school for children with ASD. The inclusion criteria, i.e. receptive language ability above 5 years age equivalent on the BPVS meant that participants with lower functioning abilities who were unable to take part in the research, were part of the group of peers our participants could compare themselves too. This was apparent in some interviews where participants reported that they are on the ‘mild end of autism’ or that others are ‘too autism’. The majority of

participants with WS also attended a school with a special education status and could compare themselves to other young people with intellectual disability, however not necessarily WS. This may influence their sense of difference from others, as evidenced in some interviews, where participants referred to their syndrome being as 'rare' or 'special'. When elaborating on their sense of difference, 44% of the WS participants used physical descriptions, e.g. facial features, heart condition and coordination difficulties as distinctive factors. Feeling different from others because of a physical characteristic (e.g. heart problem, facial features) as opposed to feeling different because of difficulties in one's social interaction may lead to distinct ways in construing the self. Furthermore, when reporting sense of difference, some participants compared themselves to their siblings or parents, or their friends outside of school. It is therefore important to bear in mind the context one uses when comparing to others and construing sense of uniqueness and separatedness.

The findings suggest that feeling more different from others is related to negative self-image. The absence of a relationship between self-esteem and self-image/sense of difference in the WS group may be attributed to positive social response to individuals with WS coupled with positive social bias as discussed above.

#### *SIP-A Aspects of Self-scores*

The SIP-A provides ten aspects of self-scores are based on the theoretical underpinning that construing is multidimensional. There were no significant differences in the ASC and WS group aspects of self-scores. Compared to normative data, both of the groups scored higher on caring, outgoing, academic and resourceful aspects of self-scores, which reflects consistently higher scores on positive self-descriptions. Lower scores on 'hesitant' aspect of self score reflects lower scores on negative self-descriptions.

#### **Is awareness and attitude to condition related to self-image and/or self-esteem?**

Awareness of condition and reaction to this awareness were explored in the SIP-A follow up interview and no correlation between these variables and self-image

and/or self-esteem was found. However, it is important to be mindful of the low numbers of participants, especially the low numbers of individuals who demonstrated a reaction to their awareness of condition. More participants would be needed to explore awareness and attitude to condition and whether these are related to self-image and self-esteem. Due to the low number of participants, awareness and reaction to awareness categories were collapsed, yet no associations with self-image and/or self-esteem were found.

#### *The Role of Cognitive Functioning*

There was a negative relationship between self-esteem and IQ score, and self-esteem and BPVS age equivalent. Harter conjectured that as children develop, they distinguish different domains of self and become more realistic in their comparisons to others (Harter, 1999). It is therefore suggested that individuals with higher IQ scores and receptive language ability may have more awareness of their condition and ability to compare self to others, which in turn may lead to greater discrepancy between the real and ideal self, i.e. low self-esteem. As IQ and BPVS scores were higher in the ASC group, this could have contributed to lower self-esteem and self-image scores.

#### **Implications on Existing Theory**

In exploring self-concepts in ASC and WS, conditions presenting with contrasting social and communication profiles, the role of social functioning in construing the sense of self is highlighted. The results demonstrate a trend of more positive self-construing in participants with WS, whose social profile is characterised by high sociability and empathy and consequently a likely positive social feedback from others. These findings support the importance of interpersonal functioning and peer acceptance and its positive affect on perception of self (Harter, 1999; Thomaes et al., 2010).

There is evidence to suggest that negative self-esteem is related to psychopathology (e.g. Coudeville et al., 2011; Courtney et al., 2008; Harter, 1993) and it can therefore be assumed that a more positive self-construing, as observed in WS, may be protective of mental health difficulties. No studies comparing mental health

difficulties in ASC and WS have been identified. While there is evidence reporting depression as the most common psychiatric disorder in ASC with rates of 2-37% (Ghaziuddin, Ghaziuddin, & Greden, 2002), there is a small number of studies reporting depression in WS with rates of 3-25% (Dodd & Ported, 2009; Kennedy et al., 2006; Stinton et al., 2010). Although the limited research suggesting lower rates of depression in WS compared to ASC supports the assertion that a more positive self-construing may be protective of negative affect and depression, more research is needed to explore the role of self-concept in ASC and WS and its association with depression.

Despite the more positive self-construing in WS, a notable feature of the condition is a disposition to high anxiety (Meyer-Lindenberg et al., 2006), with some studies reporting higher rates of anxiety in WS than in ASC (Dimitropoulos et al., 2009; Dykens, 2000). It is important to note that unlike in ASC, anxiety in WS is often non-social/object-related and this is associated with increased amygdala reactivity (Meyer-Lindenberg et al., 2006). This mechanism offers a possible explanation of the higher rates of non-social anxiety in WS compared to ASC. More research is required to compare psychopathology in ASC and WS and to explore the role of positive and negative self-concept in mental health in the two groups.

Interestingly, when compared to typically developing peers, participants in the two conditions had higher positive self-image and self-esteem and lower negative self-image. It is suggested that lower aggregate cognitive functioning in the two groups (IQ scores from 54 - 78) can account for such overly positive self-construing, which is typical in earlier stages of development. It is therefore expected that participants followed the typical developmental progression in their perception of self (Harter, 1999).

### **Applied Implications**

The SIP-A was a useful tool to explore how participants construe their self-image and self-esteem. Even with participants with ASC who demonstrated impaired social communication skills, the measure proved to be a very good aid to helping participants express their view of self with minimal use of language. This group

may present difficulties with other techniques where more language is needed e.g. Ravenette's three way technique (1997), which involves asking participants to describe themselves in three ways, used to develop the SIP-A, and therefore the measure is recommended as it overcomes possible communication difficulties.

Results of the present study support the notion that social functioning plays a central role in the development of positive self-concept. It is suggested that behavioural and emotional problems reduce as children with ASC progress through development, while individuals with WS demonstrated greater behavioural and emotional difficulties with increasing age which may have a negative affect on social interaction (Dimitropoulos et al., 2009; Dykens, 2000). This points to the need for tailored educational and clinical interventions, enhancing communication and social skills, encouraging to form and maintain friendships and in turn promoting positive self-image and self-esteem. At the same time, it is important to point to the drawbacks of therapeutic interventions implying the need to 'normalise' behaviour and highlighting the impairment rather than difference (Brownlow, 2010).

### **Critical Analysis of Study**

The study has several limitations with respect to generalisability and the depth of data gained from interviews.

#### *Generalisability*

There were difficulties with recruitment of participants in both groups. The total number of participants was lower than established a priori on the basis of power calculations (40 per group), which limits the generalisability of the study. In the WS group, it was required that a large geographical area was to be covered in the data collection process. More time and resources would be necessary to increase the number of participants. Possibly a 'snowballing' technique could have been employed in addition to using contacts provided by the WSF. Final numbers of participants in the ASC group were lower than expected due to the low response rate from schools approached. Furthermore, a diagnostic tool was not used to screen

participants in the ASC group, therefore participants may have not met the same diagnostic criteria, possibly leading to heterogeneity of the group.

Non-parametric analyses were used due to abnormal distribution of some variables. As non-parametric analyses are less sensitive at detecting an effect than parametric analyses, the ability to detect a significant difference in the two groups was limited. The groups were not equal in size and the ratio of males and females in each group was different which may have impacted on the results. Also, cognitive ability and age were differed in the two groups. To overcome this, gender, IQ and age were controlled for when completing correlational analyses. It can be argued that differences in the cognitive ability in the two groups could have contributed to the lack of statistical difference between groups. To reduce such bias in future research, it may be considered to match participants on their cognitive ability. This may however prove difficult considering the nature of a contrasting cognitive profile in individuals with ASC and WS, e.g. better visuo-spatial abilities demonstrated in ASC while WS demonstrates better verbal abilities (Brock, Shiri, & Riby, 1999).

The confounding variables noted above, lower number of participants than established a priori on the basis of power calculations and limitations associated with sample characteristics may all negatively contribute to the generalisability and power of the findings. In the light of the limitations of the current study, it is important to use caution when interpreting these preliminary results. Yet, there were some significant differences revealed in the two groups as well as significant associations between variables, when controlling for age, gender and IQ score. Replication of the study with a higher number of participants would be beneficial to further explore self-concepts in ASC and WS. It would also be desirable to match the two groups and perform parametric analyses to minimise the possibility of Type II error.

#### *Depth of Information Gained in Interviews*

There were five research assistants involved in the data collection procedure. The researcher completed the assessment with 21 participants and the remaining 13 participants were seen by one or two RAs following training on administration of

measures and observing the researcher completing the research procedure. The SIP-A follow up interview is based on how the young person scores him/herself on the measure and on exploring the discrepancies between actual and ideal self, followed by questions about the participants awareness of their condition. A semi-structured interview schedule was followed, however as the researchers had to be flexible and react on the individual information provided from each participant, there are differences the way some questions are asked and consequently in the depth and richness of data in those interviews. Some of the differences may be explained by the participant not being able or willing to elaborate on questions asked, however there were instances when participants were asked closed or potentially leading questions. Following the receipt of the transcripts, the researcher addressed this style of questioning with the relevant RAs. Answers to leading and closed questions were not included in the coding process. In the future, such issues can be overcome with more training and opportunities to provide feedback and reflect on the data collection process.

### **Further Research**

The findings and limitations of the study indicate areas of enquiry for further research. First, interviews in the current study were analysed to answer questions regarding awareness and attitude to condition, however there were more data provided on how participants construed their sense of self and the discrepancies between real and ideal self. Analysis of these data was beyond the scope of this MPhil project, however further analysis is planned to explore these accounts, e.g. mentalistic, affective and relational references, references to self agency etc. It was earlier referred to the importance of being mindful as to whom the participants compare themselves to when construing themselves in their social context. In future research, it would be beneficial to have more information about participants' educational history, e.g. whether they had previously attended mainstream school, reasons for transition to a special status school etc. Secondly, it would be beneficial to follow-up the current sample/or conduct a longitudinal study to explore changes and trends in the development of self-concepts from childhood to adolescence and adulthood. Third, it would also be beneficial to investigate parents' perception and

understanding on their child's sense of self, information about how they informed their child about diagnosis, their reaction and attitude to their condition. Similar questions were asked in the study of Cunningham and Glenn (2004) with individuals with Downs syndrome. This information would be valuable in further exploration of self-concepts in individuals with ASC and WS, gaining information on parental observations and contrasting children's reports of awareness of condition to parents' perspective of children's awareness.

### **Conclusions**

The results of the current study suggest a trend of more positive construing of self in adolescents with WS. It was argued that a likely positive social reaction towards individuals with WS coupled with positive social bias may be attributed to a more positive perception of self. Implications on existing theory were considered and positive self-construing and mental health links were discussed. Clinical implications highlighted the usefulness of the SIP-A measure in clinical work with individuals with ASC and WS and others with intellectual disability. It was concluded that higher numbers of participants would be needed to establish a link between awareness and attitude to condition and self-image/self-esteem.

Positive self-concept is closely linked with positive life outcomes and therefore further research is needed to identify areas that would benefit from input to enhance self-concept and maximise quality of life. The developmental trajectory of self-concept was highlighted and it was suggested that with behavioural and emotional problems changing with increasing age in the two conditions, there is a need for tailored interventions to promote positive self-concept and to communicate effectively with children and adolescents about their condition and how they view themselves in its light.



## References:

- Abell, F., & Hare, D. J. (2005). An experimental investigation of the phenomenology of delusional beliefs in people with Asperger syndrome. *Autism: the international journal of research and practice*, *9*(5), 515–31. doi:10.1177/1362361305057857
- Altermatt, E., & Pomerantz, E. (2003). The development of competence-related and motivational beliefs: An investigation of similarity and influence among friends. *Journal of Educational Psychology*, *95*, 111–23.
- American Psychiatric Association. (2004). *Diagnostic and statistical manual of mental health disorders (4th ed, text rev.)*. Washington DC: Author.
- Anderson, C., John, O. P., Keltner, D., & Kring, A. M. (2001). Who attains social status? Effects of personality traits and physical attractiveness in social groups. *Journal of Personality and Social Psychology*, *81*, 116–132.
- Anderson, Cameron, Kraus, M. W., Galinsky, A. D., & Keltner, D. (2012). The Local-Ladder Effect: Social Status and Subjective Well-Being. *Psychological science*, (May). doi:10.1177/0956797611434537
- Asada, K., & Itakura, S. (2012). Social Phenotypes of Autism Spectrum Disorders and Williams Syndrome: Similarities and Differences. *Frontiers in psychology*, *3*(July), 247. doi:10.3389/fpsyg.2012.00247
- Asher, S. R., & Coie, J. D. (1990). *Peer rejection in childhood*. Cambridge, UK: Cambridge University Press.
- Ashwin, C., Wheelwright, S., & Baron-Cohen, S. (2006). Finding a face in the crowd: Testing the anger superiority effect in Asperger Syndrome. *Brain and Cognition*, *61*(1), 78–95. Retrieved from <http://dx.doi.org/10.1016/j.bandc.2005.12.008>
- Asperger, H. (1944). Die Autistischen Psychopathen im Kindesalter. *Archiv für Psychiatrie und Nervenkrankheiten*, *117*, 76–136.
- Attwood, T. (2000). Strategies for improving the social integration of children with Asperger syndrome. *Autism*, *4*, 85–100.
- Baccus, J. R., Baldwin, M. W., & Packer, D. J. (2004). *Increasing implicit self-esteem through classical conditioning*. *Psychological Science*, *15*, 498–502. Blackwell Publishing. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/15200636>
- Bailey, A., Phillips, W., & Rutter, M. (1996). Autism: towards an integration of clinical, genetic, neuropsychological, and neurobiological perspectives [Review]. *Journal of child psychology and psychiatry*, *37*, 89–126.

- Baines, A. (2012). Positioning, strategizing, and charming: how students with autism construct identities in relation to disability. *Disability & Society*, (July), 37–41. Retrieved from <http://www.tandfonline.com/doi/abs/10.1080/09687599.2012.662825>
- Baldwin, J.(1902). *Social and ethical interpretations in mental life*. New York: MacMillan.
- Baron-Cohen, S, Wheelwright, S., Hill, J., Raste, Y., & Plumb, I. (2001). The “Reading the Mind in the Eyes” Test Revised Version: A ... and Adults with Asperger Syndrome or High-functioning Autism. *Journal of Child Psychology and Psychiatry*, 24(2), 241–251.
- Baron-Cohen, S., Leslie, A. M., & Frith, U. (1985). Does the autistic child have a “theory of mind”? *Cognition*, 21(1), 37–46.
- Baron-Cohen, S., Scott, F. J., Allison, C., Williams, J., Bolton, P., Matthews, F. E., & Brayne, C. (2009). Prevalence of autism-spectrum conditions: UK school-based population study. *The British Journal of Psychiatry*, 194(6), 500–509. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/19478287>
- Baumeister, R. F., & Leary, M. R. (1995). The need to belong: Desire for interpersonal attachments as a fundamental human motivation. *Psychological Bulletin*, 117, 497–529.
- Bauminger, N., & Casari, C. (2000). Loneliness and Friendship in High-Functioning Children with autism. *Child Development*, 71(2), 447–456.
- Bauminger, N., Shulman, C., & Agam, G. (2004). The Link Between Perceptions of Self and of Social Relationships in High-Functioning Children with Autism. *Journal of Developmental and Physical Disabilities*, 16(2), 193–214. doi:10.1023/B:JODD.0000026616.24896.c8
- Björck, C., Clinton, D., Sohlberg, S., Hällström, T., & Norring, C. (2007). Negative self-image and outcome in eating disorders: Results at 3-year follow-up. *Eating behaviors*, 8(3), 398–406.
- Björck, Caroline, Clinton, D., Sohlberg, S., Hällström, T., & Norring, C. (2003). Interpersonal profiles in eating disorders: ratings of SASB self-image. *Psychology and psychotherapy*, 76(4), 337–349. Retrieved from <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=med4&NEWS=N&AN=14670185>
- Bleuler, E. (1911). *Dementia Praecox*. New York: International Universities Press.
- Booth, M., & Gerard, J. (2011). Self-Esteem and Academic Achievement: A Comparative Study of Adolescent Students in England and the United States. *Journal of Comparative and International Education*, 41(5), 629–648.

- Borden, M. C., & Ollendick, T. H. (1994). An examination of the validity of social subtypes in autism. *Journal of autism and developmental disorders*, 24(1), 23–37. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/8188571>
- Bos, A. E. R., Huijding, J., Muris, P., Vogel, L. R. R., & Biesheuvel, J. (2010). Global, contingent and implicit self-esteem and psychopathological symptoms in adolescents. *Personality and Individual Differences*, 48(3), 311–316. doi:10.1016/j.paid.2009.10.025
- Bos, A. E. R., Muris, P., Mulken, S., & Schaalma, H. P. (2006). Changing self-esteem in children and adolescents: a roadmap for future interventions. *Netherlands Journal of Psychology*, 62(1), 26–33. doi:10.1007/BF03061048
- Bossaert, G., Colpin, H., Pijl, S. J., & Petry, K. (2012). Loneliness among students with special educational needs in mainstream seventh grade. *Research in developmental disabilities*, 33(6), 1888–1897. doi:10.1016/j.ridd.2012.05.010
- Bowler, D. M. (2007). *Autism spectrum disorders: Psychological theory and research*. Memory 49, 894. Wiley. Retrieved from <http://search.ebscohost.com/login.aspx?direct=true&db=psych&AN=2007-01548-000&site=ehost-live>
- Bretheron, I. (1991). Pouring new wine into old bottles: The social self as internal working model. In G. M.R. & L. A. Sroufe (Eds.), *Minnesota Symposia on Child Development: Vol.23. Self processes and development* (pp. 1–41). Hillsdale: Erlbaum.
- Brewer, S., & Cutting, X. (1976). No Title. In M. Rosezweig & A. Leiman (Eds.), *Physiological Psychology*. New York: Random House.
- Brock, J., Shiri, E., & Riby, M. D. (1999). The other end of the spectrum? Social cognition in Williams syndrome. In T. Striano & V. Reid (Eds.), *Social cognition: Development, Neuroscience, and Autism* (p. 1–13). Oxford: Blackwell.
- Brownlow, C. (2010). Presenting the self: negotiating a label of autism. *Journal of intellectual developmental disability*, 35(1), 14–21. Retrieved from <http://oro.open.ac.uk/21373/>
- Butler, R. J., & Green, D. (1998). *The child within: The exploration of personal construct theory with young people*. Woburn, MA: Butterworth-Heinemann.
- Butler, R. J., & Green, D. (2007). *The Child Within; Taking the Young Persons Perspective by Applying Personal Construct Psychology* (2nd ed.). Oxford: Butterworth-Heinemann.
- Butler, R. J., Redfern, E., & Forsythe, W. (1990). The child's construing of nocturnal enuresis: a method of inquiry and prediction of outcome. *Journal of child psychology and psychiatry*, 31(3), 447–454.

- Butler, R. J., Redfern, E. J., & Holland, P. (1994). Children's notions about enuresis and the implications for treatment. *Scandinavian journal of urology and nephrology Supplementum*, *163*, 39–47.
- Butler, R. J. (2001). *The Self-image Profiles For Children & Adolescents*. London: Harcourt Assessment.
- Butler, R. J. (2006). Investigating the content of core constructs. *Personal Construct Theory & Practice*, *3*, 27–33.
- Butler, R. J., & Gasson, S. L. (2005). Self-esteem/Self-concept Scales for Children and Adolescents: A Review. *Child and Adolescent Mental Health*, *10*(4), 190–201. doi:10.1111/j.1475-3588.2005.00368.x
- Butler, Richard J., & Gasson, S. L. (2006). Development of the Self-Image Profile for Adults [SIP-AD]. *European Journal of Psychological Assessment*, *22*(1), 52–58. doi:10.1027/1015-5759.22.1.52
- Bybee, J., & Zigler, E. (1991). Self-image and guilt: a further test of the cognitive-developmental formulation. *Journal of personality*, *59*(4), 733–45. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/1774617>
- Byrne, B. M. (1996). Academic self-concept: Its structure, measurement, and relation to academic achievement. In B. A. Bracken (Ed.), *Handbook of self-concept* (pp. 287–316). New York: Wiley.
- Capitão, L., Sampaio, A., Fernández, M., Sousa, N., Pinheiro, A., & Gonçalves, Ó. F. (2011). Williams syndrome hypersociability: a neuropsychological study of the amygdala and prefrontal cortex hypotheses. *Research in developmental disabilities*, *32*(3), 1169–79. doi:10.1016/j.ridd.2011.01.006
- Capps, L., Sigman, M., & Yirmiya, N. (1995). Self-competence and emotional understanding in high-functioning children with autism. *Development and Psychopathology*, *7*(1), 137–149. doi:10.1017/S0954579400006386
- Case, R. (1991). Stages in the development of young child's first sense of self. *Developmental Review*, *11*, 210–230.
- Cassidy, J., & Asher, S. R. (1992). Loneliness and peer relations in young children. *Child Development*, *63*, 350–365.
- Cooley, C. H. (1902). *Human nature and the social order*. New York: Scribner.
- Coopersmith, S. (1967). *The antecedents of self-esteem*. San Francisco: W. H. Freeman.
- Coudevylle, G. R., Gernigon, C., & Martin Ginis, K. A. (2011). Self-esteem, self-confidence, anxiety and claimed self-handicapping: A mediational analysis. *Psychology of Sport and Exercise*, *12*(6), 670–675. doi:10.1016/j.psychsport.2011.05.008

- Courtney, E., Gamboz, J., & Johnson, J. (2008). Problematic eating behaviors in adolescents with low self-esteem and elevated depressive symptoms. *Eating behaviors*, 9(4), 408–414.
- Crain, W. (2005). *Theories of development: Concepts and applications*. Upper Saddle River, NJ: Pearson Prentice Hall.
- Craven, R. G., & Marsh, H. W. (2008). The centrality of the self-concept construct for psychological wellbeing and unlocking human potential: Implications for child and educational psychologists. *Education and Child Psychology*, 25(2), 104-118.
- Crocker, J., & Wolfe, C. T. (2001). Contingencies of self-worth. *Psychological Review*, 108(3), 593–623. Retrieved from <http://doi.apa.org/getdoi.cfm?doi=10.1037/0033-295X.108.3.593>
- 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
- Dalgas-Pelish, P. (2006). Effects of a self-esteem intervention program on school age children. *Paediatric Nursing*, 32, 341–348.
- Dalton, K. M., Nacewicz, B. M., Johnstone, T., Schaefer, H. S., Gernsbacher, M. A., Goldsmith, H. H., Alexander, A. L., et al. (2005). Gaze fixation and the neural circuitry of face processing in autism. *Nature Neuroscience*, 8, 519–526.
- Dalton, P., & Dunnett, G. (1999). *A psychology for living*. Lostock Hall: EPCA Publications.
- Damon, W., & Hart, D. (1982). The development of self-understanding from infancy through adolescence. *Child Development*, 53, 841–864.
- Damon, W., & Hart, D. (1988). *Self-understanding in Childhood and Adolescence*. Cambridge: Cambridge University Press.
- Davies, M., Udwin, O., & Howlin, P. (1998). Adults with Williams syndrome. Preliminary study of social, emotional and behavioural difficulties. *The British Journal of Psychiatry*, 172, 273–276. Retrieved from <http://ezaccess.libraries.psu.edu/login?url=http://search.proquest.com/docview/619299022?accountid=13158>
- Dijksterhuis, A. (2004). I like myself but I don't know why: Enhancing implicit self-esteem by evaluative conditioning. *Journal of Personality and Social Psychology*, 86, 345–355.

- Dilts, C. V., Morris, C. A., & Leonard, C. O. (1990). Hypothesis for development of a behavioural phenotype in Williams syndrome. *American Journal of Medical Genetics*, *36*, 126–131.
- Dimitropoulos, A., Ho, A. Y., Klaiman, C., Koenig, K., & Schultz, R. T. (2009). A Comparison of Behavioral and Emotional Characteristics in Children with Autism, Prader-Willi Syndrome, and Williams Syndrome. *Journal of Mental Health Research in Intellectual Disabilities*, *2*(3), 220–243.
- Dodd, H. F., & Ported, M. A. (2009). Psychopathology in Williams Syndrome: The Effect of Individual Differences Across the Life Span. *Journal of Mental Health Research in Intellectual Disabilities*, *2*(2), 89–109.
- Dodd, H. F., Porter, M., Peters, G. L., & Rapee, R. M. (2010). Social approach in pre-school children with Williams syndrome: the role of the face. *Journal of intellectual disability research: Journal of Intellectual Disability Research*, *54*, 194–203.
- Doyle, T. F., Bellugi, U., Korenberg, J. R., & Graham, J. (2004). Everybody in the world is my friend” Hypersociability in young children with Williams syndrome. *American Journal of Medical Genetics A*, *124*, 263–273.
- Dubois, D. L., Burk-Braxton, C., Swenson, L. P., Tevendale, H. D., Lockerd, E. M., & Moran, B. L. (2002). Getting by with a little help from self and others: Self-esteem and social support as resources during early childhood. *Developmental Psychology*, *38*(822-39).
- Dunn, L. M., Whetton, C., & Burley, J. (1997). *British Picture Vocabulary Scale II*. Windsor, UK: NFER-Nelson Publishing.
- Dye, L., Hare, D. J., & Hendy, S. (2005). Capacity of people with learning disabilities to consent to take part in a research study. *Autism*, *9*(5), 515–31.
- Dykens, E. M. (2000). Personality- motivation: new ties to Psychopathology, etiology, and intervention. In E. Zigler & D. Bennett-Gates (Eds.), *Personality Development in Individuals with Mental Retardation* (pp. 249–270). Cambridge, UK: Cambridge University Press.
- Dykens, E. M. (2003). Anxiety, fears, and phobias in persons with Williams syndrome. *Developmental Neuropsychology*, *23*(1-2), 291–316. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/12730029>
- Elmer, N. (2001). *Self-esteem. The costs and causes of low self-worth*. Yorn: Joseph Rowntree Foundation.
- Erickson, E. (1959). Identity and the life cycle. *Psychological Issues*, *1*, 18–64.
- Erickson, E. (1968). *Identity: Youth and crisis*. New York: Norton.

- Erol, R. Y., & Orth, U. (2011). Self-esteem development from age 14 to 30 years: A longitudinal study. *Journal of Personality and Social Psychology, 101*(3), 607–619. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/21728448>
- Evans, D. W. (1998). Development of the self-concept in children with mental retardation: Organismic and contextual factors. In J. A. Burack, R. M. Hodapp, & E. Zigler (Eds.), *Handbook of mental retardation and development* (pp. 462–489). New York: Cambridge University Press.
- Evans, D. W., Brody, L., & Noam, G. (1995). Self-perceptions of adolescents with and without mood disorder: Content and structure. *Journal of child psychology, psychiatry and allied disciplines, 36*, 1337–1351.
- Farran, E. K., & Jarrold, C. (2003). Visuospatial cognition in Williams syndrome: reviewing and accounting for the strengths and weaknesses in performance. *Developmental Neuropsychology, 23*, 173–200.
- Fathi-Ashtiani, A., Ejei, J., Khodapanahi, M., & Tarkhorani, H. (2007). Relationship Between Self-Concept, Self-esteem, Anxiety, Depression and Academic Achievement in Adolescents. *Journal of Applied Sciences, 7*(7), 995.
- Festinger, L. (1954). A theory of social comparison processes. *Human Relations, 7*, 117–140.
- Fidler, D. J., Hepburn, S. L., Most, D. E., Philofsky, A., & Rogers, S. J. (2007). Emotional responsivity in young children with Williams syndrome. *American Journal on Mental Retardation, 112*(3), 194–206.
- Finkenauer, C., Engels, R. C. M. E., Meeus, W. S., & Oosterwegel, A. (2002). Self and identity in early adolescence. The pains and gains of knowing who and what you are. In T. M. Brinthaupt & R. P. Lipka (Eds.), *Understanding early adolescent self and identity. Applications and interventions* (pp. 25–56). Albany, NY: State University of New York Press.
- Fishman, I., Yam, A., Bellugi, U., Lincoln, A., & Mills, D. (2011). Contrasting patterns of language-associated brain activity in autism and Williams syndrome. *Social Cognitive and Affective Neuroscience, 6*(5), 630-638.
- Flavell, J. H., Miller, P. H., & Miller, S. A. (1993). *Cognitive Development 3<sup>rd</sup> Edition*. Englewood Cliffs: Prentice Hall.
- Flook, L., Repetti, R. L., & Ullman, J. B. (2005). Classroom social experiences as predictors of academic performance. *Developmental Psychology, 41*(2), 319–327. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/15769188>
- Fransella, F., & Dalton, P. (1990). *Personal Construct Psychology in Action*. London: Sage Publications.

- Frigerio, E., Burt, D. M., Gagliardi, C., Cioffi, G., Martelli, S., Perrett, D. I., & Borgatti, R. (2006). Is everybody always my friend? Perception of approachability in Williams syndrome. *Neuropsychologia*, *44*(2), 254–9. doi:10.1016/j.neuropsychologia.2005.05.008
- Gagliardi, C., Frigerio, E., Burt, D. M., Cazzaniga, I., Perrett, D. I., & Borgatti, R. (2003). Facial expression recognition in Williams syndrome. *Neuropsychologia*, *41*(6), 733–738. Retrieved from [http://dx.doi.org/10.1016/S0028-3932\(02\)00178-1](http://dx.doi.org/10.1016/S0028-3932(02)00178-1)
- Gervais, H., Belin, P., Boddaert, N., Leboyer, M., Coez, A., Sfaello, I., Barthélémy, C., et al. (2004). Abnormal cortical voice processing in autism. *Nature Neuroscience*, *7*(8), 801–802. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/15258587>
- Ghaziuddin, M., Ghaziuddin, N., & Greden, J. (2002). Depression in Persons with Autism: Implications for Research and Clinical Care. *Journal of Autism & Developmental Disorders*, *32*, 299-306.
- Glick, M., Bybee, J., & Zigler, E. (1985). Self-Image a Cognitive- Developmental Approach. In R. Leahy (Ed.), *The development of self* (pp. 1-53). New York: Academic Press.
- Gray, D. E. (2002). Everybody just freezes . Everybody is just embarrassed ’: felt and enacted stigma among parents of children with high functioning autism. *Sociology of Health Illness*, *24*(6), 734–749. doi:10.1111/1467-9566.00316
- Green, J., Gilchrist, A., Burton, D., & Cox, A. (2000). Social and psychiatric functioning in adolescents with Asperger syndrome compared with conduct disorder. *Journal of Autism and Developmental Disorders*, *30*(4), 279–293. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/11039855>
- Greene, D. J., Colich, N., Iacoboni, M., Zaidel, E., Bookheimer, S. Y., & Dapretto, M. (2011). Atypical neural networks for social orienting in autism spectrum disorders. *NeuroImage*, *56*(1), 354–62. doi:10.1016/j.neuroimage.2011.02.031
- Gurney, P. W. (1988). *Self-esteem in children with special educational needs*. London: Routledge.
- Haas, B. W., Mills, D., Yam, A., Hoefft, F., Bellugi, U., & Reiss, A. (2009). Genetic influences on sociability: Heightened amygdala reactivity and event-related responses to positive social stimuli in Williams syndrome. *The Journal of Neuroscience*, *29*(4), 1132–1149.
- Hansen, C. H., & Hansen, R. D. (1988). Finding the face in the crowd: an anger superiority effect. *Journal of Personality and Social Psychology*, *54*(6), 917–924. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/3397866>
- Happe, F., & Frith, U. (1996). The neuropsychology of autism [Review]. *Brain*, *119*, 1377–4.



- Hare, D. J., Mellor, C., & Azmi, S. (2007). Episodic memory in adults with autistic spectrum disorders: recall for self- versus other-experienced events. *Research in developmental disabilities, 28*(3), 317–29. doi:10.1016/j.ridd.2006.03.003
- Harrop, C., & Trower, P. (2001). Why does schizophrenia develop at late adolescence? *Clinical psychology review, 21*(2), 241–65. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/11293367>
- Hart, D., & Damon, W. (1988). Self understanding and social cognitive development. *Early Child Development and Care, 40*(1), 5–23. doi:10.1080/0300443880400102
- Harter, S. (1990). Causes, correlates and the functional role of global self-worth: A life-span perspective. In J. Kolligan & R. Sternberg (Eds.), *Perceptions of competence and incompetence accross the life-span* (pp. 43–70). N: Springer-Verlag.
- Harter, S. (1993). Causes and consequences of low self-esteem in children and adolescents. In R. F. Baumeister (Ed.), *Self-esteem: The puzzle of low self-regard* (pp. 87–116). New York: Plenum press.
- Harter, S. (1998). The development of self-representations. In W. Damon & Eisenberg N (Eds.), *Handbook of child psychology: Vol. 3. Social, emotional, and personality development* (5th ed., pp. 553–617). New York: Wiley.
- Harter, S. (1999). *The Construction of the Self: A Developmental Perspective*. London: Guilford Press.
- Harter, S. (2003). The development of self-representations during childhood and adolescence. In M R Leary & J. P. Tangney (Eds.), *Handbook of Self and Identity* (pp. 610–642). Guilford Press.
- Haslam, S. A., Jetten, J., Postmes, T., & Haslam, C. (2009). Social identity, health, and well-being: An emerging agenda for applied psychology. *Applied Psychology: An International Review, 58*, 1–23.
- Haugen, T., Säfvenbom, R., & Ommundsen, Y. (2011). Physical activity and global self-worth: The role of physical self-esteem indices and gender. *Mental Health and Physical Activity, 4*(2), 49–56.
- Hobson, R. P. (1990). On the origins of self and the case of autism. *Development and Psychopathology, 2*, 163–181.
- Hobson, R. P. (1993). *Autism and the development of mind*. Hove, UK: Erlbaum.
- Hofmann, W., Gawronski, B., Gschwendner, T., Le, H., & Schmitt, M. (2005). A meta-analysis on the correlation between the implicit association test and explicit self-report measures. *Personality and Social Psychology Bulletin, 31*(10), 1369–1385. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/16143669>

- Hoy, J. A., Hatton, C., & Hare, D. J. (2005). Weak central coherence: a cross-domain phenomenon specific to autism? *Autism*, 8(3), 267–281.
- Huws, J., & Jones, R. S. P. (2008). Diagnosis, disclosure, and having autism: An interpretative phenomenological analysis of the perceptions of young people with autism. *Journal of Intellectual & Developmental Disability*, 33(2), 99–107.
- Jackson, P., Skirrow, P., & Hare, D. J. (2012). Asperger through the looking glass: an exploratory study of self-understanding in people with Asperger's syndrome. *Journal of autism and developmental disorders*, 42(5), 697–706. doi:10.1007/s10803-011-1296-8
- James, W. (1892/1961). *Psychology: The Briefer Course* (p. 44). New York: Harper.
- James, W. (1890/1950). *The Principles of Psychology by William James. Volume One*. London: Dover Publication Inc.
- Jerome, A. C., Fujiki, M., Brinton, B., & James, S. L. (2002). Self-esteem in children with specific language impairment. *Journal of Speech, Language and Hearing Research*, 45(4), 700–714. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/12199400>
- Jobe, L. E., & White, S. W. (2007). Loneliness, social relationships, and a broader autism phenotype in college students. *Personality and Individual Differences*, 42(8), 1479–1489. doi:10.1016/j.paid.2006.10.021
- Johnson, M. (2011). Active and passive maladaptive behaviour patterns mediate the relationship between contingent self-esteem and health. *Personality and Individual Differences*, 51(2), 178–182.
- Jones, R. S. P., Zahl, A., & Huws, J. . (2010). First-hand accounts of emotional experiences in autism: A qualitative analysis. *Disability & Society*, 16(3), 293–401.
- Jones, W., Bellugi, U., Zona, L., Chiles, M., Reilley, J., Lincoln, A., & Al., E. (2000). Hypersociability in Williams syndrome. *Journal of Cognitive Neuroscience*, 12, 30–46.
- Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child*, 2, 217–250.
- Kegan, R. (1982). *The evolving self: Problem and process in human development*. Cambridge, MA: Harvard University Press.
- Keller, A., Ford, L. H., & Meacham, J. A. (1978). Dimensions of self-concept in preschool children. *Developmental Psychology*, 14(5), 483–489. doi:10.1037//0012-1649.14.5.483

- Kelly, B. (2005). Chocolate ... makes you autism': impairment, disability and childhood identities. *Disability Society*, 20(3), 261–275.  
doi:10.1080/09687590500060687
- Kelly, G. (1955). *The Psychology of Personal Constructs*. New York: Routledge.
- Keltner, D., Gruenfeld, D. H., & Anderson, C. (2003). Power, approach and inhibition. *Psychological Review*, 110, 265–284.
- Kennedy, J. C., Kaye, D. L., & Sadler, L. S. (2006). Psychiatric Diagnoses in Patients with Williams Syndrome and Their Families. *Journal of Psychiatry*, 20(1), 22-31.
- Kernis, M. H. (2002). Self-esteem as a multifaceted construct. *Understanding early adolescent self and identity Applications and interventions Brinthaup*, 57–88. Albany.
- Kernis, M. H., & Goldman, B. M. (2003). Stability and variability in self-concept and self-esteem. In Mark R Leary & J. P. Tangney (Eds.), *Handbook of self and identity Leary* (pp. 106–127). New York, NY, US: Guilford Press.
- Kim, J. A., Szarmari, P., Bryson, S. E., Streiner, D. L., & Wilson, F. J. (2000). The Prevalence of Anxiety and Mood Problems among Children with Autism and Asperger Syndrome. *Autism*, 4, 117–132.
- King, C. A., Naylor, M. W., Segal, H. G., Evans, T., & Shain, B. N. (1993). Global Self-Worth, Specific Self-Perceptions of Competence, and Depression in Adolescents. *Journal of the American Academy of Child & Adolescent Psychiatry*, 32(4), 745–752.
- Klein-Tasman, B. P., Li-Barber, K. T., & Magargee, E. T. (2011). Honing in on the social phenotype in Williams syndrome using multiple measures and multiple raters. *Journal of autism and developmental disorders*, 41(3), 341–51.  
doi:10.1007/s10803-010-1060-5
- Kling, K. C., Hyde, J. S., Showers, C. J., & Buswell, B. N. (1999). Gender differences in self-esteem: A meta-analysis. *Psychological Bulletin*, 125, 470–500.
- Kroger, J. (2007). *Identity Development. Adolescence through Adulthood* (2nd ed.). USA: Sage Publications.
- Krysko, K. M., & Rutherford, M. D. (2009). A threat-detection advantage in those with autism spectrum disorders. *Brain and Cognition*, 69(3), 472–480.  
Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/19036491>
- Leary, M.R., & MacDonald, G. (2003). Individual differences in self-esteem: A review and theoretical integration. In M. R Leary & J. P. Tangney (Eds.), *Handbook of Self and Identity* (pp. 401–420). New York: Guilford Press.

- Lee, A., & Hobson, R. P. (1998). On developing self-concepts: a controlled study of children and adolescents with autism. *Journal of child psychology and psychiatry, and allied disciplines*, 39(8), 1131–44. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/9844983>
- Leitner, L., & Thomas, L. (2003). Experiential personal construct psychotherapy. In F. Fransella (Ed.), *International Handbook of Personal Construct Psychology*, (pp. 257-264). Chichester: Wiley.
- Levitt, M. Z., & Hart, D. (1991). Development of self-understanding in anorectic and nonanorectic adolescent girls. *Journal of Applied Developmental Psychology*, 12(3), 269–288.
- Leyfer, O., Woodruff-Borden, J., Klein-Tasman, B. P., Fricke, J., & Mervis, C. B. (2006). Prevalence of psychiatric disorders in 4 to 16-year-olds with Williams syndrome. *American Journal of Medical Genetics*, 141B, 615–622.
- Lincoln, T. M., Mehl, S., Ziegler, M., Kesting, M.-L., Exner, C., & Rief, W. (2010). Is fear of others linked to an uncertain sense of self? The relevance of self-worth, interpersonal self-concepts, and dysfunctional beliefs to paranoia. *Behavior therapy*, 41(2), 187–197.
- Lombardo, M. V., & Baron-Cohen, S. (2010). Unraveling the paradox of the autistic self. *Wiley Interdisciplinary Reviews Cognitive Science*, 1(3), 393–403. doi:10.1002/wcs.45
- Major, B., Barr, L., Zubek, J., & Babey, S. (1999). Gender and self-esteem: A meta-analysis. In W. Swann & J. Langlois (Eds.), *Sexism and stereotypes in modern society: The gender science of Janet Taylor Spence* (pp. 223–253). Washington DC: American Psychological Association.
- Malti, T. (2006). Aggression, Self-Understanding, and Social Competence in Swiss Elementary-School Children. *Swiss Journal of Psychology*, 65(2), 81–91.
- Margalit, M. (1994). *Loneliness among children with special needs*. New York: Springer-Verlag.
- Marsh, H. W. (2007). *Self-concept theory, measurement and research into practice: The role of self-concept in educational psychology*. Leicester, UK: British Psychological Society.
- Marsh, H. W., Craven, R. G., & Debus, R. L. (2000). Separation of competency and affect components of multiple dimensions of academic self-concept: A developmental perspective. *Merrill Palmer Quarterly*, 45, 567–601.
- Marsh, H. W., Craven, R. G., & Martin, A. (2006). What is the nature of self-esteem: Unidimensional and multidimensional perspectives. In M. Kernis (Ed.), *Self-esteem: Issues and Answers* (pp. 16–24). Psychology Press.

- Martens, M. ., Wilson, S. J., Dudgeon, P., & Reutens, D. C. (2009). Approachability and the amygdala: insights from Williams syndrome. *Neuropsychologia*, *47*, 2446–53.
- Maxwell, T. (2006). Researching into some primary school children's views about school: using personal construct psychology in practise with children on the special needs register. *Pastoral Care Education*, *24*, 20–26.
- Mead, G. (1934). *Mind Self and Society*. Chicago: The University of Chicago Press.
- Mervis, C. B., Morris, C. A., Bertrand, J., & Robinson, B.(1999). Williams syndrome: findings from an integrated program of research. In Helen Tager-Flusberg (Ed.), *Neurodevelopmental Disorders* (pp. 65–110). Cambridge: MA: MIT Press.
- Mervis, C. B., Morris, C. A., Klein-Tasman, B. P., Bertrand, J., Kwitny, S., Appelbaum, L. G., & Rice, C. E. (2003). Attentional characteristics of infants and toddlers with Williams syndrome during triadic interactions. *Developmental Neuropsychology*, *23*(1-2), 243–268. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/12730027>
- Mesibov, G. B., & Handlan, S. (1997). Adolescents and adults with autism. In D. J. Cohen & F. R. Volkmar (Eds.), *Handbook of autism and pervasive developmental disorders* (pp. 309–322). New York: John Wiley & Sons.
- Mesibov, G. B., & Shea, V. (1996). Full Inclusion of Students with Autism. *Journal of Autism & Developmental Disorders*, *26*(3), 337–46.
- Meyer-Lindenberg, A., Hariri, A. R., Munoz, K. E., Mervis, C. B., Mattay, V. S., Morris, C. A., & Berman, K. F. (2005). Neural correlates of genetically abnormal social cognition in Williams syndrome. *Nature Neuroscience*, *8*(8), 991–993. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/16007084>
- Meyer-Lindenberg, A., Mervis, C. B., & Berman, K. F. (2006). Neural mechanisms in Williams syndrome: a unique window to genetic influences on cognition and behaviour. *Nature reviews. Neuroscience*, *7*(5), 380–93. doi:10.1038/nrn1906
- Michalak, J., Teismann, T., Heidenreich, T., Ströhle, G., & Vocks, S. (2010). Buffering low self-esteem: The effect of mindful acceptance on the relationship between self-esteem and depression. *Personality and Individual Differences*, *50*(5), 751–754.
- Mohammad, A. (2010). Relationship Between Self-esteem and Academic Achievement Amongst Pre-University Students. *Journal of Applied Sciences*, *10*(20), 2474-2477.
- Muris, P., Steerneman, P., Meesters, C., Merckelbach, H., Horselenberg, R., van den Hogen, T., & van Dongen, L. (1999). The TOM test: a new instrument for assessing theory of mind in normal children and children with pervasive

- developmental disorders. *Journal of autism and developmental disorders*, 29(1), 67–80. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/10097996>
- Nakagawa, S. (2004). A farewell to Bonferroni: the problem of low statistical power and publication bias. *Behavioral Ecology*, 15(6), 1044–1045.
- Ochs, E., Kremer-Sadlik, T., Solomon, O., & Sirota, K. G. (2001). Inclusion as social practice. Views of children with autism. *Social Development*, 10(3), 399–419.
- Oliver, C. (1986). Self-concept assessment: a case study. *Mental Handicap*, 14, 24–25.
- Paradise, A. W., & Kernis, M. H. (2002). Self-esteem and Psychological Well-being: Implications of Fragile Self-esteem. *Journal of Social and Clinical Psychology*, 21(4), 345–361. doi:10.1521/jscp.21.4.345.22598
- Pennington, B. F., & Ozonoff, S. (1996). Executive functions and developmental psychopathology. *Journal of child psychology and psychiatry, and allied disciplines*, 37(1), 51–87. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/8655658>
- Perner, J., Frith, U., Leslie, A. M., & Leekam, S. R. (1989). Exploration of the autistic child's theory of mind: knowledge, belief, and communication. *Child development*, 60, 688–700.
- Piers E. V. (1994). *Revised Manual for the Piers-Harris Children's Self-Concept Scale*. Western Psychological Services, Los Angeles, CA.
- Pijl, S. J., & Frostad, P. (2010). Peer acceptance and self concept of students with disabilities in regular education. *European Journal of Special Needs Education*, 25(1), 93–105. doi:10.1080/08856250903450947
- Plesa-Skwerer, D., Ammerman, E., André, M.-C., Ciciolla, L., Fine, A. B., & Tager-Flusberg, H. (2011). A multimeasure approach to investigating affective appraisal of social information in Williams syndrome. *Journal of neurodevelopmental disorders*, 3(4), 325–34. doi:10.1007/s11689-011-9100-9
- Plesa-Skwerer, D., Sullivan, K., Joffe, K., & Tager-Flusberg, H. (2004). Self-concept in people with Williams syndrome and Prader-Willi syndrome. *Research in developmental disabilities*, 25(2), 119–38. doi:10.1016/j.ridd.2003.05.003
- Pober, B. R., & Dykens, E. M. (1996). Williams syndrome: An overview of medical, cognitive and behavioural features. *Child and adolescent psychiatric clinics of North America*, 5, 929–944.
- Porter, M., Coltheart, M., & Langdon, R. (2007). The neuropsychological basis of hypersociability in Williams and Down syndrome. *Neuropsychologia*, 45, 2839–49.

- Powell, S., & Jordan, R. (1992). Using Photographs to Develop Autobiographical Memory in Children with Autism. *Proceedings of the International Conference on Living with Autism*. Autism Research Unit: University of Sunderland.
- Premack, D. G., & Woodruff, G. (1978). Does the chimpanzee have a theory of mind? *Behavioral and Brain Sciences*, *1*(4), 515–526.
- Punshon, C., Skirrow, P., & Murhpy, G. (2009). The not guilty verdict: psychological reactions to a diagnosis of Asperger syndrome in adulthood. *Autism*, *13*(3), 265–83.
- Rahmani, P. (2011). The relationship between self-esteem, achievement goals and academic achievement among the primary school students. *Social and Behavioral Sciences*, *29*, 803–808.
- Ravenette, T. (1997). *Personal Construct psychology and the practise of an educational psychologist*. Great Britain EPCA Publications.
- Ravenette, T. (1999). *Personal construct theory in Educational Psychology: A practitioner' s view*. London: Whurr Publications.
- Ravenette, T. (2003). Constructivist intervention when children are presented as problems. In F. Fransella (Ed.), *International handbook of personal construct psychology* (pp. 283–293). Chichester: Wiley.
- Renouf, A. G., & Harter, S. (1990). Low self-worth and anger as components of the depressive experience in young adolescents. *Development Psychopathology*, *2*(3), 293–310.
- Rhodes, N., & Wood, W. (1992). Self-esteem and intelligence affect influenceability: The mediating role of message reception. *Psychological Bulletin*, *111*(1), 156–171. doi:10.1037/0033-2909.111.1.156
- Robins, R. W., Trzesniewski, K. H., Tracy, J. L., Gosling, S. D., & Potter, J. (2002). Global self-esteem across the life span. *Psychology and Aging*, *17*, 423–434.
- Robinson, J. C. (2007). *An exploration of self-construing and the development of a new self-image profile for young children (aged 4-6 years)*. University of Leeds, D.Clin.Psychol.
- Rosset, D., Santos, A., Da Fonseca, D., Rondan, C., Poinso, F., & Deruelle, C. (2011). More than just another face in the crowd: Evidence for an angry superiority effect in children with and without autism. *Research in Autism Spectrum Disorders*, *5*(2), 949–956. doi:10.1016/j.rasd.2010.11.005
- Rowe, D. (2003). Personal construct psychology and me. In F. Fransella (Ed.), *International Handbook of Personal Construct Psychology*, (pp. 397–404). Chicago: Wiley.

- Santos, A., Silva, C., Rosset, D., & Deruelle, C. (2010). Just another face in the crowd: evidence for decreased detection of angry faces in children with Williams syndrome. *Neuropsychologia*, *48*(4), 1071–8. doi:10.1016/j.neuropsychologia.2009.12.006
- Shavelson, R. J., & Bolus, R. (1982). Self-Concept: The Interplay of Theory and Methods. *Journal of Personality Assessment*, *74*(1), 3–17.
- Shavelson, R. J., Hubner, J. J., & Stanton, G. C. (1976). Validation of Construct Interpretations. *Review of Educational Research*, *46*, 407–441.
- Sigman, M., & Ruskin, E. (1999). Social competence in children with Autism, Down syndrome and other developmental delays: A longitudinal study. *Monographs of the Society for Research in Child Development*, *64*(1):115-30.
- Stager, S., & Young, R. D. (1982). A self-concept measure for preschool and early primary grade children. *Journal of Personality Assessment*, *46*(5), 536–543. Retrieved from [http://www.tandfonline.com/doi/abs/10.1207/s15327752jpa4605\\_16](http://www.tandfonline.com/doi/abs/10.1207/s15327752jpa4605_16)
- Stern, D. N. (1985). *The interpersonal world of the infant*. New York: Basic Books.
- Stinton, C., Elison, S., & Howlin, P. (2010). Mental health problems in adults with Williams syndrome. *American journal on intellectual and developmental disabilities*, *115*(1), 3–18.
- Stinton, C., Tomlinson, K., & Estes, Z. (2012). Examining reports of mental health in adults with Williams syndrome. *Research in developmental disabilities*, *33*(1), 144–52. doi:10.1016/j.ridd.2011.09.002
- Stojanovik, V. (2006). Social interaction deficits and conversational inadequacy in Williams syndrome. *Journal of Neurolinguistics*, *19*(2), 157–173. Retrieved from <http://centaur.reading.ac.uk/13853/>
- Stojanovik, V., & James, D. (2006). Short-term longitudinal study of children with Williams syndrome. *International Journal of Language and Communication Disorders*, *41*(2), 213–223.
- Strauss, E., Sherman, E.M.S., & Spreen, O. (2006). *A compendium of neuropsychological tests: administration, norms, and commentary*. 3rd ed. New York: Oxford University Press, p. 189-200.
- Stromme, P., Bjornstad, P. G., & Ramstad, K. (2002). Prevalence estimation of Williams syndrome. *Journal of Child Neurology*, *17*(4), 269–271.
- Sullivan, K., & Tager-Flusber, H. (1999). Second-order belief attribution in Williams syndrome: Intact or impaired? *American Journal on Mental Retardation*, *104*, 523–532.



- Swann, W. B., Chang-Schneider, C., & Larsen McClarty, K. (2007). Do people's self-views matter? Self-concept and self-esteem in everyday life. *American Psychologist*, *62*(2), 84–94. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/17324034>
- Szatmari, P., Archer, L., Fisman, S., Streiner, D. L., & Wilson, F. (1995). Asperger's syndrome and autism: Differences in behavior, cognition and adaptive functioning. *Journal of the American Academy of Child and Adolescent Psychiatry*, *34*, 1662–1671.
- Tafarodi, R., & Swann, W. (1995). Self-liking and self-competence as dimensions of global self-esteem: initial validation of a measure. *Journal of Personality Assessment*, *65*, 322–342.
- Tager-Flusberg, H. (1991). Semantic processing in the free recall of autistic children. *British Journal of Developmental Psychology*, *9*, 417–430.
- Tager-Flusberg, H., Skwerer, D. P., & Joseph, R. M. (2006). Model syndromes for investigating social cognitive and affective neuroscience: a comparison of Autism and Williams syndrome. *Social cognitive and affective neuroscience*, *1*(3), 175–82. doi:10.1093/scan/nsl035
- Tager-Flusberg, H., & Sullivan, K. (2000). A componential view of theory of mind: evidence from Williams syndrome. *Cognition*, *76*(1), 59–90. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/10822043>
- Tajfel, H., & Turner, J. C. (1979). An integrative theory of intergroup conflict. In W. G. Austin & S. Worchel (Eds.), *The social psychology of intergroup relations* (pp. 33–47). Monterey, CA: Brooks/Cole.
- Thomaes, S., Reijntjes, A., Orobio De Castro, B., Bushman, B. J., Poorthuis, A., & Telch, M. J. (2010). I like me if you like me: on the interpersonal modulation and regulation of preadolescents' state self-esteem. *Child Development*, *81*(3), 811–825. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/20573106>
- Thomas, S., Butler, R., Hare, D. J., & Green, D. (2011). Using Personal Construct Theory to Explore Self-Image with Adolescents with Learning Disabilities. *British Journal of Learning Disabilities*, *39*(3), 225–232.
- Trzesniewski, K. H., Donnellan, M. B., & Robins, R. W. (2003). Stability of self-esteem across the life span. *Journal of Personality and Social Psychology*, *84*(1), 205–220. Retrieved from <http://doi.apa.org/getdoi.cfm?doi=10.1037/0022-3514.84.1.205>
- Udwin, O. (1990). A survey of adults with Williams syndrome and idiopathic infantile hypercalcaemia. *Developmental Medicine and Child Neurology*, *32*(2), 129–141.
- Verhoeven, E. W. M., Marijnissen, N., Berger, H. J. C., Oudshoorn, J., van der Sijde, a, & Teunisse, J. P. (2012). Brief report: relationship between self-

awareness of real-world behavior and treatment outcome in autism spectrum disorders. *Journal of autism and developmental disorders*, 42(5), 889–94.  
doi:10.1007/s10803-011-1311-0

- Volkmar, F. R., Cohen, D. J., Bregman, J. D., Hooks, M. Y., & Stevenson, J. M. (1989). An Examination of Social Typologies in Autism. *Journal of American Academy of Child and Adolescent Psychiatry*, 28(1), 82–86.
- Wechsler, D. (1997). *Wechsler Adult Intelligence Scale—3rd Edition*. San Antonio, TX: Harcourt Assessment.
- Wechsler, D. (1999). *Wechsler Abbreviated Scale of Intelligence (WASI)*. San Antonio, TX: Harcourt Assessment.
- White, S. W., Oswald, D., Ollendick, T., & Scahill, L. (2009). Anxiety in children and adolescents with autism spectrum disorders. *Clinical psychology review*, 29(3), 216–29. doi:10.1016/j.cpr.2009.01.003
- Williams, J. C., Barratt-Boyes, B. G., & Lowe, J. B. (1961). Supravalvular aortic stenosis. *Circulation*, 24, 1311–1318.
- Wing, L. (1981). Asperger's syndrome: a clinical account. *Psychological Medicine. Cambridge University Press*, 11(1), 115-129.
- Wing, L. (1998). The history of Asperger syndrome. In E. Schopler, G. B. Mesibov, & L. J. Kunce (Eds.), *Asperger syndrome or high-functioning autism?* (pp. 11–25). New York: Plenum press.
- Wing, L., & Gould, J. (1979). Severe Impairments of Social Interaction and Associated Abnormalities in Children: Epidemiology and Classification. *Journal of Autism and Developmental Disorders*, 9, 11–29.
- World Health Organisation. (1992). *ICD-10 Classifications of Mental and Behavioural Disorder: Clinical Descriptions and Diagnostic Guidelines*. Geneva: World Health Organisation.
- Zigler, E. (1999). The individual with mental retardation as a whole person. In E. Zigler & D. Bennett-Gates (Eds.), *Personality development in individuals with mental retardation* (pp. 59–70). Cambridge: Cambridge University Press.
- van Steensel, F. J. a, Bögels, S. M., & Perrin, S. (2011). Anxiety disorders in children and adolescents with autistic spectrum disorders: a meta-analysis. *Clinical child and family psychology review*, 14(3), 302–17.  
doi:10.1007/s10567-011-0097-0

APPENDICES:

APPENDIX 1

The University  
of Manchester

MANCHESTER  
1824

**Secretary to Research Ethics Committees**  
**Room 2.004 John Owens Building**  
Compliance and Risk Office  
University of Manchester, Oxford Road  
Manchester, M13 9PL  
Tel: 0161 275 2206/2046  
Fax: 0161 275 5697  
Email: [timothy.stibbs@manchester.ac.uk](mailto:timothy.stibbs@manchester.ac.uk)

Ref: *ethics/11258*

Dr Dougal Hare,  
School of Psychological Science,  
S26 Zochonis Building.

23<sup>rd</sup> November 2011

Dear Dr Hare and Mrs Tucker,

**Research Ethics Committee 4**

*[Tucker, Hare, Birch: Self-concepts in adolescents with autism and Williams Syndrome (ref 11258)]*

I write to thank you for coming to meet the Committee on 9th November 2011 and to confirm that it gave the above research project, after the submission of amendments / clarifications, a favourable ethical opinion.

This approval is effective for a period of five years and if the project continues beyond that period it must be submitted for review. It is the Committee's practice to warn investigators that they should not depart from the agreed protocol without seeking the approval of the Committee, as any significant deviation could invalidate the insurance arrangements and constitute research misconduct. We also ask that any information sheet should carry a University logo or other indication of where it came from, and that, in accordance with University policy, any data carrying personal identifiers must be encrypted when not held on a university computer or kept as a hard copy in a location which is accessible only to those involved with the research.

Finally, I would be grateful if you could complete and return the attached form at the end of the project or by the end of October 2012.

We hope the research goes well.

Yours sincerely,

Dr Deborah Bentley  
Secretary to University Research Ethics Committee 4

Dear Parent/Guardian

**Re: Invitation to participate in a new and exciting research project supported by the National Autistic Society and the Williams Syndrome Foundation.**

My name is Helena Tucker, I am a postgraduate student at the University of Manchester (School of Psychological Sciences) under the supervision of Dr Douglas Julian Hare. I am carrying out a study investigating how adolescents with autism and adolescents with Williams Syndrome perceive and understand themselves.

We would like to invite you and your child to take part in this exciting and novel research project, so that the knowledge in this important area may be expanded. The study has been approved by the University of Manchester Research Ethics Committee, the National Autistic Society and the Williams Syndrome Foundation.

Self-understanding is an important factor in a child's development as it affects life outcomes such as academic and social achievement. The knowledge in this area is very incomplete, therefore further research and better understanding of the issue would be highly beneficial for the young people involved, their parents, carers, teachers and other professionals.

To express our appreciation for your participation we would gladly provide reports on the well established measures of assessment used in this study (Wechsler Abbreviated Scale of Intelligence and the British Picture Vocabulary Scale) to you, and with your permission, to the school your child is attending. By taking part in this study, your child's attainment levels will not be affected.

Please find attached the Participant Information Sheet explaining all details of the project and Consent Form. In order to take part in this study would you please sign and return the consent form in the envelope provided together with the enclosed questionnaires.

Please do not hesitate to contact me if you have any questions or if you would like to arrange a session.

I look forward to hearing from you.

Kind Regards,  
Helena Tucker

Division of Clinical Psychology  
Second Floor Zochonis Building  
Brunswick Street, Manchester M13 9PL.  
Tel: 0161 306 0400 Mob: 07894 535100  
Email: Helena.tucker@postgrad.manchester.ac.uk

**Research Title: Self-concepts in adolescents with autism and Williams syndrome.**

### **Participant Information Sheet**

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for your consideration.

#### **Who will conduct the research?**

Name of researcher: Helena Tucker

Name of project supervisor: Dr Dougal Julian Hare

The School of Psychological Sciences at the University of Manchester.

#### **What is the aim of the research?**

This research aims to assess how adolescents with autism and adolescents with Williams syndrome perceive and understand themselves. We want to gain better knowledge of their self-concept (how they perceive themselves) as better understanding of self-concepts in young people with autism and WS will be useful for parents, teachers and other professionals. Young people who have positive self-concept are happier, healthier and achieve more in life, therefore it is of great importance to identify areas that need input to enhance self-concept, maximise achievements and life outcomes and to communicate effectively with young people about their condition and how they view themselves in its light.

#### **What would the parent/guardian be asked to do if I took part?**

If you decide to take part you will be asked to:

- sign a consent form
- complete 2 brief questionnaires. This will take approximately 10 minutes.

If you decide for your child to take part you will be asked to:

- sign a consent form for your child's participation

### **What would my child be asked to do?**

If you decide for your child to participate, your child will be informed about the study and asked if s/he wants to take part. S/he will be made aware that taking part is voluntary and that he/she can withdraw at any point.

If s/he wishes to take part, s/he will complete five tasks/measures. These tasks are often perceived by children as enjoyable and include simple and fun activities such as puzzles/non verbal problem solving, word and picture matching, etc. In total it will take around 40 minutes to complete. This can be done in multiple sessions depending on your child's preference. The sessions will take place at the school/educational facility the child is attending. A home visit could be arranged if preferred.

Bellow are details of all the measures used:

- The British Picture Vocabulary Scale-II – a simple test where words are matched pictures.
- Wechsler Abbreviated Scale of Intelligence – two simple tasks focusing on vocabulary and non verbal problem solving.
- The Smarties test – brief test assessing understanding of other people's knowledge and belief.
- The Self-image Profile for Adolescents - brief survey investigating the individual's self-image – 'what I am like and what I would like to be like'. With your permission, we would use an audio-recording devise to capture the spoken word.

### **What happens to the data collected?**

The study has been approved by the University of Manchester Research Ethics Committee, the National Autistic Society and the Williams Syndrome Foundation. Your and your child's data will be treated with full confidentiality. The materials will be kept safe and destroyed when the results have been analysed. Results from this study will be included in a postgraduate thesis.

To express appreciation for your participation we offer to provide reports on the well-established measures of assessment used in this study: Wechsler Abbreviated Scale of Intelligence (WASI) and the British Picture Vocabulary Scale (BPVS) to you, and with your permission, to the school your child is attending. This will be beneficial for you and the educational professionals and will have no affect on your child's attainment levels.

If you wish to receive reports on the above measures (WASI and BPVS) please contact Helena Tucker, Division of Clinical Psychology, Second Floor, Zochonis Building, Brunswick Street, Manchester, M13 9PL. Tel: 0161 306 0400. Email: [Helena.tucker@postgrad.manchester.ac.uk](mailto:Helena.tucker@postgrad.manchester.ac.uk)

### **What happens if I do not want to take part or if I change my mind?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason and without detriment to yourself.

### **Criminal Records Check**

The researchers have undergone and achieved a satisfactory CRB clearance.

### **Contact for further information**

Helena Tucker, Division of Clinical Psychology, Second Floor, Zochonis Building, Brunswick Street, Manchester, M13 9PL. Tel: 0161 306 0400. Email: Helena.tucker@postgrad.manchester.ac.uk

### **What if something goes wrong?**

*You should provide contact details for any agency which might provide assistance if the participant subsequently wants help or advice. This might be yourself, or in the case of vulnerable subjects, a specialist agency.*

*If a participant wants to make a formal complaint about the conduct of the research they should contact the Head of the Research Office, Christie Building, University of Manchester, Oxford Road, Manchester, M13 9PL.*

**Title of Research: Self-concepts in adolescents with autism and Williams syndrome.**

**Participant Information Sheet (Adolescent)**

*The information below will be read out to pupils and verbal consent will be sought. It will be used flexibly and adjusted to the level of ability and understanding of the pupil.*

I would like to ask you to take part in a study project.

This project is about children and young people with autism / Williams syndrome [as appropriate] and how they think about themselves.

It is up to you if you want to take part or not.

We will do some simple and fun activities/tasks like looking at and naming pictures and doing puzzles, and I will ask you some questions about you.

If you do not enjoy it and want to stop, you just need to tell me. We can stop at any time. It is ok if you do not know answers to any questions or if you do not want to answer at all.

It will take us about 40 minutes. We do not have to do it all at once. We will stop when you had enough and we can finish it later. It is ok if you change your mind and do not want to finish at all.

Your parents will be asked to fill in a questionnaire/answer some questions about you too.

Your parents and, if your parents allow this, your school could ask for results of/how well you have done on some of the tasks we do together. Would that be ok with you?

Do you have any questions?

Would you like to take part?



**Project Title: Self-concepts in adolescents with autism and Williams syndrome**

**CONSENT FORM**

If you are happy to participate please initial all relevant boxes and sign the consent form below. Please return the form in the provided envelope.

- |  |   |
|--|---|
| 1. I confirm that I have read the attached information sheet on the above project, considered the information and received satisfactory answers to any questions.      | <b>Please<br/>Initial<br/>Box</b><br><input style="width: 60px; height: 40px; border: 1px solid black;" type="text"/> |
| 2. I understand that my participation in the study is voluntary and that I am free to withdraw at any time without giving a reason.                                    | <input style="width: 60px; height: 40px; border: 1px solid black;" type="text"/>                                      |
| 3. I agree for my child to participate in the above study.   | <input style="width: 60px; height: 20px; border: 1px solid black;" type="text"/>                                      |
| 4. I agree to the use of audio-recording of the Self-Image Profile measure/survey with my child with possible use of anonymous quotes.                                 | <input style="width: 60px; height: 40px; border: 1px solid black;" type="text"/>                                      |
| 5. I agree to the school having access to my child's reports on the Wechsler Abbreviated Scale of Intelligence (WASI) and the British Picture Vocabulary Scale (BPVS). | <input style="width: 60px; height: 40px; border: 1px solid black;" type="text"/>                                      |
| 6. I agree to take part in the above project.  | <input style="width: 60px; height: 20px; border: 1px solid black;" type="text"/>                                      |

Name of parent	Date	Signature
Name of child	Date	Signature (not required)
Helena Tucker		
Name of person taking consent	Date	Signature

Please provide your child's school contact details, or if preferred, your personal contact details in order to arrange the assessment session.

Name of Participant.....

**THE SMARTIES TEST**

Administration and scoring guidelines

1. Produce a Smarties box from your bag and ask the child: "What's in here?"

Participants answer .....

2. Open the box, and to the subject's surprise, a pencil emerges. Say: "No, it's a pencil."

3. Put the pencil back into the box, close the box, and asked two Prompt Questions:

Reality Prompt: "What's in here?" .....

Own-Response Prompt: "When I first asked you, what did you say?"  
.....

4. Now let's say we are going to get your friend/mum and ask them the same question

"Who should we get?" (Subject names next person.)  
"S/he hasn't seen this box. When s/he comes in, I'll show her/him this box just like this and ask: [Name] what's in here?"

Prediction Test: "What will [Name] say?" .....

Reality Check: "Is that what's really in the box?" ..... (if answer is "No"):

"What is really in the box?" .....

5. Own-Response Check: "Do you remember, when I took the box out of my bag [experimenter reenacts that episode] and asked you what was in it, what did you say?"

.....

Scoring:

0... Incorrect, does not understand procedure

1... Self correct response

Answers **correctly questions number 3**: reality prompt – pencil, own response prompt – smarties &

Answers **incorrectly question number 4**: prediction test – pencil, reality check – pencil/smarties

2... Self correct response & correct attribution

Answers **correctly questions number 3**: reality prompt – pencil, own response prompt – smarties &

Answers **incorrectly question number 4**: prediction test – smarties, reality check – pencil

**SIP- A Follow up Interview Schedule**

*Explore participants' ratings on self-description items:*

How come you gave yourself a rating of .... on.....(e.g. friendly, feel different to others, friendly, confident, worry a lot etc.)?

How do you know you are .....

Why do you think you are different to others? Etc.

*Explore discrepancies in real and ideal self:*

You said you would like to be more friendly (more intelligent, worry less, etc.) Can you tell me more about that?

(Butler, 2001)

*Explore awareness of condition and reaction to this awareness:*

What do you know about ASC/ WS?

If I did not know what ASC/ WS is how would you explain it to me?

How does having ASC/ WS make you feel?

What are the advantages/ disadvantages?

If you could change something about you, what would you change?

(Cunningham & Glenn, 2004)

**Interview Transcripts**

The researcher completed 21 of the 34 interviews. The remainder was completed by the five research assistants. Pseudonyms were used to maintain confidentiality.

**Transcript ASC 1**

When completing SIP-A part one (What are you like?) no comments were made by the participant other than indicating scores on individual items.

R: Right, this time you are going to go through them again and instead of answering what you are like now, I'm going to ask you how you would like to be. Ok? What about 'kind' you gave yourself a number two, how would you like to be?

P: A professor.

R: You'd like to be a professor?

P: Yes.

R: Would that maybe be looking at intelligent?

P: Yes.

R: Professor is intelligent, so you gave yourself a number two, what would you like to be? Would you like to be more intelligent?

P: Yes.

R: What number would you like to be?

P: Number four... Number five.

R: You'd like to be number five. And why is that? Why would you like to be more intelligent?

P: Because I want to build stuff.

R: You'd like to build stuff, all right very good. What kinds of things would you like to build?

P: Everything...creatures...build robots.

R: That's really interesting.

P: I build bio chemicals.

R: Bio chemicals, ok that sounds very intelligent.

P: Yep.

R: How about...let's have a look at kind, you gave yourself number two. Would you like to be more kind or less kind?

P: More.

R: What number would you like to be?

P: Three.

R: You'd like to be number three, ok. You said that on happy right now you are number three, what would you like to be?

P: Number four.

R: You'd like to be more happy?

P: Yes.

R: What about friendly, you gave yourself number two, why did you give yourself a number two of friendly?

P: Yes sometimes I hit people because....erm...

R: Because?

P: Because of people keep on bugging me.

R: I see, so sometimes you're not very friendly because you hit them?

P: Yes.

R: I see. So you would you like to be more friendly?

P: Yes.

R: What number would you like to be?

P: Number three.

R: You'd like to be more friendly. Why do you think it's good to be more friendly?

P: To be nice to people.

R: Ok, that's a very good answer. What about funny, you gave yourself a number three, how would you like to be?

P: Number three.

R: You'd like to be number three, ok. What about helpful, you gave yourself number one, what number would you like to be?

P: Two.

R: You'd like to be number two. On hard working you gave yourself number six.

P: Not so hard working.

R: Not so hard working, sorry number one, you are right, not so hard working. You'd like to stay the same?

P: Yes.

R: 'Talkative' you gave yourself number three, how would you like to be?  
P: More.  
R: You'd like to be more talkative, why would you like to be more talkative?  
P: So I can tell people about my stories.  
R: You like telling people about your stories?  
P: Yes.  
R: Ok, what about confident, you said you're not very confident.  
P: I want to be this confident [indicates a higher score on the scale by pointing].  
R: You want to be this confident, ok. What about fun to be with, you gave yourself number one, how would you like to be?  
P: More [indicates a higher score on scale by pointing].  
R: You would like to be more fun to be with, ok. On good looking, how would you like to be?  
P: [Indicates a higher score on scale by pointing].  
R: You'd like to be more good looking?  
P: Yes.  
R: What about feel different from others, you said you feel quite different from others, why is that?  
P: The same.  
R: Why do you think you feel different from others?  
P: Sometimes they're too autism.  
R: Right...do you know what autism is?  
P: Yes.  
R: What does it mean?  
P: I don't know.  
R: Because you said some others are a bit too autism, I wonder what you meant?  
P: It's something like... kids are different from the outside world.  
R: Very good and how are they different?  
P: Because they are...because they act in different ways.  
R: Ok, they act different ways. And how do you feel about yourself? Do you have autism?  
P: Yes.  
R: And what does that mean for you having autism?  
P: Little bit hard.

R: Is it a bit difficult?

P: Yes.

R: And why is it difficult?

P: Because people keep on bugging me.

R: Do you think it's because you have autism?

P: Yes.

R: And you find that quiet difficult?

P: Yes.

R: Ok very good. We will come back to that in a minute, let's just finish these scores. Here on lazy you gave yourself number four, how would you like to be?

P: Number three.

R: You'd like to be less lazy, ok. What about annoying, you gave yourself number two?

P: Number one.

R: Less annoying, ok. Moody was number two.

P: What's moody?

R: Moody means when you get into a bit of a mood, and sometimes you are not too nice to people, you get a bit tired and maybe you don't feel like doing things.

P: Number one.

R: You'd like to be less moody, ok. Ooh we didn't do this one...mess about, what are you like for mess about? Do you mess about at school?

P: A little bit...one.

R: A little bit, ok. And how would you like to be?

P: I think one.

R: Number one, ok. Shy, you said your not really shy, how would you like to be?

P: Six.

R: You'd like to be more shy or less shy?

P: Less shy.

R: Less shy, ok.

P: About the same.

R: You'd like to stay the same, ok. What about 'cheeky' you said you're number two, would you like to be less or more cheeky or the same?

P: What's cheeky?



R: Hmm what is cheeky, you could be a bit cheeky at school if you make fun of people or you don't listen to your teacher.

P: Number one.

R: Loud, you said on loud you are number two.

P: Number one.

R: You want to be less loud. Sarcastic, would you like to be more or less sarcastic or stay the same?

P: Number two.

R: You said you worry a lot, why do you worry a lot?

P: Something goes wrong can kill me.

R: You're afraid if something goes wrong that it's going to kill you?

P: Yes.

R: And why do you think you worry about that?

P: Afraid something going to happen like the whole classrooms going to fall down and with everyone in it.

R: Oh is that what you worry about?

P: Yes.

R: And would you like to worry less?

P: Number Four.

R: You'd like to worry less, number four, ok. Now on bossy...how would you like to be?

P: Same.

R: You'd like to be the same. What about short-tempered?

P: Number one.

R: You'd like to be less short-tempered. What about getting bored, how would you like to be?

P: Less bored.

R: Ok, you know we were talking about autism before and did very well at explaining what it is.

P: Yes.

R: Do you think there are any good things about having autism?

P: No....Maybe yes.

R: And what good things do you think there are about having autism?

P: Get to play...computers. I want to read my book please.

R: You want to read, of course, thank you so much you were so helpful, very good well-done.

### **Transcript ASC 2**

When completing SIP-A part one (What are you like?) no comments were made by the participant other than indicating scores on individual items.

R: So you put that you don't feel very funny.

P: My friend says I'm not very funny. I tell jokes...I just don't tell them what [laughs].

R: Ok, so why do you think you are not very funny?

P: My friend does think I'm not very funny.

R: And how do you feel about that, that your friend thinks that you are not very funny?

P: I just think I'm kind of funny with that.

R: So you think you are funny but your friends don't think you are funny. Is that right?

P: Yeah.

R: Ok, you gave yourself a high number on being intelligent. Can you tell me a bit more about that?

P: Well I'm kind of good at maths but I'm not good at literacy so that why I scored myself number five.

R: Ok, what about fun to be with, you only gave yourself number two, why is that?

P: No one likes me.

R: You think that no one likes you?

P: No one likes me.

R: And why do you think that?

P: Mike is always with Shane and Shane keeps pushing me away from Mike.

R: Are these people from your class?

P: Yeah.

R: So you would like to be more fun to be with?

P: Maybe.

R: You said number five

P: Yeah.

R: And what do you think that would look like is you are more fun to be with?

P: I don't know. Maybe I have more friends [laughs].

R: You would have more friends yeah?

P: Yes.

R: Ok, and how would you feel about having more friends?

P: Ok.

R: Would you like that?

P: Yeah.

R: Ok, now you put that you don't feel very different from others.

P: Yeah, I kind of don't feel different from others. I feel like the same.

R: Ok. What about lazy, you said you are not very lazy. Is that right?

P: Yeah, if you count Monday, Tuesday, Wednesday, Thursday and Friday [laughs].

R: Yeah, so you are not lazy in the week?

P: Yeah.

R: What about annoying you gave yourself number three.

P: I'm kind of annoying to Mike [laughs].

R: And you said you would like to be less annoying.

P: Little bit less annoying.

R: Ok, look at this one, short-tempered, you gave yourself number five. Why is that?

P: I hate when it's too loud.

R: So is that when you get a bit short-tempered?

P: Yeah.

R: Ok, and getting bored, you gave yourself number three. Why is that?

R: Because I have a DS when I get bored.

R: Ok, very good. I only have a couple more questions to ask. Can you tell me what you know about autism?

P: Not very much.

R: Do you know what it is? What that word means?

P: Not at all. So far you either speak differently or something like that.

R: Sorry did you say you think differently?

P: No, I said speak differently. Even some people get confused.

R: Sorry, I didn't hear you properly. Can you tell me something else about it?

P: Erm...

R: What about your school. Why do you go to this school?

P: Because I've got autism.

R: And what is autism?

P: I told you I don't know I think people get confused like you got confused just then.

R: I did, didn't I?

P: Yeah [laughs].

R: Ok, well done, we will leave it here. Thank you.

### **Transcript ASC 3**

R: How kind do you think you are?

P: [Indicates by pointing to the scale].

R: Number five?

P: Yes, please.

R: What about happy?

P: [Indicates by pointing to the scale].

R: Number six, very happy.

P: Because I have been a very quiet and patient girl waiting.

R: Ok, very good. What about friendly?

P: I can shake everyone's hand or give them a hug.

R: Ok, very good. So what number do you think you are?

P: [Indicates by pointing to the scale].

R: Ok, what about helpful?

P: I am helpful. I am helpful for sorting out things to other people.

R: What number do you think you are then?

P: [Indicates by pointing to the scale].

R: Ok, what about funny, which one do you think you are?

P: [Indicates by pointing to the scale].

R: What about hardworking?

P: Because I was hard work for building my lego friends said because my fingers were getting red and achy.

R: So you are very hard working?

P: Yes, number six.

R: What about talkative?

P: What is talkative?

R: That means you talk a lot.

P: Talk a lot.

R: Do you talk a lot or do you not talk very much?

P: I talk a lot yes.

R: What number do you think you are?

P: [Indicates by pointing to the scale].

R: Number five. What about confident?

P: What's confident?

R: Well the opposite of confident is shy, when you keep yourself to yourself. Confident is when you...maybe like getting up and talking in front of people.

P: Yes I do.

R: Ok, so what number do you think you are?

P: [Indicates by pointing to the scale].

R: Three, ok somewhere in the middle. What about sporty?

P: I was good at sports day playing the hurdling race remember last summer in 2011?

R: I don't think I was here. Was it a good day?

P: Yes, it was a fantastic day.

R: So what number are you then?

P: [Indicates by pointing to the scale].

R: Ok. What about intelligent?

P: What is intelligent?

R: It means clever.

P: I am a clever girl.

R: What number would you be?

P: [Indicates by pointing to the scale].

R: Five, ok. What about fun to be with?

P: I am fun to be, mum.

R: With your mum?

P: With mum and Adam, my best friend cousin.

R: What about at school?

P: I know, I know. I have...fun to be with Shaun, Mike, Nicole, Peter and Fiona.

R: Ok, what number do you think you are?  
P: [Indicates by pointing to the scale].  
R: Ok, six. What about good looking?  
P: I was very good looking all the nice things and all sort of place.  
R: Ok, here good looking means what you think about your appearance, the way you look. Do you like the way you look?  
P: Yes, I like the way I look.  
R: Ok, which number, do you think you are very good looking?  
P: Yes, very good looking [indicates by pointing to the scale].  
R: Ok, number six. What about feeling different from others.  
P: Well the others are different, the all sorts of hair or eyes or clothes or shoes or different coloured skin.  
R: Ok, do you think you behave the same as other children?  
P: Yes.  
R: You do, ok. Do you think you are very similar to people in school?  
P: Oh yes I am similar, to people at school, yes, I am.  
R: So that would mean you don't feel different to other people.  
P: No, I don't feel very different.  
R: What number do you think you would be?  
P: [Indicates by pointing to the scale].  
R: Zero, ok. What about lazy?  
P: I'm not gonna be lazy.  
R: You are not laze at all?  
P: [Indicates by pointing to the scale].  
R: You would be zero or one?  
P: One please.  
R: What about annoying?  
P: Arg, it gives me headache and sore ears so I want piece and quiet so I think I will go on zero.  
R: Ok. What about moody, do you ever get moody?  
P: Sometimes I get moody.  
R: What number do you think you are?  
P: One please.  
R: What about messing about. Do you mess about?

P: Yes.

R: Do you mess about a lot or just a bit?

P: Just a little bit.

R: Ok, what number do you think you are?

P: Zero.

R: Zero means not at all.

P: How about one?

R: Ok.

P: I chose one for a change.

R: Ok, what about shy? Are you a shy person?

P: No

R: You are quite a confident person.

P: Yes.

R: What number do you reckon you would be?

P: Zero.

R: Ok, not shy at all. What about cheeky?

P: I get a bit cheeky sometimes when I play tricks like I sneak through the door so Carol wouldn't notice me.

R: Ok, so what number do you think you would be for cheeky?

P: One.

R: What about loud, do you think you are loud?

P: Yes, I shout at someone and someone might get upset and we might run to the library but I kept calm.

R: Ok I see. So what number do you think you would be?

P: One.

R: One? A little bit loud then. What about sarcastic?

P: Yes...What's sarcastic?

R: Sarcastic means that you might not say nice things about somebody else.

P: No.

R: No, ok. What number do you think you would be, not at all?

P: Not at all.

R: Do you worry a lot?

P: Yes, just some...just a little bit.

R: What number do you think you would be?

P: Oh dear, it is very hard to choose.

R: It is, I know.

P: I think I chose one.

R: What about bossy?

P: I don't get bossy.

R: You don't get bossy?

P: No, well I...I do get bossy sometimes.

R: Ok, what number do you think you would be. Not at all, very much or somewhere in the middle?

P: Oh, it's a bit difficult.

R: It's ok, take your time.

P: Zero

R: What about short-tempered? Do you get short-tempered?

P: Yes I do.

R: What number?

P: A lot or somewhere in the middle?

P: [Indicates by pointing to the scale].

R: Number two.

P: Last one.

R: Yes, last one. Do you get bored?

P: I don't get bored [indicates by pointing to the scale].

R: You don't get bored, you keep yourself busy, number one. Fantastic, well done. Right this time you are going to go through them again and instead of answering what you are like now I'm going to ask you what you would like to be. Ok? What about 'kind' you gave yourself a number five, would you like to stay the same or be more kind or less kind?

P: More kind, more kind please.

R: What about happy? You put yourself as very happiest. Would you like to stay the same?

P: Yes.

R: What about friendly. How would you like to be?

P: More friendly [indicates by pointing to the scale].

R: Now what about funny, you said number three. Would you like to change that?

P: Yes.



R: What would you like to change it to?  
P: It's getting quite difficult.  
R: You are doing really well, well done.  
P: I know.  
R: Would you like to be more funny?  
P: Yes [indicates by pointing to the scale].  
R: Ok.  
P: Lot's more helpful.  
R: Ok. What about hardworking?  
P: Erm...[indicates by pointing to the scale].  
R: Ok, what about talkative?  
P: Keep that.  
R: What about confident?  
P: Keep that.  
R: Would you like to be more or less confident?  
P: More confident please [indicates by pointing to the scale].  
R: What about intelligent. You said number six.  
P: [Indicates by pointing to the scale].  
R: Ok, number six. Fun to be with you said six.  
P: Yes please.  
R: And good looking...  
P: Yes please.  
R: Ok, we'll keep them the same. Different from others you said you are zero. How would you like to be  
P: Erm...  
R: Would you like to stay the same?  
P: Yes.  
R: Lazy...  
P: I'm not lazy after all.  
R: What number would you like to be?  
P: [Indicates by pointing to the scale].  
R: Ok, not at all lazy.  
P: Annoying...  
P: Yes [indicates by pointing to the scale].

R: Keep it the same, ok. What about moody?

P: Keep it the same please.

R: What about shy?

P: Stay the same.

R: What about cheeky?

P: Stay the same.

R: What about loud?

P: I always shout loud at the children and they will get upset.

R: Would you like to change that?

P: [Indicates by pointing to the scale].

R: You would like to never be like that. Ok. What about sarcastic?

P: Stay the same.

R: Worry, you said you worry a little bit. Would you like to worry less, more or stay the same?

P: Stay the same please.

R: Bossy.

P: I don't get bossy.

R: Keep that the same then?

P: Yes.

R: What about short-tempered? Would you like to be less, more or the same

P: Same please.

R: Erm getting bored.

P: I don't get bored.

R: Would you like to keep it that way?

P: Yes.

R: Ok, well done. You have done very well. See on this one, on friendly you said you are number four and want to be number six. Can you tell me a bit more about that?

P: Yes.

R: How are you friendly?

P: I was friendly to mum because I want her to be my friend and she wants to look after me and she does.

R: Why do you think its good to be friendly?

P: Hmm...

R: Why do you think that's a good thing to be friendly?

P: You should always be kind to your friends and be polite...no being nasty to someone.

R: Do you think you have a lot of friend in school?

P: Yeah, I have a lot of friends in school.

R: And what do you think your friends think about you?

P: I think they all like me.

R: Very good and why do you think they like you?

P: Because I am a good girl, I can do anything.

R: Ok, you said you are fun to be with. How do you know you are fun to be with?

P: Fun to be with, like playing with other children in the playground or taking turns on the computer or drawing pictures.

R: Ok, very good. You said you are not very confident, you are somewhere in the middle.

P: I am not very confident, I am somewhere in the middle yeah.

R: So how do you think being more confident would be better?

P: Not sure.

R: Ok, you just would like to be more confident?

P: I just would like to be more comfortable.

R: Ok. Well done, you have done excellent on answering all these questions.  
(No questions were asked about the participant's condition on request of the participant's parent).

#### **Transcript ASC 4**

When completing SIP-A part one (What are you like?) the participant made the following comments:

P: A lot of people say I'm funny.  
I am happy in school but I get very worried at home and that makes me very sad and I get very stressed about it.  
I get a bit shy when I see new people I get like embarrassed and all that.  
Good looking, erm... I don't tend to look in the mirror.  
I always feel different from others.  
Annoying...well you have to ask my sisters [laughs].

Moody...depends what my day has been like.

Mess about...depends if...what type of day I have. If it is a hyper day than I mess about a lot like when I was off my tablets I had to be doing my teachers' head in but when I m on my tablets I don't do that.

Loud...if I'm angry.

Sarcastic...It's hard with me cause people say I am sarcastic to them but if they are sarcastic to me I can't take it in because of the way I am, I don't get sarcasm really but I don't notice sometimes that I'm being sarcastic I just see it as messing but I can sometimes give it and no take it.

R: So you are not sure that you are actually doing it?

P: Yeah, I'm just not sure I am actually doing it. I just say sorry if they get angry because I wouldn't say I'm being sarcastic because I don't really know what that is.

P: Worry...erm I worry if there is not bread in the house, it just really gets to me so much its really annoying cause its stresses me so much.

P: Bossy...I don't really boss people around. Do you mean like?

R: Yeah, like bossing people around.

P: Yeah I do that a lot at home but I do it only when I am home I like tell me sister don't get in the shower now, you're not getting in the shower now, I want to get my shower but I only do that because if I get my routine messed up but I don't know if that classed as being bossy to do with the routine. That's one thing...that the woman [refers to a social worker] is coming around to explain about my routine getting messed. I don't exactly wanna be bossy I just do it cause I wanna stay calm.

R: I see, ok. What about the next one?

P: Get bored...Depends what I'm doing. Like I don't get bored at school...I am doing something I am with others like but when I'm at home...my sisters are rubbish to talk to so I just tend to like walk around but then when I get bored I get like bossy...like nasty with everyone and get in a mood because I'm bored.

When completing SIP-A part two (How would you like to be?) the participant made the following comments:

P: Good looking...I'm not worried about that just as long as I smell all right I'm not bothered about anything cause looks don't wind me up, it's smells that wind me up so if you...for example if you have the ugliest face ever but you smelled all right I wouldn't care but if you had like a beautiful face but you stunk I wouldn't be

bothered about your looks I would just be bothered about the smell because just...yeah.

R: Ok.

P: Feeling different from others...its not like that I'm different, it's the fact that I feel like I'm singled out cause my sisters...lots of people do things that I can't do so I feel like I'm getting...so I feel just like that...like mainstream, like I would want to be like that.

R: So you feel you would like to be less different from other people?

P: Not exactly, probably I would like to be just about three.

R: So not too different?

P: So like not too different but I can do the same things.

R: Ok.

P: Mess about...it's not really bad to mess about because it's a bit of fun but one would be better so it doesn't get so lively as it gets.

R: Ok. What about shy, how would you like to be?

P: Zero, you get even more embarrassed when you're shy don't you? You feel more ashamed because you like that...I don't like it.

R: Are you ok if I ask you some questions about these scores?

P: Yeah.

R: You already said a lot about it, which is fantastic. Erm...you said you would like to be a lot more happier. Can you tell me a bit more about that?

P: It's not like...its like I can be happy but I like get depressed like sad a lot because I see others...like my sisters are the ones cause I'm always with them. Like at school I don't get sad, like I might get upset if I had an argument with someone but it gets sorted but when I'm at home there doesn't seem to be ever like anything like they all do things but I can't and I get very...like I can be a bit happy but then I can get sad very easy because I want to do what they are doing like go out on my own but I never get to do it so I always get a little bit stressed about it.

R: Hmm. How old are your sisters? Are they older or younger?

P: One is 19, one is 17, one is 13. I am 15.

R: I see, so you are the second youngest.

P: Yeah like the one that's 19...like I hate her. I can't... like she is jealous of me cause she sees that I get more things than them but I don't, I only get a bit more attention from my mum because I...like if my mum wants to take me out they get

very angry about that because they think that my mum is just singling them out but I think that I'm getting singled out because they can all pick themselves and go out but I sit there bored again so I get more and more stressed so I can be happy at some times but I get very sad easy when I see something that I can't do which is quite a lot of the time and it always seem to be around my oldest sister.

R: Ok, so you said you get upset when there are things you can't do like going out on your own. Is there something else you get upset about?

P: Just like all...like things you can do like go out do things like have mates and all that sort of stuff. Like go to a proper school...like I know this is a proper school but I mean like being with the thing. So I get quite depressed because of all that and that's why this always happens [points to 'get bored' item on the scale].

R: Because you get bored?

P: Yeah, very easily like there is nothing to do. I would be doing something for a minute and then I would be like why do I have to do this? Why can't I just do that? So I like get very...like it leads to outburst and that happens quite a lot.

R: So that kind of goes along with this one, when you said you feel quite different from people because you can't do the same things, is that right?

P: Yeah...God the smell is coming back [smelling her jumper] dampness cause there was a bit of water in it but...it'll get washed tonight...See this is worrying now.

R: I see, like you said you worry a lot about these things, right?

P: Yeah, I'm terrible for worrying, terrible for worrying. I worry about things that...I think my mum is bit the same she worries about things before it even happened. Like she worries about what will happen, what might even happen. But I always tend to do that quite a lot like worry. For example like now when I go home and someone starts fighting but my mum and dad, everyone tells me...stop...don't worry about it until it's actually happened but I am worrying in case this happens. And I worry, I know this sounds very bizarre but I get worried like if we only have a tiny bit of bread left like I start mindering my mum and dad to get some and sometimes like I get annoyed because I would like...I would happily pick myself up and get it to stop me worrying about it but I have to wait all the time and the more I'm waiting the more I get worried about it so making like...like me not being able to go out and do things makes me worry more like in case things are not going to change. So like if I know you were worrying about something you would go sort it

out wouldn't you? I would have to go out for someone to go out and sort it out for me, which takes about a year. Like I am getting worried about, like my social worker...I'm supposed to get my shower built because of my routine and that and I'm getting worried because my social worker has been off for four months so I haven't been able to get that sorted and I'm worrying constantly over that.

R: So is that about your shower?

P: Because in the house I have to have a certain time when I have my shower and have to be first in the shower...I don't know...its just because the way my routine is organised because the more I am wondering around the more I'm wound up because I'm looking for things to moan about that are worrying me because I have to constantly look for something to do so having my shower calms me down but because everyone else in the house I take about an hour in the shower and they can't all have a shower then. And after ten o'clock I won't let them have a shower because I want to go to bed and if everyone has a shower we are all up till one o'clock in the morning and then my mum doesn't get happy about that either because she can't get them up for school so I need another shower built so they can have their showers when they want and I can go to my own shower so I don't have to worry about everyone else, I can just do what I want.

R: So you are waiting for that to get sorted out?

P: I have not heard nothing else from her for months.

R: I see. Ok. Let's have a look at this. Here on friendly you said you wanted to be more friendly. Can you tell me something else about that?

P: Well like I get annoyed with people a lot and like if I like...can you like explain a bit more what friendly means?

R: Yeah, so friendly...say you have people at school that you are friendly with or...

P: Like you are nice with them?

R: Yes...like...

P: I do that quite a lot but its sometimes hard for me because I feel like I'm being nice but I'm doing something wrong everyone tells me, like when I was talking about my sisters like that's the part of the sarcasm like when I'm talking to them I'm thinking in my head that I'm being perfectly fine with them, doing nothing but actually I'm doing something bad but I don't know. Because like my mum and dad say although you like think you are being friendly you're actually doing something

bad but I like think what have I done bad? I don't know I have done something bad, I only said what you said.

R: I see. Ok. Thank you.

R: Is it ok if I ask you some questions about autism now?

P: Yeah that all right.

R: Ok, can you tell me what you know about it?

P: It's your social skills, you like...it's like your life, isn't it? It's different, its like autism is lots of things, it can be anything, can't it? It's like a rainbow, isn't it? And there is like...one side is like...what's the word...it's like severe and there's like mild and there is like...everyone of them is like different types and like the severe ones are like the ones who don't speak and like who...there is like in the middle like those who do speak but they can't communicate. They like flap their arms and that and then there are other ones like me but can't do...like with the social skills and things and that's what autism is really, just your social skills and all the life things.

R: That is a very good explanation. Can you tell me a bit more about...you know how you feel about having autism?

P: I do get a bit jealous of mainstream, I would rather be mainstream but I mean it doesn't like...what I'd prefer is if everyone would like stop rubbing it into me that I'm like autistic cause I don't really like to know I am autistic cause what the problem is...is like when I'm on the streets, the thing why my mum and dad don't let me go out is because I just...you'd look at me and you wouldn't think I've got autism have you? But you would look at like...I'm not being nasty but like you'd look at someone else like Ben and them...I'm not being horrible but you would know straight away there is something wrong because of the way they act but you wouldn't look at me and think she's got autism but so when I'm out on the streets, like when I'm out with my mum somewhere it seems annoying cause when I go out I just act like a normal mainstream person but there seems to be like little problems that shot at me like if I do a little bit like...like yesterday I walked in town like that with my hands [hands lifted to her chest] and cause I don't like walking with my hands down the side I just walk like that and straight away the lads started to skit me about it but I didn't look like I was doing anything but straight away they were skitting me and saying I look like something so I don't know why, you wouldn't think when you look at me but like when I go out people tend to like take the piss



out of me but I don't know how they get to see that and plus I am an easy target cause straight away I just start arguing back with them cause I just can't let it go.

R: Ok.

P: Like my sisters would let it go but then they start...like if you ignore them then they like start following you around trying to get you more reacting but I don't know what makes them wanna do that.

R: That must be hard when you are out and that happens.

P: That's why I can't go out like cause I have to have my mum and dad with me but then I feel like I like a baby cause my sister is 13 and she can go into town on her own and I'm not allowed to do that and when my mum and dad say that they will take me out they all start moaning that I'm just my mum's favourite. But I can be out with my mum sometimes...yesterday I went for a walk and the lads started saying "Look at that mong" and I just ignored them and they started throwing things and then my mum turned around and told them to pack it in and then they like started saying like: "Look at her". But then my dad saw the lads and told them off and saw these other lads and asked them if they've seen them and they said that they're always like that when they do that all the time they tend to do it like...but my dad gets so angry with them all the time.

R: I am sure he does. Hmm. Do you think there are any good things about having autism?

P: Hmm, not really. It's not there is like nothing good but if you're like more on the severe side you won't notice the difference cause you couldn't tell cause when you're so severe you wouldn't understand, you wouldn't know the difference between that and that but with like the type of me you can...because you can see...cause you'd look and wouldn't think like she's got autism cause you're like clever and that because you're mild, it's just you notice more things and you can tell the difference between them things. So you seem to have a look at it and think, well why can't I do that? Cause you can do it, you wanna do it but then you get told that you can't do it but yeah it's not the best of things to have.

R: Hmm. If there was something you could change, would you change anything?

P: What you mean like my needs or what?

R: Like about you having autism or about...

P: Well, it's not exactly the autism that's the problem it's the other things that like to do with autism like the OCD and ADHD, its more them. Like my AHDH is a

problem but when I'm off my tablets but I don't mind cause it's now sorted. But its more with my OCD, that's what makes me get very very stressed a lot cause I just want it to go the way I've said it so that's the one I would rather change the OCD because I get so worked up that's what makes me so worried about things.

R: Ok. Thank you so much for answering all these questions. You did very well.

### **Transcript ASC 5**

When completing SIP-A part one (What are you like?) no comments were made by the participant other than indicating scores on individual items.

R: Ok, so this time we are going to go through them again and instead of answering what you are like now I'm going to ask you what you would like to be. Ok? What about kind you gave yourself a number six.

P: Oh yes, you see I first was really... don't know how to be kind but since I got this maturity, since I was eleven...when I was nearly twelve, I started to see a new gate, a gate of sensibility and maturity.

R: Ok, so you think you would like to be the same?

P: Oh yes, very the same.

R: Happy, do you want to stay the same?

P: Yes.

R: On friendly you gave yourself number six. Why do you think you are friendly?

P: Maybe because since I've got this maturity I've been well...lets say I have been more friendly than when I was eleven or ten.

R: I see. How old are you now?

P: I am twelve. Twelve and a half, nearly 13.

R: So you want to stay the same?

P: Yes.

R: What about funny, you gave yourself number six.

P: Yeah, I've got all my jokes.

R: I see, so you want to stay the same?

P: Yes.

R: What about helpful?

P: Stay the same.

R: What about hard working?

P: Yes, I've been a lot of hard working at school and erm I do...I do my best.

R: What about talkative, do you want to stay the same?

P: Oh yes, I like chatting with my mates as well as chatting with the members of staff.

R: Ok, you said you are very confident. Tell me a bit more about that.

P: Well, the only reason I said I was six at confident was that I was acting like some kind a leader of...like if I...like if I...so I feel very confident cause like I am the strategiest of class Melanie (classes are named by the teacher's name) and if I was in World War II, I could have made a sergeant.

R: Very good. So you would like to stay very confident.

P: Yes, stay the same.

R: On sporty you gave yourself number five, how would you like to be?

P: I would like to be more sporty, yes I would like to be number six. Besides I was only kidding about the whole thing. See...look at how much weight I lost. First I was like chubby but not I am like...slimmed down to that...It was amazing that and if you move to good looking that would definitely stay the same.

R: Ok, very good. Fun to be with, you gave yourself number six.

P: Oh yeah, very much. Most of all, the most important...most of people like me... they really me and they always follow me around and I am really good at drawing and most of all...it is kind of a...well...my life style, I am fun to be with.

R: So you would stay the same then?

P: Oh yes.

R: What about intelligent. You gave yourself number six.

P: Well I was...well I was...I wasn't intelligent when I was little. Can you imagine how intelligent I got by focusing on every website and putting it in my brain and in fact I have a very good memory I can even remember that Toy Story two was made in 1999 when I was born.

R: Ok. Very good. So you want to stay the same?

P: Yes.

R: Ok, let's have a look at these. You said you don't feel different from others. Is that right?

P: Well, no.

R: Why is that?

P: Well, first of all I started of...when I first came to school I met two people that really felt that I was different. It was Mike and Patrick one of my best friends. The spirit about them is inside this classroom and that's why I agreed to be in this classroom and anyway...

R: So you don't feel different from others at all?

P: Yeah, I don't feel different from others.

R: Ok, what about lazy. You gave yourself number one. Would you like to stay the same or be different?

P: I'd like to be like none at all because I'm like hypergenetic with timing and all.

R: Ok. What about annoying you gave yourself a zero. Would you like to stay the same?

P: Yes and I used to be annoying but now I find that...again like I found with this maturity that I've been matured and stopped being annoying.

R: Ok, is that similar with being moody?

P: Yes.

R: Ok, you would stay the same?

P: Yes.

R: What about mess about, you said you were number one.

P: I would give it a definite zero. I never mess about on a job like this.

R: You are doing really well. On shy you gave yourself number three. Would you like to be different?

P: I would like to be number one.

R: Why would you like to be less shy?

P: Because I have...In all concerts I have a little bit of stage fright at first but then as soon as the final line comes up I reveal my face, look on the ground and keep doing the song. Could you imagine what its like to first step into the light of maturity?

R: Ok, very good, so its number one. On cheeky, you gave yourself number six. Would you like to be less cheeky or stay the same?

P: Well I think I would give it like half percentage to what is it now.

R: Ok, so you would give yourself number three.

P: Yeah because I do it sometimes as a joke.

R: I see. What about loud. You gave yourself number two. How would you like to be?

P: One.

R: What about sarcastic? You gave yourself number one. How would you like to be?

P: I would be in between zero and one.

R: Ok, let's have a look at the next one. Worry a lot.

P: I would give it two.

R: You'd like to worry less?

P: Well yes, I am kind of...don't want to worry about anything. I am kind of scared of wasps they are not sort of my favourite bug.

R: You said you are not at all bossy. Would you like to stay the same?

P: Oh zilch.

R: What about short-tempered, how would you like to be?

P: I would give it a definite zero because it takes me a long time to get tempered...not at all.

R: Ok, very good, I only have a couple more questions. Do you know anything about autism?

P: Well autism it's like the treasure of this school, like a big little diamond that's in-sealed in every student of this school.

R: So what does autism mean, say if I didn't know what it was?

P: It means you have this like sort of like this little problem and this school is helping you out. It's kind of like the next generation of helping out. Besides when I was younger I did not know anything about this autism let alone that like it can get too worse but as you know you improve something....what is the most important to some people but not important to others...and the answer is your mind.

R: You mind?

P: Yes, they try to improve your IQ every day you are still in the school. The answer is right in the...its like...erm...in our teachers...in our headmistress' words.

R: Ok, so do you know if you have autism?

P: Well I did know now, I really did know now.

R: And you said that when you were younger you didn't know. How did you find out?

P: Well, when my mum told me that I have autism, honestly now that I know about this autism I really am getting a feel of kind of special, like a special jewel.

R: Ok, so do you think there are any good things about having autism?

P: It really good because they help you to calm down, they give you like special therapies like Bowen, I would love it and I love the school and when I probably leave it when I'm older I would probably miss it, I would miss my mates.

R: Ok, and do you think there are any bad things about having autism?

P: Bad things? Well only that it stresses you out, sometimes it makes you more frustrated but whenever the teacher will always be there to help, will always be here...here to help you out.

R: And how does having autism make you feel?

P: It makes me fee very special.

R: Ok, thank you. Well done, you have done really well on these questions.

### **Transcript ASC 6**

When completing SIP-A, no comments were made by the participant other than indicating scores on individual items.

R: Ok so we are going to have a look at some of these scores you have done in a bit more detail...so friendly, you said that you were very friendly.

P: Yes, Yes. I be very much friendly.

R: How do you know that you are very much friendly?

P: Because everyone!

R: Because of everyone? You've got lots of friend then?

P: Yes. Yes I do! Yes because I'm a listener!

R: What does it mean to be friendly?

P: 'Coz' friendly to be nice. And you shake hands towards others.

R: I see. You also said that you would like to be a bit more funny than you are?

P: Yes, because there was a little bit.

R: What does it mean to be funny?

P: [Laughs] to be very much.

R: How does it make other people feel?

P: Happiness!

R: And you would like to be more like that?

P: Yes! Haha [laughs] funny!

R: So confident, you said you were very confident. So how do you know that?

P: To be very confident is to talk.

R: Hmm so how do you know that you are very confident?

P: In maths.

R: So what kind of things can you do when you are confident?

P: What kind of things can you do? Like writings, like meeting peoples.

R: Is it good to be confident?

P: Yes! Yes it's ok just relax [yawns].

R: Shy, you said you were not very shy?

P: Yes I'm very shy.

R: Here you said that you were not very shy.

P: Yes a little bit shy.

R: Hmm so why do you think you are only a little bit shy?

P: I'm on number one [indicated by pointing to the scale].

R: Ok, you said you were not very shy. So how do you feel when you meet someone that you don't know?

P: To be shy, to be shy. To be leaving.

R: When you're introduced to people that you have not met before and they say hi, do you feel ok with that?

P: Yes, yes.

R: Ok. Different from others, you said that you were very different from other people.

P: Yes. Yes I am very different.

R: Why do you think that is?

P: That means that I'm different to the other peoples.

R: Hmm so what's different about you?

P: Different about me? I'm so tired because I'm thinking hard now.... So tired....  
[Makes a snoring noise].

R: Can you tell us why you're different from other people? What makes you think that?

P: Because I'm different from the ladies.

R: In which way?

P: In class ten.

R: Different from the children in your class? In what way? Can you give me an example?

P: In class twelve. Yes.

R: Is it a good thing to be different?  
P: Yes, yes good thing!  
R: Why?  
P: Because I love being different. Little bit of different things.  
Teacher: Why are you different?  
P: Because I'm different! I'm different!  
Teacher: Do you not know?  
P: I don't know.  
R: That's ok! ... So you said you worry a little bit about things, why do you worry?  
P: Because I worried, because I was shy. What you doing Hannah?  
Teacher: What am I doing?  
P: Hannah, don't be shy to the other friends.  
Teacher: Why are you worried?  
P: I'm worried about Lisa, because she is my friend! I'm leaving soon.  
R: Ahh so you're worried about leaving your friend?  
P: I'm sorry I'm sorry... quite a lot [groaning noise].  
R: What you sorry for?  
P: I promise I love Andrea because she is my friend.  
Teacher: Yes Andrea and Lisa are both your teachers and your friends.  
R: I'm sure you'll still keep in contact.  
P: Because they are friendly. Lisa nice to be friendly.  
R: Yes.  
Teacher: And you still have three years left at school yet.  
R: So that's still quite a long time yet.  
P: Yes I have a long time yet.  
R: If you could change anything about ...  
P: I could change my friends, mum and dad.  
R: If you could be different in anyway...  
P: It's ok. I'm different anyway, to be part to be born. It's getting bored.  
R: You are getting a bit bored? Well we've just got a couple of questions left on this one and then we are going to start something else.  
P: What?  
R: I will show in a minute.  
Teacher: Well finish this and you will find out.



P: Ok.

R: Do you know what autism is? .... Have you heard that word before?

P: Not a word I've heard before.

Teacher: Are you listening? Concentrating? Being sensible?... Have you heard the word autism?...

P: Autism.

Teacher: have you heard that word before?

P: Yes! ... Oh Andrea is going to miss us! Oh I promise! [makes loud noises].

Teacher: Being sensible please, so I can go back to class and tell Lisa.

P: Yes please. Yes ok I promise. I am finished now anyway.

R: Thank you.

P: Thank you.

R: Have you heard the word autism?

P: Autism ok yes.

R: What is autism?

P: Yes. Thank you for introducing to me... I don't know, I know [makes loud noise].

R: Thank you, you've done brilliantly.... That is the end of the questions now. Thank you very much.

### **Transcript ASC 7**

When completing SIP-A, no comments were made by the participant other than indicating scores on individual items.

R: See on this one, friendly, you gave yourself number six. How do you know you are friendly?

P: A lot of people say that I am friendly and I know for myself that I am very friendly.

R: What about feeling different from others, you said you were number five.

P: I didn't really understand that one so I just put something.

R: So how about with your friends at school...Do you feel the same as them or do you feel different?

P: Yes I do feel the same yeah.

R: Ok, you also said you would like to worry less. Do you worry quite a lot?

P: Yeah I do. I bottle things up but I don't bottle things up as I did. But yeah, I'd rather not worry [laughs].

R: And bossy you said you want to be a lot less bossy. How are you bossy?

P: [Laughs] I do tell my brothers not to do things...

R: Are they younger than you?

P: Yeah.

R: Ok, some of the questions are about autism. Is it ok if we ask you about that?

P: Yeah.

R: We spoke about autism together before, you were telling me about how you find it and how it effects you...

P: Yeah, I find autism now as erm...I know that I am different but I know that I can get on with it and I don't mind telling other people and I know I can trust them and I find that I have two friends when I go away and my mum did tell them and explained that I find it difficult and since then they helped me a lot and I find it that when I tell people they do treat me differently but not badly but they treat me better than they actually did so I find it better.

R: When did you find out that you had autism?

P: I don't remember it actually...I think it was when I matured a little bit more and I think I think my mum said you have autism and stuff like that and she explained what it was and stuff but there is some things that I still ask mum and she explains what is it.

R: Ok, what is it that you find most difficult about it?

P: Erm...explaining to people like talking to people and explaining how I feel. I mean I got better but I would like to work on it a little bit more.

R: Do you think there are any good things about having autism?

P: No.

R: Ok. I am just going to go back to some of these scores...why do you think you are confident?

P: Erm...I don't know actually...I think this school has made me more confident and I can do a lot more things without worrying and I have changed and I don't worry about it so I feel confident in going...doing more, doing new things.

R: Is that something that you used to get worried you...about change?

P: Yes, I used to hate change and I mean I still hate it now but I don't worry as much.

R: What was it like on the mainstream school you went to?

P: It was horrible [laughs].

R: Why did you find it horrible?

P: No one understood me and that. And I found the work difficult and that because no one understood where I was coming from and how to help me and that.

R: So did you feel that was a big change in coming here?

P: Yeah.

R: Did you feel like you were understood more?

P: Yeah.

R: You know when we were talking about feeling different from others, you said you don't feel different from people in the school. What about...do you have friends outside of school?

P: I don't have any local friends, I have two friends who live in Manchester. I don't feel very different from them because I'm just a person they are and despite what I have I'm still the same. I mean I might think differently and my brain can work differently but I don't really care [laughs] knowing about autism I can get it out there and feel better about myself as soon I can trust someone then I can tell them and then it's out there and I feel better.

R: So you think that telling people that and having that explanation makes it a bit easier?

P: Yeah.

R: What do you tell people when you tell them about it?

P: I have my mum there with me to sort of help me explain it more and I just say I've got autism and my brain like works differently and stuff like that and my mum can explain it a bit more because she experienced it. Like I mean it's coming from me but she obviously experienced it a lot more having a child with autism anyway.

R: Ok. Well, thank you very much, that was really helpful.

### **Transcript ASC 8**

When completing SIP-A, no comments were made by the participant other than indicating scores on individual items.

R: Ok Thank you. Is it ok if I ask you a few questions about how you scored these?

P: Yes.

R: Ok. What about happy, you said you would like to be more happy. Could you tell me a bit more about that?

P: Hmm. Just get more happy and that. I already am but I'd just like it a little bit more. Don't want to worry a lot you know.

R: Ok, so you said about worrying you said you would like to worry less.

P: Yeah, I don't want to worry at all. I don't want to. I don't know how, I just sometimes have days when I do but... yeah.

R: Ok, so you want to worry less.

P: Yes.

R: Ok, so what kind of things you worry about?

P: Sometime when I'm in school, sometime in FE playing football that's all. But I do enjoy it you know but sometimes when I make a mistake I don't want to start and that which I worry about but maybe he won't do it again but he might.

R: What do you mean he won't do it?

P: Like 'skitting'.

R: I see, ok. Now you said you are quite friendly. How do you know you are friendly?

P: I just give people smiles, say how are you and that.

R: Ok, do you think you have a lot of friends?

P: Yeah.

R: Ok, do you have friends in school or elsewhere?

P: Anywhere, anywhere yeah.

R: Ok. What about funny, you said you want to be more funny.

P: Yeah, tell jokes more, interact more with kids and that.

R: Why do you think it is good to be funny?

P: Because they like you.

R: Ok, very good. Hard working you said you want to be more hard working.

P: Like help around the house more, I'd say yeah.

R: Why do you think that is a good thing?

P: It means I'm helping out in the house.

R: Your mum would be happy? [laughs].

P: Of course [laughs].

R: Ok. What about talkative, you said you would like to be more talkative.

P: Yeah, like interact more, communicate more I think.

R: Ok, do you think you have sometimes problems with that?

P: Sometimes, but I feel confident when I do.

R: Ok, that's very good. Confident is actually the next one. You said you were quite confident. Why do you think you are confident?

P: Because I'm here at this school, it's gonna help me to be more confident, at this school yeah.

R: Is that what you found here yeah?

P: Yeah more than I did before.

R: What kind of school did you go to before?

P: A high school.

R: How did you find it there?

P: Just boring, it was nothing. They were idiots.

R: Ok, so what was your confidence like there?

P: Not that good to be fair.

R: So do you think that has changed?

P: Yeah, a lot yeah. It really has changed a lot.

R: Hmm...why do you think it changed?

P: Because I'm with this school.

R: Very good, ok. Now on good looking you said you want to be more good looking. Why do you think that?

P: I don't like the way my hair is. I'm not like the good looking lads but I'll improve one day, loose some weight.

R: Ok, now this one you said you are number four on feeling different from others. Why do you think you are different from others?

P: Because I'm autistic.

R: Hmm.

P: But sometime I don't show it, like when I'm at home I don't show it, I'm different.

R: And you said you would like to be more different from others. Is that right?

P: Yeah, more different in the school.

R: I see, ok. In what way do you mean?

P: Like they are autistic. I want to feel like I don't have autism. Like I do, but I don't show it, I don't act like other kids do.

R: So you think you would like to be more like people that do not come to this school?

P: Yes, that's exactly yes.

R: Ok. Now...you mentioned autism. Can you tell me what you know about autism?

P: That they think different which when people...I mean I take things as a joke but when it gets too far I sometimes don't but...I mean like kids in the school if someone said like... they like take offence but I take it like a joke. I'd just say like...I'm not gonna say that because you're my friend but...erm...other kinds in the school would. I don't wanna be like that. I want to take things as a joke.

R: So you don't want to say things too...

P: Seriously.

R: Ok, is there anything else you know about autism?

P: That they worry too much. They are not capable sometimes of doing things.

R: Ok. How do you feel, how do you find it being autistic?

P: Sometimes hard like other people but I just lift my head up and just interact basically.

R: So it is something you might struggle with sometimes...with interaction?

P: I sometimes don't know what to say in conversation and that, that's the thing but you know... I like football and that so I do speak you know but if for example my dad is speaking with all of his friends I don't know what to say but you know I do interact, that's the main thing.

R: Ok, fantastic. Erm...do you think there are any positive things about having autism? Any good things about it?

P: Not sure.

R: I know that is a hard question, do you think there is something you can think of is good about it?

P: Erm...If someone else had autism then it probably would be like you know you can speak to someone using your language you know...speak the same as I would like. You know but there are lads out there like me who speak like me but don't have autism, which is good. I can't think of anything else.

R: Ok, that a very good answer. Is there anything you can think of that's bad about it, that is negative?

P: Well say like I'd say a joke in FE, they like don't get it. They haven't got sense of humours and they don't fuss, they are not like lads who say like "you all right Zack" or like "How are you doing mate?" They don't do that in FE with me, that's like what I don't like about it cause they are supposed to be...you know on my side but you know but they like... you know don't understand really, not like other lads. They are quiet and I don't like that.

R: I see, ok. Is there anything else that you find difficult about it?

P: I had an idea before but then it went erm...I don't know.

R: That's ok. If you could change anything about yourself, would you change something?

P: Me not having autism basically.

R: How do you think that would change things for you?

P: I would be able to talk better, look better but I know that's not gonna happen.

R: Hmm. Ok, thank you for that. I think you did excellent at answering these questions, I know some were quite difficult. And as you said... it is very good that you focus on the good things and stay positive.

P: Yeah.

R: Ok, are you ok to finish there? Do you have any questions?

P: I'm fine. I'm fine.

R: Ok.

### **Transcript ASC 9**

When completing SIP-A part one (What are you like?) the participant made the following comments:

[Confident]

P: I'm starting to build up on that. I'm getting better at it.

R: Why do you think you are getting better?

P: Because when I first started here I was a lot different to what I'm like now.

R: And why do you think that is?

P: Because I felt that I had a lot of help over time and I've known myself a lot better over the years, it's just taken a lot longer too... yeah.

R: That is interesting that you say you know yourself better.

P: This is part of the autism I think that you might...its hard to explain but its like I think I'm a completely different person to what I was a few years ago.

R: In what way do you think you are different?

P: Just that I'm a lot more, just got a lot more independence, a lot more erm...just all around skills I'm just better than I was a few years ago because yeah I didn't really have a good high school life but then I went here and then they really helped me over time, they really improved me. Even I see pictures of me a few years ago and I think I've changed a hell of a lot which I think it's for the better.

R: Ok, that is very good.

[Intelligent]

P: I would give myself four again. There are lots of fours, I think I'm quite a balanced character.

[Feeling different form others]

P: Number four because I feel different sometimes, to be honest I do.

R: Why do you feel different from others?

P: Certain ways I notice sometimes I act, sometimes I act different to what other people sometimes do. It's the situations sometimes...but it's quite erm... I already know that autism is a bit of a hidden condition its when you don't notice it that much but its actually there. Most of it is just through social communication the way they can't show it on their faces.

[Moody]

P: Three. But I'm not sure if that's slightly moving now because I'm older, because of the changes, just moving on a bit. ... Not sure if it should be higher but leave it at three.

[Shy]

P: I give that a three. Sometime I get a bit quiet in front of new people.

[Sarcastic]

P: Three I think. I can be a bit sarcastic sometimes. You can hear it in my voice.

[Worry a lot]

P: Give that four.

R: do you worry sometimes?

P: To be honest I do. Anxiety is one of the main problems I have. In certain situations I just get this anxiety and it sometimes builds but I can recognise it. Sometimes it's hard to control but I try to think of the strategies to help me with that



and hopefully it might disappear one day, hopefully.

R: That's very good that you think about strategies to cope with the anxiety

P: Yes. I get anxiety and a bit of stress. Its like mixed really. Sometime it can change me.

[Friendly]

P: Stay the same. I do try to be friendly, there are just times when you loose the friendliness. It depends on what they do to you

[Talkative]

P: Stay the same. I used to chat a lot. That's something I improved on. When I was younger I didn't know facial expressions on people and I used to talk a lot, a lot more than I do now. It's part of my social communication. I sometimes couldn't notice the difference, sometimes in their voices, sometimes how they act in their face but I'm a lot better at that now.

[Confident]

P: Stay the same. I think the more confident the better. But then you can be too confident, it's good to keep a balance really.

[Sporty]

P: Stay the same but you never know about the future, I might want to do some more, maybe go to he gym. Maybe keep it at three. I don't want to go all the time like some other people.

[Feel different from others]

P: Maybe try to get it on to number three for feeling different from others. I'm still trying to build on that, trying to stop myself thinking that I am...trying to get myself a bit out of it but erm...sometimes it's hard though, hard to detect it, sometimes I think I can't. Sometimes it's hard to change.

[Worry a lot]

P: Maybe in the future. Maybe it's a good thing to try and worry less a bit. That will take time though so it's best to keep it there [same score] for now. It's a hard one really because people develop over time, so I might just grow out of stuff.

R: So you think that in the future you would like to worry less?

P: Maybe, yes, keep it at three...cause I know my mum worries a lot so maybe it is in the family and my uncle can be a bit short-tempered sometimes so both of them

can be in the family really. So I think I recognize that it's a part of the family. But then I again I might be a bit more short-tempered just because sometimes I might have a bit of a struggle just like different things, like in can set that off a bit more. It's just the way I am.

R: Ok. So you we already talked a bit about autism and mentioned a few things. Can you tell me a bit more about what you know about autism?

P: It is difficult to explain...

R: How does it feel having autism?

P: It's quite mixed really. Sometimes I might fight it, sometimes I just have to get on with it because that's just who I am but I am agreeing on it a more than I did in the past like I think when I was in my teenage years I was starting to feel a bit...get a bit...erm...but I don't know if I still feel it now, I am trying to control it a bit more, just to say that's the way I am, just trying just live with it really.

R: Do you think there are any positive things about having autism?

P: Erm...that's a hard one. Erm...people could help you more that's the one thing about autism people can help you more, bit more...might get a bit more support from people.

R: Is that something that you found? That people give you more support?

P: Sometime yeah. But sometimes I do keep my condition to the minimum sometimes, I don't like it too much spread around.

R: And what do you think are the negative things about autism?

P: Yes, slightly bit more negative than positive I think. It can be a bit of a struggle sometimes. The anxiety for starts, it might kick off, sometimes even without any notice, it can just come, erm...stress levels all sorts like that can be a part of it. Confusion sometimes like in my head cause I get things like that a bit. A bit of frustration. It's like mixed really.

R: Before you mention things about social contact and understanding people. How do you feel about that?

P: Doing better now. I understand how people react to different things and that, I am a bit better. I am a lot better at understanding that kind of stuff.

R: Ok. You did really well at answering all these questions. Thank you.

### **Transcript ASC 10**

When completing SIP-A, no comments were made by the participant other than indicating scores on individual items.

Participant chose not to complete the SIP-A follow up interview.

### **Transcript ASC 11**

When completing SIP-A part one (What are you like?) no comments were made by the participant other than indicating scores on individual items.

P: Hard-working... I don't work hard a lot.

P: Talkative... I don't like to talk a lot, I think talking might distract my feelings... some talking might hurt my feelings.

P: Lazy... of course I'm not... might be a zero for that.... No way I should be lazy no way.

P: Annoying... No, I'm not annoying

P: Moody... Never moody, no way.

R: What about mess about do you mess about?

P: What does that mean?

R: It means, for example, when you're in the classroom and your supposed to be doing work do you not do your work and get distracted and do other things?

P: Yeah I do that... I do that a lot because I'm more concentrated on staying at home and playing my games.

P: Shy... because I don't talk a lot

P: Cheeky... especially in school... most people think I'm cheeky cause I do things that they don't like.

R: What kinds of things do you do that are cheeky?

P: I find their weaknesses and use them on them... of course I'm not... well... I use music, I use loud music... erm so I'm a three on that. I don't shout, no, I don't talk, I don't say something loud I just be loud with music. Especially game music.

R: What about sarcastic?

P: What does that mean?

R: Sarcastic means that you might say some mean things to people, you might speak to people in a not very nice way.

P: I can be kind of when I'm old... not happy at all.

P: Bossy...of course I am, cos I wanna do the things I wanna do.

P: Bored...especially in school and home when I don't find things very exciting that often.

R: OK so now what we're going to do is we're going to go through those words again. But now I want you tell me what you'd like to be like. So for kind you put yourself as number five, so would you like to be more kind less kind or stay the same?

P: Erm, I'm happy with that... in fact I'm happy with all of them... Oh what does confident mean?

R: It means that... well the opposite of confident is shy, so shy means that you don't like to talk in front of people, you like to keep yourself to yourself. Whereas confident is...

P: Well I don't talk to people very close to me so I talk away from them... stay back...keep away from me...so lets all of them the same stick it with that.

R: So you want to keep all of them the same?

P: Yeah. I'm not switching.

R: No?

P: No, no way. Erm... let me see my rank.

R: What about with this one, getting bored, you said you'd like to stay that way but you put that one quite high. Do you think you'd like to be less bored? Would you like to find more interesting things to do?

P: Yeah, I'm finding I'm getting bored often.

R: So do you think you'd like to change that number would you like to put it as one lower?

P: No I don't want to lower that no... cause I'm getting bored going to school almost every time like five days, that's boring for me... that's why I put it as a four.

R: So what about this one you put as friendly that your number five, which is very friendly.

P: All of my favourite staff are in other classes that will be very boring for me... Erm... if I find my favourite staff at these past years. Can I look at my rank please because I think I've finished with that now.

R: OK, thank you for answering all the questions.

### **Transcript ASC 12**

When completing SIP-A, no comments were made by the participant other than indicating scores on individual items.

R: Can you tell me what you know about autism?

P: [No response].

R: Erm...we mentioned earlier that you have autism. How do you feel about that?

P: [No response].

R: Does it make you feel any different? Your sister said it made her feel happy. Does it give you any feelings?

P: [No response].

R: Do you feel any different from others? Or do you just feel the same as everybody else.

P: [Nods].

R: Just feel the same as everybody else?

P: Yeah.

R: Are there any good things about having autism or are there any bad things about having it?

P: I don't want it.

R: You don't want it?

P: I don't never want to have it.

R: No, is it a bad thing?

P: Yes.

R: Are there any good things about it?

P: No.

R: Ok, well done, we will leave it there I think, you have done really really well.

### **Transcript ASC 14**

When completing SIP-A, no comments were made by the participant other than indicating scores on individual items.

R: Ok, so I've got here that you are very much kind, at the highest level; why do you think that?

P: I think I am kind to me friends.

R: Yeah, good; can you think of anything else?

P: Shaking hands and saying please, please and thank you.

R: Very good. Ok, funny, you've put you think you are very funny.

P: Yeah, hilarious.

R: Why's that?

P: Cause I tell jokes.

R: Ok, and you've put very confident, why do you think that is?

P: Erm...

R: Confident means that you can be brave when you are in front of people

P: Gangs of lads, groups of lads.

R: What's that? You don't get nervous in front of gangs of lads?

P: Yeah. Me mum does.

R: Your mum does, but you don't?

P: No I don't.

R: What about if you had to get up in front of the classroom and you had to read your story out; how would you feel about that?

P: Erm...bored

R: Bored? So it wouldn't make you worried?

P: Never worried.

R: Ok, so you said you're not at all shy.

P: A little bit, yeah.

R: A little bit?

P: Yeah.

R: You said you don't worry a lot. Why is that?

P: Worry about thunder.

R: Is that the only thing you worry about?

P: Yeah, thunder is really hard.

R: If you could change something about yourself, what would you change?

P: Erm...I'd like to be a man

R: You'd like to be a man, ok.

P: I'll stay like this.

R: You want to stay the way you are?  
P: Stay the same.  
R: How about lazy, you said you are little bit lazy.  
P: I sometimes put my feet up.  
R: You like to put your feet up?  
P: I'm lazy when I have a lie in...I just like relax.  
R: Ok, you also said you are very loud and maybe you'd lie to be less loud?  
P: Cause I shout.  
R: I see. I just wanted to ask you about autism. Do you know what it is?  
P: No.  
R: Not heard of it before?  
P: No, don't remember. Don't know.  
R: Ok, thank you very much.

### **Transcript ASC 16**

When completing SIP-A, no comments were made by the participant other than indicating scores on individual items.

R: Look at this one, you said you are number six on friendly. Can you tell me why you think you are number six?  
P: Because I like to be friendly, I make cup of tea and coffee.  
R: You make people cups of tea and coffee?  
P: Yes.  
R: So how do people know that you are friendly?  
P: Because I like to be friends around school.  
R: So have you got friends at your school?  
P: Mike.  
R: Mike is your friend?  
P: Yes.  
R: Ok, well done. On confident you said you are number four and you would like to be more confident. Can you tell me more about that?  
P: Very confident means...What is confident mean?  
R: Confident means you are not shy...you like to talk to people.  
P: I'd like to talk to staff more about things.

R: You'd like to speak to staff more about things?

P: Yes.

R: What kind of things would you like to talk to them about?

P: What we did for lessons.

R: Ok, very good. Here on this one you said you would like to be more different from others. Can you tell me why?

P: Because I need to be less different than others to be happy.

R: You want to be less different to be happy?

P: Yes.

R: Ok, so why do you think you feel different to others?

P: I think I ...what is feel different from others?

R: Well, if you think about your friends are like and what you are like, do you think you are different or similar or the same?

P: The same.

R: You think you are quite the same?

P: Yes.

R: Ok, well done. You also said that you worry sometimes. What kind of things do you worry about?

P: When Ben is screaming and is anxious.

R: I see, ok.

R: Now can I ask you some questions about autism?

P: Yes.

R: Do you know what it is?

P: Yes, it is for disabled people who go to special schools like this school.

R: Ok, so what does autism mean?

P: Don't know.

R: Ok, and what about you, do you have autism?

P: Yes.

R: And what does it mean for you?

P: It means being disabled and...and have...Arsenal in 2000.

R: Do you think there are any bad things about having autism?

P: No.

R: And what are the good things about having autism?

P: Some people have wheelchairs.



R: Ok, very good. You have done really well. One last questions, if you could change something about you, what would you change?

P: I would do really well.

R: Ok, very good. Well done.

### **Transcript WS 1**

When completing SIP-A part one (What are you like?) the participant made the following comments:

My name is Ross the Boss sometimes, I try not to be bossy all the time but it never works.

When completing SIP-A part two (how would you like to be?) no comments were made by the participant other than indicating scores on individual items.

R: Ok, very good. Now why would you like to be louder?

P: I like loud noises. It makes me feel like I can do the same.

R: I see. You also said you are friendly.

P: I speak friendly and appropriately to my friends and they really think it's nice.

R: What do you think are the advantages of being friendly?

P: You get to communicate with lots of people who you have never seen before, and to be honest, I don't mind who I see as long as I feel happy and friendly to them.

R: Ok. Why do you think you are confident?

P: I'm strongly confident. I'm confident because when I travel to different places, I feel confident to take on any challenge. That's what I think is a challenge and I am confident.

R: Ok. How do you know you are fun to be with?

P: I'm fun to be with because I make my friends laugh, because I joke a lot, make jokes that are quite funny, enough to make them laugh. I hang out with them more than ever. The best thing about being fun to be with is that you have friends who think you are fun and nice.

R: Is it important to you that people think you are funny?

P: Yes, it's important.

R: Do you feel different from others?

P: I'm not very different from others. The only things that are different...erm...I really can think about this one – can we move to another one?

R: Sure we can. Don't worry. Why would you like to be less bossy?

P: Because I always sometimes feel like telling people what I want them to do for me, cause it's what I like doing. But I want to be less bossy so everyone can choose what we all want to do as a group. I feel like that's more better.

R: Ok. Very good. Now I will ask you some different questions. Can you tell me what you know about WS?

P: I don't know much about it.

R: Do you know if you have it?

P: I think I do.

R: Anything you've been told by your parents?

P: I remember when I was a baby I had a heart operation cause my heart was crushed in, so they did an operation so it would beat.

R: I see. Does having WS make you different from others?

P: Yes.

R: Can you tell me how?

P: Some people might have disabilities [sighs] it's hard to explain it all.

R: How do you feel about yourself?

P: I feel quite embarrassed. I wish it didn't happen. It's not something I wanted. I just wanted to not have any problems at all and be myself.

R: Do you feel like you're not yourself with WS?

P: Yes, it makes me feel awful.

R: I see. If you could change something, what would you change?

P: I really don't know.

R: Thank you for sharing those things with us. I know it is difficult to talk about it sometimes but you did really well.

P: Ok.

### **Transcript WS 2**

When completing SIP-A part one (What are you like?) the participant made the following comments:

P: Always happy me.  
Very friendly me, too much.  
Hardworking... have to be if you're in the army.  
Very very talkative I could, I could, I could talk for 24 hours.  
R: You say you're not very confident at all, would you like to be more confident?  
P: Yes, I'm quite a sissy sometimes.  
[Sporty] I hate sports, I hate PE.  
R: Would you like to be more sporty?  
P: No.  
R: What about intelligent you gave yourself a number four.  
P: Hell yeah.  
R: Would you like to be more intelligent?  
P: Yep very intelligent.  
R: Ok so on this one you gave yourself number five, for feeling very different from others...  
P: Yeah, I'm not like me dad or me mum.  
R: And how would you like to be?  
P: Same, its better feeling different from everybody else it's like having your own days.  
R: What about mess about, you don't mess about at all?  
P: No.  
R: And how would you like to be?  
P: Mess about a lot more, let everyone do the work for me, let everyone else do the work.  
P: Loud... I love being loud, very loud.  
R: You said you worry a lot on this one...  
P: Yeah, if I go for like...if my mum said we going out ready and she takes me to the doctors for an injection I just can't deal with it. I don't like walking over Carlisle bridge.  
R: I see. Last one bored, you said you get bored quite a lot. Would you like to get bored less?  
P: Yeah. If there were more stuff happening down here it would be more pleasant. There's not enough fun round here you know.

R: You said that you were kind, you gave yourself number three that's somewhere in the middle, but you said you would like to be more kind. Can you tell me a bit more about that, why do you think your number three right now?

P: Cause I am very nice to people and I'm not like everyone else. I don't go...I don't get mad very easily, I'm very kind. Yeah I'm not anybody, I'm not like anybody else.

R: Very good, and you said you would like to be more kind?

P: Yeah, I'm not very kind sometimes.

R: Now let's have a look at funny, you said you were somewhere in the middle. Why is that?

P: Because if like I smack my head and my niece is around she think it's funny, if I dropped a needle in my ear she would think it were funny. I'm clumsy the clown me.

R: I see. What about your friends, do they think that your funny?

P: I don't know, I think they do yeah.

R: Ok, and you said you would like to be more funny?

P: Yeah, would do, I would like to be like a comedy act.

R: What do you think are the advantages of being funny?

P: If like you trip someone over and everyone laughs.

R: Ok. You said you're not very confident, at all? Why is that?

P: I'm not. Because it's hard isn't it really? Because when you're doing like a gig for instance I play the bagpipes, so then I have to, I get a little bit stressed, because everyone's like play that tune play that tune. I can't deal with it, I just wana play my own stuff.

R: I see. And you said that you would like to be more confident?

P: Yeah.

R: How do you think you could be more confident?

P: Put earplugs in and not listen to anybody else just myself.

R: And what about when you're with your friends, do you feel confident?

P: Don't know, I feel a little bit not right. Cause my family is my mum and dad though, it's not school, school isn't really family, is it really. So like if you're going out and they take you up a hill and that.

R: So you feel more confident with your mum and dad?

P: Yeah.

R: Ok. So you were talking about being friendly, you said you were very friendly. When you were going through that you said that you were sometimes too friendly. What did you mean by that?

P: I'm a little bit over the top like no-one else. Cause like I could go too far, if you know what I mean?

R: What kinds of things would you do when you go 'too far'?

P: It's like having a bit of a laugh but then it's not funny, if you know what I mean?

R: What about with people that you know and people that you don't know?

P: Scary, that's how I think.

R: You mean with people that you don't know?

P: Yeah.

R: Do you think your quite friendly with people that you don't know really well?

P: I have to be friendly, well that's me.

R: On this one, different from others, you said your quite different from others, you gave yourself number five. Why do you think you're different from others?

P: Yeah. Cause like other people don't play bagpipes, other people don't play in a rock-band, well some do but like I play my own different music. That's my fame, bagpiping is my fame so like if I got outside everyone knows me for my piping so that's like, that's like, cause I'm different.

R: Tell us a bit more about school. What do you do at school?

P: It's not school its college.

R: Of course, college, ok I'm sorry.

P: It's further education. It's a bit boring, very boring sometimes.

R: And what about the army you said ...

P: I love it, I love it! Army cadets is brilliant.

R: So what do you do there?

P: Well, marching, shooting that I use a gun like big boys, like the machine guns and all of that. Erm, get to meet like royal people, I haven't met any yet but I soon should do.

R: Very good. It sounds like you really enjoy that.

P: Sometimes it gets a little bit boring though cause it's the same lessons.

R: What about the people that are there, do you have any friends there?

P: Yeah, one of the sergeants is my friend.

R: Very good. And with this one, where you said you feel quite different from others... maybe when you don't think about your band but maybe think about college or where you go. Do you feel different from others there?

P: Yeah.

R: In what way do you think you feel different?

P: Cause I don't really like school you know. I just want... when I left erm... least year... erm when I went. I just wanna get... I just feel like I wana get out and get a job now. Cause it's the same boring lessons all the time, there's no fun in them, it's a load of rubbish.

R: What kind of job would you like?

P: Either be a professional piper or have me own circus... Yeah I like circuses.

R: Very interesting.

P: You know these...that come round now, the big ones, I'd like me own.

R: Very good. Here you said you worry a lot. Why do you think that you worry a lot?

P: Erm cause am... cause like if I'm going out and people don't say where I'm going, then its high up, I'm very scared of heights.

R: Oh are you?

P: I don't like them, I don't mind going on an aeroplane but like that's it.

R: That's very brave if you don't like heights.

P: It's alright being in an aeroplane though your inside, aren't you? It's not like your just stepping out of somewhere and there's a big drop is it?

R: You are right, yeah. And you said you would like to worry less, is that right?

P: Yeah.

R: Why would you like to worry less?

P: Because I'm doing my duke of Edinburgh silver, so...

R: I only got as far as bronze.

P: You've done your bronze? You've only done your bronze?!

R: Yes it's the lowest level I know.

P: Silver is harder that bronze. Three days of walking non-stop, why did I put my hand up to do it?! [laughs].

R: Are you enjoying it?

P: It's alright... it just gets a little bit painful sometimes.

R: It sounds like your really busy; you've got lots of things going on. Who else do you go with in your group for your treks?

P: Loads of people, there's about six of us.

R: Because you all go off in a group together, don't you? Out in the wilderness for a few days?

P: Yeah but that's a good thing though... cause it's like it's army training really but it's not as well. But I think of it as army training, you're going out, you're going camping, you're nowhere, you're walking around to see if there's any enemies it's wicked.

R: Is everybody the same age who you go with?

P: Yeah.

R: Fantastic. Is it ok if we ask you some questions about William's Syndrome?

P: Yeah.

R: Can you tell me what you know about it?

P: Well its like, if you say like a really hard word I wouldn't understand it, cause I'm not normal like my mum and dad. They understand words I don't... that's all I know, well I don't really know much. I've got a narrowing artery, I don't know about that, that's all I know.

R: Ok, so you know that it's some problems with your health?

P: Yeah,

R: With your heart?

P: Yeah.

R: And also understanding some words, do you have problems with that?

P: Yeah. Cause some words I wouldn't know, cause like some words have like weird letters and I don't get it.

R: Do you struggle with reading sometimes?

P: Yeah.

R: Ok, and do you remember when someone told you first about WS? Did your parents tell you about it?

P: I try and ask them, but I don't really know, cause I feel scared of asking them really. I ask my mum how many years I've got to live cause it's, cause of...erm heart conditions you could stop anytime, so you know... but I don't think that'll happen because I'm good.

R: Your keeping active aren't you?

P: I'm very active.

R: Good, and is that why your kind of a bit scared about asking mum and dad about it?

P: Yeah.

R: They're quite worried about you do you think?

P: Yeah. I think I'm worried about myself all the time.

R: I see. You know with having WS...do you sometimes feel different from others?

P: Yeah. I feel like, you know like when you're out and you see someone driving a car or a motorbike and you say mum I want one...you just feel like going into the road and getting smacked over because it's that rubbish sometimes... you just don't wana be you know...rubbish sometimes. Like when you wanna do something and you can't because of the heart condition. Everyone should be able to do all the stuff they want to do, isn't that fair enough?

R: Yes that is true; its quite difficult isn't it when you feel like you can't do the things you'd like to do?

P: Yeah.

R: Do you think there is any good things about having WS?

P: No, nah.

R: And what do you think are the bad things about it, the things you don't like?

R: Heart problems, the way you look as well. When I go out some people laugh at me and I don't like that. Like my mum and dad are normal compared to me, they haven't got a heart conditions and that, they're alright. They can mix in with people different, like more than I can, I'm too scared to, in case they might start on me ya know.

R: I see, so you feel like even the way you look is a bit different?

P: Yeah.

R: Ok, well I know there have been a lot of hard questions so thank you for answering those. You did really well. Thank you.

### **Transcript WS 3**

NB: This interview transcript is incomplete. Some questions asked by the research assistant in this interview have not been fully transcribed. The researcher attempted to recover the recording to transcribe the full interview however it has been deleted.



When completing SIP-A, no comments were made by the participant other than indicating scores on individual items.

R: Ok, thank you for completing that, now I'm going to ask you some more questions. Is that ok?

P: Yeah.

R: How do you know that you are friendly?

P: I'm nice to people.

R: Do you have a lot of friends?

P: [Nods].

R: What kind of things do you do with your friends?

P: Chat to them.

R: Ok. Could you tell me more about being confident?

P: I'm not confident chatting to people I don't know. I think I feel different from others. Like when my brother goes to the shop, I'd like to go but I can't. I'd like to be able to go to the park and things.

R: Ok. What about sporty?

P: I'd like to be more sporty. It's good exercise and it's healthy.

R: What about intelligent?

P: When I'm older I might be able to get a job. I'd like to work in a nursery.

R: Would you?

P: Yes.

R: Very good. You said you are good looking...

P: I think I am but I don't think other people think so.

R: Ok. You said you worry sometimes is that right?

P: When people are ill, always worry about someone else. Or when I have nightmares, worry, worry, worry. I don't want to worry at all. I don't like worrying. My nan worries a lot so maybe that's where I get it from.

R: Ok. Do you think you are shy?

P: Oh no! I'm not shy to anyone, I'll go over and talk to them.

R: Very good. And what about short-tempered?

P: Yeah I get angry easily. I'm impatient. I'd like to find a way but I think if I had something; stress ball or go for a walk, I think I'd like to do that instead.

R: Do you get bored easily?

P: I'd like to get bored less. I like to plan ahead or I'll go off like a bottle of pop.

R: Ok, thank you. Now can you tell me what you know about WS?

P: I don't know.

R: Do you know what it means?

R: I haven't got chromosome seven, am I right mum?

R: Ok. If someone has WS what are they like?

Mum: Can you remember what is in that WS book?

P: You can tell they have it, definitely. You can tell by the face, it looks different. I'd just like to be like other people and go out with my friends and go to parties.

P: I think I'd be alright if I had a friend who was like me and could come to my house to play. They don't, they are just nasty to me. I'd like a friend though. I think it's just that other people don't want to be friends with me. I'd just like another girl my age to do pampering, have sleepovers and pyjama parties.

P: Yeah but I'm made up I'm not normal, so I don't have to go to the park drinking.

P: I think you should go on telly and tell people. I don't think people understand what WS is. If you explain it to normal people.

#### **Transcript WS 4**

When completing SIP-A, no comments were made by the participant other than indicating scores on individual items.

All questions asked about item scores and discrepancies between real and ideal scores were answered - 'I don't know'.

R: Ok, well done on all of these questions you completed. Now I'm going to ask you a few questions about WS. Do you know what WS is?

P: No

R: You don't?

P: No.

R: Do you have WS?

P: [Nods].

R: You do?

P: [Nods].

R: Do you know anyone else with WS?

P: No.

R: You don't, ok. You just know you have it?

P: [Nods].

R: Do you think there are any good things about having WS?

P: No.

R: Is there any bad things about it?

P: Erm...No

R: Is there something you maybe do not like about having WS?

P: No.

R: Ok, we will leave it there, thank you.

### **Transcript WS 5**

When completing SIP-A, no comments were made by the participant other than indicating scores on individual items.

R: You said you are very friendly. You gave yourself number five. Can you tell me a bit more about that? Why do you think you are friendly?

P: I'm not very good at explaining but erm...I am friendly with my family but sometimes I don't think I am very friendly with my friends as I am... but I try to talk to people but it's a bit difficult sometimes.

R: Do you find it a bit difficult sometimes to talk to your friends?

P: Yes, cause they wonder off somewhere else [laughs].

R: But you said you are very friendly with your family?

P: Yes, I think so.

R: So do you feel like you have a lot of friends?

P: No.

R: Not really?

P: No, that's a no.

R: Ok, here you said that you feel very confident.

P: Yes, because I can show everyone else that I can do things that make you confident but other times, I think I could be a lot more confident, but other times...I just am really.

R: So you feel like you are quite confident and show people that you can do things quite well yes?

P: Yes.

R: Fantastic, very good. On this one you said you worry a lot and you would like to worry less. Can you tell me a bit more about that one? Why do you worry?

P: Because I get scared because I hear noises. But I know worrying is not gonna get you anywhere. I get worried about things at school as well as at home.

R: What kind of things do you worry about at school?

P: Just the stairs, going up the stairs but I worry cause I don't think that people just, people you know pushing down the stairs. I just worry about that, I just need to hold on...

R: So you make sure you are safe on the stairs?

P: Hmm.

R: That's very good. It's important to keep safe. And you said you wanted to worry less. How do you think you can worry less and why is it important?

P: Because my mum doesn't want me to worry about anything because as a mum you think I don't want your child to worry but I do but sometimes its not my fault but I know sometimes people might think I am you know...I am strange but...that what I worry about but at the end of the day I need to not worry about anything...I need to improve on it because I don't like worrying.

R: You don't like worrying, ok, that's very good. You said sometimes people think you are strange...

P: Yeah because I worry and I know...I know that's what I do. That's just me.

R: It is hard not to worry sometimes, isn't it? I know I sometimes worry about things.

P: Yeah but I don't like making my mum sad...that's just my mum [laughs].

R: You said you are quite shy. Why do you think you are shy?

P: Erm, because erm when...I don't know why I'm shy, I just think that maybe it's because of that...maybe some people think that I am a bit scary but I'm not, I'm just me, that my answer [laughs].

R: Very good, that a very good answer. You said you are number four on feeling different from others. So that's feeling quite different sometimes?

P: Yeah because sometime its hart to, not just me but other people, because it because I can't explain my condition as well as other people but I do try.

R: You said you can't explain your condition. What do you know about it?

P: Yeah...erm one of my chromosomes number 7 is lost, that's how I explain it but I don't think people want to listen [laughs].

R: That is a very good explanation, well done.

P: At the end of the day I am at school, I am there to learn and really make everyone happy, not make everyone angry because I don't like making people angry because then you just make them more angrier. So I don't I know...I think I should behave so that I do not make anyone angry but if I do then I will apologise.

R: Ok, that very good. You said you try to explain to people what WS is and that sometimes people don't listen. Do you sometimes find it difficult when people do not understand what it is?

P: Yes, cause they make you sometimes angry [laughs] or... cause sometime I think to myself ...why are they getting angry...but I try to explain how it is but its difficult to explain, I don't think people want to listen as much as the teachers listen to me.

R: It sounds like you really try to explain to people what WS is. That's very good because a lot of the time people do not know what it is do they?

P: Yeah, but they sometimes ask because they want to know what it is because then you try to get them to know but I thing at the end of the day ...erm...I need to learn things about other conditions but I need to know things about my condition as well.

R: Ok, that's very good. Is there anything else you know about your condition?

P: Erm..I think what...I think because children have different conditions erm...I think that my means that some children find it difficult they get bullied...they might just stand there on their own. I try to talk to people but...I try to explain it in a nice way...I don't want to explain it in a horrible way.

R: Ok, very good, you have done so well on these questions. Thank you.

### **Transcript WS 6**

When completing SIP-A part one (What are you like?) the participant made the following comments:

P: People are jealous of me lots, when I play the piano they say they want to play like me.

P: Everyone thinks I'm clever. I am very good with stories. I'm a really good reader and I spell easily but I have a hard time with sums.

P: I do like my face, I do like it. I like my physical appearance because I know it won't change. I think I am good looking.

When completing SIP-A part one (What are you like?) no comments were made by the participant other than indicating scores on individual items.

R: Ok, we have gone through all of these points, and there are some things that you said would like to change. What are they?

P: I would not like to be sporty, and then I would like to be less lazy and I would like to be less worried, so I need to get my friendship sorted.

R: Ok, you mentioned about worrying. You said you would like to worry less. Could you tell me a little bit more about that?

P: I've just, over the year I had a friend but I had to say good bye because I couldn't trust him and I am worried that I've made a mistake. I just worry too much about what I should do. Like who shall I speak to about it.

R: Ok, I see, so you would like to worry less about it.

P: Yes.

R: Ok. How do you know that you are friendly?

P: Well, lots of people said that I have got lots of new friends every day and that I am friendly, I make them smile and things like that.

R: Ok. What are the advantages of being friendly?

P: Advantages, you get lots of new friends and people like you.

R: Are there any disadvantages to being friendly?

P: Yes. Erm, no. There is no disadvantages. I have fallen out with someone who did not want me to be their friend anyways so.

R: I see. Here you said that you get bored a bit. Can you tell me a bit more about that one?

P: Well yeah, sometimes you know I have nothing to do so I have to find something that will not make me bored.

R: So you would like to be less bored?

P: Yeah.

R: Ok, very good. Now, is it ok if I ask you some questions about WS?

P: Yes.

R: Can you tell me what you know about it?

P: I know a lot about WS. I know that... I know that my WS is that I can't turn my hand out, so I do that [hand gesture] and I do it the other way. It's just that God made me with that. I know that, that what happened to me and I know I was born with it and I know that I can't change it but I know it makes me beautiful. So that's what I know about it. And I know I have it for the rest of my life.

R: Ok, and how does having WS make you feel?

P: Ooh, well, its ok, its ok but I would like to carry heavy things, I can't carry heavy things at all, but yeah, I can carry a guitar and say piano. I can catch a ball quite easily but I have other jobs to do, so for example if people want me to get the ball they tell me to run instead of catch it so they know, you know, I can do things for them. They make me do little jobs which is very nice like I can run and get the ball and bring it back on the pitch.

R: Very good. Do you think there are any advantages to having WS?

P: The only advantage I learned is that people like think you are special when you have it, so that's one of the advantages that I've learned.

R: Ok, and do you think there are any disadvantages?

P: I don't know, I guess it depends on what sort of WS you have. Like mine is really rare, no one else has it so mine is unique, but if you have like a 'slurpy' WS, like people blowing their nose all the time you know, so different WS have different advantages and disadvantages.

R: Ok, you are doing very good. If you could change something about yourself, what would it be?

P: I don't know what I would change, you know I would change myself really, be me really, I would change the way I feel about WS and make myself better.

R: You said you would change how you feel about WS, what would you change about that?

P: I would just feel good about it now because I know what it means now.

R: You understand it now, ok. So understanding what it means, how does that feel?

P: Happy, happy. My friends have a funny way of saying special, they say like you are damn special or you are flipping special. That's what my friends use for me so, because they knew I was, it just made me happier really.

R: So you feel special and happy?

P: Yeah. I feel loved.

R: That's very good. How do you feel about WS and your friendships and relationships? Do you think that has anything to do with it?

P: Yeah, yeah it has, because like the drummer that I've you know stopped being friends with, you know I want to get it sorted out, done over with but he doesn't want to do anything to sort it out so it like I...hassling him, I want to sort it out. It can mean that you are very sensitive. Very sensitive yeah, that's what it can mean.

R: Very good, you have done excellent. Thank you.

### **Transcript WS 7**

When completing SIP-A part one (What are you like?) no comments were made by the participant other than indicating scores on individual items.

R: We are going to do something different, this time we are going to go through them again and instead of answering what you are like now I'm going to ask you what you would like to be. Ok?

P: Yes.

R: Here on kind, would you like to be more kind, less kind or stay the same?

P: I am all kind.

R: So you are very kind?

P: Yes.

R: Ok. What about happy?

P: Yes, I am happy all the time.

R: Ok. You said you are very friendly. How would you like to be?

P: A lot friendly.

R: Ok, number six then.

P: Yes.

R: What about helpful? You said you are very helpful.

P: Yes.

R: Is that how you would like to be?

P: Yes.

R: Ok. Hardworking, you said you are very hardworking. Is that how you would like to be?

P: Yes?



R: Ok. What about talkative, you said you were very talkative. How do you want to be?

P: Yes.

R: You want to be very talkative?

P: Yes.

R: What about confident you said you were very confident would you like to be a bit less or would you like to stay confident like you are?

P: I am happy with the way I am

R: Ok, very good. What about sporty you said you are very sporty

P: Yes I am sporty all the time

R: Ok. What about intelligent, that means you are very clever or smart

P: Yes, I am clever all the time

R: Fun to be with, you gave yourself number four. Would you like to be more fun to be with?

P: Yeah, six please.

R: Ok, why is that?

P: Because I like to be having lot of fun it gives me more time to have fun with people I know and some people I don't know.

R: And what do you think is good about being fun to be with?

P: When I go to show to see something happening cause a long time ago my parents took me to see a show in London. A long long time ago but they don't do it anymore because we used to watch it on TV but now I've got videos.

R: I see, very good. Let's have a look at this one, good looking, you gave yourself number three. What would you like to be?

P: I think I would choose number five.

R: You would choose number five. Ok, and why is that?

P: Because sometimes I have different clothes on that makes me happy. That's why I'm looking...looking good cause I'm I have nice stuff on all the time.

R: Ok, now on feeling different from others, you said you are number five so you feel quite different from others?

P: Yes.

R: Can you tell me why?

P: Cause some people are different from other people and some are not different from other people.

R: Ok, and why do you think you are different from other people?

P: I just don't know.

R: You are not sure...ok when you compare yourself to other people what do you think is different?

P: I can't remember.

R: Ok, that's ok. So if you could choose, you gave yourself number five, would you like to be less different or would you stay the same?

P: I would be happy with number five.

R: So you like to be different from others?

P: Yes.

R: Ok, very good. Lazy...you gave yourself number six that means you are very lazy. Is that right?

P: Yes.

R: Would you like to be less lazy?

P: No.

R: No, you want to be number six?

P: Yes.

R: Ok. What about annoying, you gave yourself number five, that means you are quite annoying. How come you gave yourself that kind of score?

P: Because sometimes my dad is the same with me. Sometimes he is annoying and sometimes I am annoying but sometimes...sometimes both of us are annoying .

R: So what do you do when you think you are annoying?

P: Play tricks.

R: Ok, so would you like to be less annoying or...

P: More.

R: You want to be more annoying?

P: Yes.

R: Ok. What about moody you said that you're not at all moody.

P: No.

R: What about messing about you said that you mess around sometimes. What do you do when you mess about?

P: I like to mess in my bedroom sorting things out that should be in the right place and like to mess with the stuff that's messy I put back it in its own place.

R: Ok. Mess about here means that you would be silly and do silly things maybe in at school in your class when you are supposed to be doing work and you turn around and speak to your friend.

P: Yeah [laughs].

R: What kind of things do you do when you mess about? When you are supposed to be doing your work?

P: [No answer].

R: Do you get distracted?

P: A lot.

R: Would you like to mess about more, less or stay the same?

P: Stay the same.

R: What about shy you said you are very shy, you gave yourself number six. How come you gave yourself such a high score?

P: Because sometimes ...when I'm shy I don't know what's coming up right behind me of if I'm shy I tell my parents that I'm shy all the time.

R: And would you like to be less shy?

P: Yes please.

R: And what number would you like to be?

P: I have number three.

R: Ok, number three. Well done, we are nearly there. Cheeky...you said number three, sometimes cheeky. What would you like to be?

P: More [laughs].

R: You want to be more cheeky.

P: [Laughs and nods].

R: What about loud you gave yourself number five. What would you like to be?

P: Less loud.

R: What number would you like to be then?

P: Two.

R: And why would you like to be less loud?

P: Because I don't want people shouting at me and sometimes I want them to get used to it that I'm not loud.

R: Ok, very good. What about sarcastic, you said you're not at all sarcastic. How would you like to be?

P: I'd be happy the way it is.

R: You said you worry quite a lot. Is that right?

P: Yeah.

R: And why do you worry?

P: Because when something get wrong I worry all the time.

R: Do you?

P: Yes.

R: And how would you like to be? Would you like to worry less or more or the same?

P: The same.

R: Ok. Bossy you said you're not at all bossy.

P: No.

R: Ok, what number would you like to be? You gave yourself a zero.

P: I will be happy with zero.

R: And then you said you not at all short-tempered. What would you like to be?

P: Same.

R: Same? Ok.

R: And then you said you get bored sometimes what number would you like to be?

P: Number three please.

R: Ok, well done, you have done very well. See on this one, friendly, you gave yourself number six. Why was that?

P: Because when I'm friendly I'm always friendly all the time.

R: Ok, so do you have a lot of friends?

P: Yes.

R: Ok, on confident you gave yourself number five. How do you know you are confident?

P: I just don't know.

R: You think you are quite confident?

P: Yes.

R: Ok, I only have a couple more questions to ask. Do you know what WS is?

P: Erm... I don't know.

R: You don't know what WS is?

P: I don't know.

R: Ok.

P: Because my mum knows about it.

R: Does she? And what does she know about it?

P: Erm...she knows everything about WS because I'm...because I don't know.

R: Ok, and do you have WS?

P: I don't.

R: You don't, ok. And do you know anything about it?

P: I don't know.

R: Ok, thank you, you have done very well.

### **Transcript WS 8**

When completing SIP-A, no comments were made by the participant other than indicating scores on individual items.

Participant chose not to complete the SIP-A follow-up interview.

### **Transcript WS 9**

When completing SIP-A, no comments were made by the participant other than indicating scores on individual items.

Participant did not respond to questions exploring discrepancies between real and ideal self.

R: Ok, can I ask you questions about WS?

P: [Nods].

R: Do you have WS?

P: Yes.

R: Can you tell me what you know about it?

P: Erm...like special needs.

R: And how do you feel about that?

P: Happy.

R: So do you think having WS is a good thing?

P: Yes.

R: And are there any bad things about it?

P: No.

R: Ok, thank you very much. Well done.

### **Transcript WS 10**

When completing SIP-A, no comments were made by the participant other than indicating scores on individual items.

Participant did not respond to questions exploring discrepancies between real and ideal self.

No questions were asked about the participant's condition on request of the participant's parent.

### **Transcript WS 11**

When completing SIP-A, no comments were made by the participant other than indicating scores on individual items.

R: It was quick. You have done very well. I am going to go through them now and ask a few questions on the ones that you have changed. A lot of them you have just said that you would like to stay the same but this one - hardworking you said you would like to be a bit less hardworking. Why is that, why do you think you want to be a bit less hardworking then you are at the moment?

P: Because I want to help this little dog.

R: You want to...

P: Help my dog.

R: So you don't want to be as hardworking so you can help your dog?

P: Yeah.

R: Anything else?

P: Looking after my parents.

R: And your parents, ok. How about talkative you said you're not very talkative and you want to be a bit more. Why is that? Why do you want to be more talkative?

P: Don't know.

R: You are not sure?

P: No.

R: Do you want to be a bit more confident and talk to people a bit more?

P: Yeah, yeah.

R: Yeah, ok. You said you don't worry a lot at the moment but you would like to worry a lot more. Why do you want to worry a bit more?

P: I don't know.

R: You said you don't worry at all now.

P: Sometimes I do but sometimes I don't.

R: But you want to worry more?

P: I don't know.

R: Ok. You said you were very lazy, why do you want to be a bit less lazy?

P: Erm... so I can go back to bed.

R: Ok brilliant so a couple more questions on this then. I am going to ask you a few questions on WS, is that ok?

P: Ok.

R: What do you know about it?

P: When I was a little baby erm I was got Williams syndrome and I had...I don't know.

R: What did you have when you were a little baby?

P: I think I had heart problems, didn't I?

R: I see. How does having WS make you feel?

P: Sad.

R: Sad, why does it make you feel sad?

P: Because I want to be like my mum and dad.

R: Why do you want to be like them and not like you are?

P: Because I hate it.

R: I see. Can you tell me about why you hate it?

P: Because it makes me feel really angry inside. I get fed up.

R: You get fed up with it?

P: Yeah.

R: I see. Do you think there are any good things about having WS?

P: That when you are on your thingy you don't get used to taking it and I don't like doing that.

R: Don't get used to change when you're on your?

P: Period.

R: Oh so you don't get used to that.

P: No.

R: What else is there that's good?

P: Erm that I like...I like making drinks and stuff for Isobel or my mum.

R: Yeah, what drinks do you like making what's your favourite drink to make?

P: I like Diet coke.

R: Diet coke is brilliant. So you said it makes you feel sad. How would you like to be then? Would you like to change? Or would you like to stay the same?

P: Change.

R: How would you like to be?

P: Don't know.

R: No, ok shall we leave it there.

P: Yeah.

R: Yeah, you did excellent and answered all the questions really well. Well done.

### **Transcript WS 12**

When completing SIP-A, no comments were made by the participant other than indicating scores on individual items.

R: Ok, very good. So you said you would like to be less talkative?

P: Yes.

R: And why is that?

P: It's because I don't like talking too much.

R: Don't like talking too much.

P: No because it might be annoying sometimes.

R: So you just want to not talk as much?

P: No.

R: Ok. You said you were sometimes a bit moody but you want to be a bit less, why?

P: Because I don't want to be upset or angry or anything that's why I get little bit moody sometimes.

R: And you don't want to get like that?

P: No I don't want to be moody at all.



R: Ok. How does being moody make you feel?

P: Erm... sometimes I do get a little bit stressed out sometimes, I do calm a lot...a lot but sometimes I get hugs if I am upset or angry.

R: Does that help to calm you down?

P: Yeah.

R: Very good.

P: Yeah.

R: You said you were sometimes loud but you want to be a bit less loud. Why is that?

P: Cause I get really excited sometimes but I just like to not be so loud.

R: So excitable, you want to calm down a bit.

P: Yeah.

R: And one more you said you're sometimes worried a lot. Why is that?

P: I don't know it just happens sometimes.

R: And you would like to worry less then?

P: Yeah.

R: Why so?

P: I don't want to worry, I don't want my mum to be worried about me if I am worried about somebody or just talk to people.

R: How do you feel when you are worried?

P: Upset sometimes, cuase I can't help myself when I am worried.

R: Brilliant, thank you they were top answers.

R: I'm going to ask you a few questions on WS now.

P: Yeah, yeah.

R: Because I want to learn a bit more about it.

P: Yeah.

R: Can you tell me what you know about WS?

P: Problems with the heart.

R: Problem with your heart?

P: Yeah .

R: Does that stop you doing things you want to do? Or can you still do things normally?

P: Still can do things.

R: Is there anything else or just a problem with your heart?

P: Just problem with the heart but not any more...used to when I was little but not anymore though.

R: Ok. And how do you feel about having WS?

P: Erm...a little but difficult.

R: A little bit difficult?

P: Yeah. I have problems walking,

R: I see.

R: Are there any good things about having WS or any bad things about having it?

P: Well good things you are very happy all the time and you have treats and stuff.

R: That's a good thing isn't it?

P: Yeah, yeah.

R: Are there any bad things?

P: No not really no.

R: Ok, thank you very much.

### **Transcript WS 13**

When completing SIP-A, no comments were made by the participant other than indicating scores on individual items.

R: Why do you want to be less kind?

P: Because when people get on my nerves I want to be...I'm not nice at all. That when someone keeps nagging me.

R: You said you want to be less friendly? Why is that?

P: Because if I'm alright with the person I will be alright, I will be friendly to them. But if someone like keeps saying my name then I will be annoying, I just go.

R: You said you were very funny.

P: Yep.

R: Why did you give yourself that score?

P: My friends think I'm funny.

R: Is it good or bad being funny?

P: Good because people like you.

R: Ok, what about talkative. You don't want to be more talkative?

P: No because that means someone could say your annoying, I'm not that kind of man who likes talking too much, I don't like that.

R: Good stuff, what about this one – fun to be with. What happens if you are fun to be with?

P: Yes, it's like my girlfriend, she's always... well she does come here and she's fun.

R: Ok You want to stay the same on feeling different from others. So is it good to be different or bad?

P: Bad because people are mean when you are different and or nice.

R: You said you worry a lot.

P: Yeah, I do worry a lot.

R: So do you think it would be nice if you worried a lot less?

P: No because I do worry about my grandma and that, because she's got diabetes and that and my nana's got it and my grandma's got it bad like my nana. So when I was going to stay there and she goes upstairs and she falls over.

R: Ok.

R: Now, can you tell me what you know about WS?

P: I don't really know, means that people bug me more.

R: You feel that people get on your nerves?

P: Yeah.

R: Can you tell me more about that?

P: [No response].

R: Why do you think people bug you more?

P: Like other people in class and teachers, especially in my old school, they weren't nice.

R: And was that because of having WS?

P: I don't know.

R: Ok, thank you very much.

#### **Transcript WS 14**

When completing SIP-A, no comments were made by the participant other than indicating scores on individual items.

Participant responded 'I don't know' to questions exploring discrepancies between real and ideal self.

P: I am just going to ask you some questions on WS because I don't really know anything about it and want to learn a bit more from you. What do you know about WS?

P: Hmm...I can't read.

R: Does it stop you doing anything else?

P: [No response].

R: How does it make you feel, or how do you feel?

P: It's not good.

R: Does it make you feel sad?

P: Yeah.

R: Do you feel different from others?

P: Yeah.

R: In what way, what way do you feel different?

P: Erm people can run faster than me.

R: And are there any good things about having WS?

P: [No response].

R: What about bad things apart from not being able to run as fast as you want to. Is there anything else?

P: Getting into trouble, with people.

R: Ok. How would you like to be, is there anything you would like to change?

P: Erm...I want to see my family more often.

R: Is there anything else?

P: No.

R: Ok. Thank you for your help.

### **Transcript WS 15**

When completing SIP-A, no comments were made by the participant other than indicating scores on individual items.

R: How do you know that you are friendly?

P: I say hello to people. Have conversations.  
R: How do you know that you are kind?  
P: Because I am kind.  
R: Do people tell you that you are kind?  
P: [Nods].  
R: What do you do that's kind?  
P: I kiss my mum.  
R: And how do you feel different from other people?  
P: [No response].  
R: Let's have a look at this one, why do you want to be less bossy?  
P: I think it would be better.  
R: Ok, well done. And why is it that you worry a lot?  
P: I worry when something happens. That's why I worry.  
R: Ok. Well done. Now, can you tell me what you know about WS?  
P: People get WS and that sort of thing. You can talk to people when they have WS.  
R: Do you have WS?  
P: Yeah.  
R: And how do you feel about that?  
P: It makes me feel happy.  
R: Why do you think it makes you feel happy?  
P: Because it does, its just real life for me.  
R: What are the good things about having WS?  
P: Playing outside, talking to your friends, and that sort of thing with the WS. So it's part of life.  
R: Do you think there's anything not so good about having WS?  
P: I'm all good.  
R: Ok, thank you.

### **Transcript WS 16**

When completing SIP-A part one (What are you like?) the participant made the following comments:

P: I don't like being moody but it's how I am.  
P: Occasionally I have a naughty side but I try to be good.

P: If I was shy I would have ran behind the sofa when you came. I remember being shy on my brother's 18<sup>th</sup> birthday when I went to buy my brother a cake. This lady who knew me but I didn't know her came up to me and I was shy. I was embarrassed.

R: Now, this time we are going to go through them again and instead of answering what you are like now I'm going to ask you what you would like to be. So here if we look at this one here 'kind', you said you were very much 'kind'. Would you like to change this or keep it the same?

P: Yes definitely, I'll keep that the same. Yes I am happy with that.

R: Talkative, you said 'very much'.

P: I like being talkative.

R: Good looking?

P: [Laughs] I'd never change that. I want to keep all these same [point to the positive self- image part of the measure].

R: Ok then. What about moody? You've put very much, would you like to change this one?

P: No.

R: No, you like being very moody.

P: Yes [laughs].

R: Mess about, you said occasionally. How would you like to be?

P: I like messing about [indicates score by pointing to the scale]

R: Shy?

P: I would change this to a one, be a little bit shy but not much.

R: Why is that? Do you think it is good to be a bit shy?

P: No [laughs]... When I was younger, I was all over the place you know, if my mum's friends came over I would be talking to them. Ahhh there was one time, when I just got in school and one of the teachers came over and I said to her 'oh no I just need to go somewhere else'.

R: I see, so when you were younger you used to sometimes say things, but you think you should have been a bit quieter.

P: Yeah that's right. So I'll give it a one to only be a bit shy.

R: Ok so how about cheeky?

P: Wouldn't change it.

R: Sarcastic?

P: No, keep that one.

R: Worry...how would you like to be?

P: Even if I worry I know I will be alright, as I'm in like a...erm what do you say...erm like a gang of friends, like four or five of us. Depending on what mood we are in...one of them has anger problems, you know he can't control his anger and I'm like with him...there's four of us in a gang. We look after each other and make sure we are all right.

R: So if you had anything to worry about do you talk to your friends?

P: Yeah they would just know about it straight away...the majority of time I tell them about anything. I even talk to them about it on Facebook if I am worried...for instance I talk about my problems and why...I just say why to them.

R: Ok. What about bossy? How would you like to be?

P: The same.

R: Short-tempered? You put very much. How would you like to be?

P: I could never be able to change that one [laughs].

R: If you could change, how would you like to be?

P: I'd put it between one and tow, no one.

R: On get bored, you put one. How would you like to be?

P: Less. I am talkative but you know when you're a teenager you don't really feel like talking much. I would stay the same for the same for the rest of them.

R: Ok, very good. Actually, I thought you are quite talkative.

P: [Laughs] Well I've got to be haven't I because there is a nice lady in the room.

R: [Laughs] Ok then, here you have put confident, what do you think confident means?

P: Well it means you can chat to people and not be shy. I can easily confidently get the bus to town... I can probably almost do just about anything just as long as I have the confidence to do it.

R: very good. So, friendly, how do you know you are friendly?

P: Well to be honest ...my teachers know about this... but apparently I am one of the best behaved students and I have been one of the best behaved students in both schools I have been too.

R: I see, that is very good.

P: I've only had probably about one or two bad reports, but nothing serious, just about an argument between me and somebody.

R: Ok. Well with this one you have put you feel a bit different to others. Can you explain to me a bit about why you feel like this?

P: Hmm, some o my friends have different disabilities compared to me, and I have a heart problem. But I just say forget about it and I just want to enjoy my life.

R: Ok. You say you have a big temper?

P: Well sometimes if I am playing out with my friends, depending on what they say I can get out of control. I flip, I mean I really flip, I really flipped yesterday, you know I'm telling you the truth here...

R: Thank you for being honest with me.

P: Well somebody said something to me and I didn't want to do anything. I tried to walk away, but then they said it again, so I said to him 'look here, you're different and I am different, and we both have different opinions and then I went bright red and got really angry. Even now, I'm calm now, but if he said something I could get really offensive.

R: I see.

P: I'd say 'don't say that' or 'I'd walk out 'or... I'd do something else, something else much worse.

R: Ok. Now can I ask you about WS?

P: Yes.

R: Can you tell me what you know about it?

P: I've got a friend in my class actually and she has WS as well, she's nearly like the same as me, just about everything... like curly hair and a bad heart. Well she's probably got everything about the same as me really, but I've just got a deeper voice. My voice cracked when I was twelve, horrible it was, next day I woke up with this strange ticking in my voice, and my mum said your voice have broken. I said ok, am I going to be ok, she said you'll be fine. I've been fine ever since.

R: Ok, do you know anything else about WS?

P: No, that's all I've got to say.

R: Ok, thank you very much, you did really well.

### **Transcript W17**

When completing SIP-A part one (What are you like?) the participant made the following comments:



P: Everybody says I'm fun to be with.

P: [Feeling different from others] I am number zero because I hang around friends that got the same syndrome as what I've got.

R: So you feel quite the same as others?

P: Yes, because I've got WS.

P: I don't mess about because then people think you are naughty or cheeky. I can honestly tell you that I'm not compared to others.

P: Sometimes I worry in case something happens to my family or my relative but that will be just it, if it is my friends then I can help them you know.

P: I get angry sometimes but it's just... just now and again. But like when I'm on a computer and it shuts off I'm like what the heck has happened, what the heck has happened? So I'm number two for that.

P: I only get bored on like a long trip to holiday, I'm like waiting for it to happen.

When completing SIP-A part two (How would you like to be?) the participant made the following comments:

P:

[Kind] stick with that one because then people might still recognise me as the normal me and not like someone who is not that kind at all.

[Hard working] If I didn't work then I would get a detention and I don't like to be in detention.

[Fun to be with] I want to stay the same [number six] because I don't want to be that kind of person who doesn't want to be like...fun to be with.

[Good looking] I think I would like to be number six because many of the girlfriend I go out with they like play the game on me you know and they dump me you know...

R: Now let's look at this one - friendly, you said you are very friendly. Can you tell me more about it? How do you know you are friendly?

P: Because everybody gives me positive suggestions every time I tell a joke. They are always laughing themselves to tears. Ever since I first started this school I didn't know what kind of person I would have had erm... but then over the years I've seen people... like I'm there...like You Tube funny and that's stuff and then I thought why don't I make myself a person that is funny? You know now I am that kind of guy that does most of the fun stuff around here.

R: Ok, very good. You also said you are very confident, didn't you? How do you know you are confident?

P: Because from my past school...they didn't treat me as well as this school has, for the last few years I had a bully at my old school, he used to bully me a lot, he used to tease me a lot and I didn't feel that kind of confidence that you feel like in some other school because I felt like a trapped person in like a little...like a guy that is claustrophobic but when I went to this school they got me settled in, they showed me the fun side of being at a school and it's from there that I've got my confidence.

R: That is really good. It sounds like you are enjoying it here.

P: I am because we've got a talent show and I'm gonna be in it.

R: What are you going to do?

P: I know you might think it's strange but I actually do ventriloquism.

R: Very good, I think that's fantastic. Now let's have a look at this one. You said that you don't feel different from others at all. Can you tell me a bit more about that?

P: Because I...when I was at my old school I felt very different, I felt like very much like...but when I come to this school I saw one of my friends Lisa and she said it's gonna be all right and erm...we had about three people with Williams. I was the fourth one at the school with the WS because it's about like disorders, it's like Downs syndrome but it is more sophisticated.

R: Ok, so you said know other people who have the same syndrome. So is that why you think don't really feel different from others?

P: True. That is the reason why I don't feel like erm...feel different from others. Because now like I have a lot of friends, I've got like a buddy system that's taking me out every Saturday and it's like a lot of fun has happened through my life. I never thought it was going to happen you know.

R: That is very good. I am going to come back to that point but for now let's just have a look at this one – you said you worry a lot and that you want to worry less. Can you tell me a bit more about that one?

P: I erm...I used to be a naughty kid. I used to get in a lot of trouble, I used to see how everything was made and I used to take it all apart and then I'd like have like my stomach turning, it made me feel like funny inside my head and I used to worry quite a lot. But sometimes I worry but it's just like when I get lost now, I don't break stuff anymore.

R: Ok. Now is it ok if I ask you some questions about WS?

P: Yes, yes, go ahead.

R: Say if I didn't know what it was, how would you explain it to me?

P: WS has been going on for ages and ages because when I had the WS my mum used to be worried sick about me. She would care, she cared a lot for me and I had high liver problems that kept making me you know...and I was born with a heart murmur on my heart but erm...But I'm a lot different to other people with WS because like the facial features haven't changed when the people that has the really like genetical side of the WS their face changes, they have like short noses and all that stuff really. They have a WS website, all about WS and erm...I used to talk to a lot of strangers, that's a part of WS and kids with WS talk to people that are strangers and strangers are like...you don't know what they're gonna be like. So I watch about that. I don't talk to strangers as much as I used to. I watch what I do because I know there is a down side and a positive side of talking to strangers.

R: Ok. Very good. It sounds like you know a lot about WS, don't you?

P: Yes.

R: Now, what is it like for you having WS? How does it feel for you?

P: When I have had a lot of tasks from the past about my WS and it is all because...most of the time because of my walking. Erm I've got a funny hip, which made me paralysed for a bit because I used to have those fits when you collapse. Not like collapse like in genuine collapse like having a fit or anything but it was just that my legs stopped working and I had to go to the hospital because of it. And I don't have them now.

R: Ok. Do you think there are any good things about having WS?

P: Yes, there is good things about having WS because people... I haven't told you this but WS people have hobbies. Some people can be with erm...may be interested in washing machines, they may start collecting washing machines, but erm...some people can be collecting bus tickets you know and my is the most expensive hobby ever because you know I am interested in puppets so I have started collecting them you know and I've learnt a lot of things about the hobby that I do. It's like a dying act you know because a lot of ventriloquists nowadays they have died and all that stuff and it's really rare that you see a person do it.

R: Ok, that is very good. Now, do you think there is any things that are not good about having WS? What are the downsides to it?

P: The down side of having WS is got to be the sensitive hearing because when I was a little kid there used to be like a mobility fish and chip shop and every time it would ring I would have to cover my ears, I would scream and all that because my ears were really hurting and nowadays people whistle and I say stop it because I have sensitive ears and if you upset my sensitive ears then you've had it, you've had it.

R: Ok. It was interesting what you said earlier about strangers. I wonder what you think about WS and what people with WS are like with others, like with friendships and relationships. What do you think about that?

P: I get along with nearly everybody as you've seen because I am sometimes...sometimes there have been things who have let me down and I tell them to get the hell out of here because I don't want to know their sight anymore. And sometimes people with WS can relatively relate to others because they like the same music or same kind of hobby ad they like say...ooh I like that song, yeah I've heard that before.

R: Now, if you could change anything about yourself, what would you change?

P: It would be my hearing because I know there is a lot of people with hearing problems and I have the most rarest because you know some people have hearing aids, or some people have those things you have to like connect through your head and all that stuff really because like I've seen people who have like this device connected to their ear and that made them hear things. I just wish it would go away, my sensitive hearing because then I would be more of a normal person then.

R: Thank you very much. You have given me some fantastic answers. You have done really well. Thank you.

### **Transcript WS 18**

When completing SIP-A part one (What are you like?) the participant made the following comments:

P:

[Good looking] My boyfriend says I'm always good looking so I think number five.

[Fun to be with] My friends say that I'm fun to be with when I text them or when I'm on Facebook, they always say that.

[Feeling different from others] I do feel different from others because my sister doesn't wear glasses and I do because I'm like short-sighted or something like that. Well, my family is Russian and I speak it so...

R: So what number do you think you would give yourself?

P: I think I would say about four.

[Annoying] Some friends say I'm annoying but not all of them, so number three.

[Loud] Sometimes I'm loud, when I'm bored I speak to myself loudly.

[Worry a lot] If my family is like kind of gone through bad stuff I worry about it.

[Get bored] When I'm at home on my own I get bored.

When completing SIP-A part two (How would you like to be?) the participant made the following comments:

[Happy] Stay the same because I like to stay happy and be cheerful. Sometimes people think I'm mad because I'm like all hyper, some people think it's like cool to be mad.

[Sporty] Stay the same I really hate sports day, it's sports day tomorrow.

R: Can you tell me how you know that you are friendly? You said you are very friendly?

P: Because if like someone gets lost in school and they don't know where to go I would always like ask them what lessons do you have and they like say I don't know, and if they don't know I would tell them to go to learning support and they will tell you where to go.

R: So you are very friendly by helping people out?

P: Yeah.

R: You said you are very confident. Why do you think you are very confident?

P: Because I like doing stuff like practice and I go horse riding every Thursday so yeah...

R: So you think you are quite confident?

P: Yeah.

R: Ok. On feeling different from others you said you are number four. Could you tell me a little more about that?

P: Like cause sometimes I like...like my friend who has WS wears glasses for reading and I have to wear my glasses every time. So yeah.

R: So is that why you feel different from others?

P: Yeah.

R: And is there anything else that makes you feel that you are different from others?

P: I am crazy [laughs].

R: What do you mean by that?

P: Like I'm really happy like when I'm with my friends like I go hyper.

R: And do you think that other people don't really get like that?

P: Hmm...I can't say no, but yes, I'll just some in the middle.

R: Ok. You said you worry a lot didn't you?

P: Yeah.

R: Are you ok to tell me more about that?

P: My nan has got cancer so it's kind of worrying if she is going to stay alive or not so yeah.

R: I'm sorry. That must be difficult to think about those things. You said you wanted to worry less didn't you?

P: Yes.

R: Ok, ok. You are doing really well. Are you ok to carry on?

P: Yeah that's fine.

R: You also said you are intelligent.

P: Yeah, I'm on grade five on violin and my sister is on grade three. I just get really happy if I...yeah.

R: Ok, that very good. Now is it ok if I ask you some questions about WS?

P: Yeah, yeah.

R: Can you tell me what you know about it?

P: Well it's also called the happy syndrome and like that's why I smile a lot and like be cheerful. There isn't really a difference so yeah.

R: What do you mean by there is not really a difference?

P: Like it's like if I'm like in a mood I get really kind of down and if I'm really happy I'm like happy so yeah.

R: I see. I wonder if someone didn't know what WS is and they asked you, what would you say?

P: I would say like its kind of like a condition and lots of people have it and its like really rare for people and it can be like cool like really good and sometimes like weird.

R: Ok, so you said there is some things that are good about it. What do you think is good about having WS?

P: Because it's like it is making me feel different, it's like really good, really fun so I like being cheerful and happy.

R: Do you think there is anything that's not good about having WS?

P: No...not really.

R: Ok. You were earlier talking about your boyfriend and you said that he has got autism. Is that right?

P: Yeah, yeah.

R: What do you know about autism then?

P: Well sometimes like he can't spell and I like have to help him and sometimes he is like kind of crazy and really mad [laughs] and I'm like I have to be with this chap all the time [laughs].

R: And if you think about the two different syndromes, WS and autism, do you think there is anything similar or different about them?

P: My boyfriend can smile sometimes like if he is in a good mood then he is like mad and crazy. I would say if like someone had autism and there was no one to help them I would like want to help cause I want to like help people to learn and to like do different things.

R: Do you think there are any bad things about autism?

P: Sometimes there are like...it can make people angry and stressed out but like I said my boyfriend in not like that.

R: Ok. Do you think there any bad things about autism?

P: I like if he is working, that's good. He's really good like and it makes it interesting.

R: Ok, very good. And last questions, we were talking about feeling different from others and generally the way you are. If there was something you could change about yourself, what would you change?

P: Erm...I don't know, that's kind of tricky. I would like to have my hair changed, the colour of my hair.

R: Ok, very good. Thank you very much. You have done really well.

