

**Identification with Stigmatised Groups:  
Does Group Identification Lead to Poor Self-Esteem?**

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### **Thesis declaration form**

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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## Overview

The focus of this thesis is the effect that receiving a stigmatised label can have on self-esteem. It investigates how diagnostic labels can identify individuals as belonging to a stigmatised social group and how stigma impacts on self-esteem. The thesis is presented in three parts: a systematic literature review, an empirical paper and a critical appraisal.

Part one, the systematic literature review, examines research to date that explores the relationship between group identification and self-evaluation within two stigmatised groups: people with learning disabilities and people with mental health problems. The review highlights that group identification has a positive or negative impact on self-esteem depending upon whether the group is viewed positively by its members and whether coping strategies for stigma are present. The majority of these findings came from the mental health literature as there is a paucity of robust literature on group identification and self-esteem among people with learning disabilities. Recommendations are made for further research to focus on group identification and self-esteem among people with a lifelong condition.

Part two, the empirical paper, investigates the relationship between group identification, coping with stigma and self-esteem among adults with Autism Spectrum Condition. It found within its sample recruited online via ASC forums that group identification could protect self-esteem if the individual felt unaffected by stigma and could reject negative stereotypes, but self-esteem was not affected by group identification if coping with stigma was not present. Clinical implications are considered.

Part three, the critical appraisal, considers methodological and conceptual issues of the current thesis and concludes with reflections on the research process.

## Table of Contents

<b>Thesis Declaration Form</b> .....	2
<b>Overview</b> .....	3
<b>Table of Contents</b> .....	4
<b>List of Tables</b> .....	7
<b>List of Figures</b> .....	7
<b>Acknowledgements</b> .....	8
<b>Part One: Systematic Literature Review</b> .....	9
Abstract.....	10
Introduction.....	11
Method.....	17
Search Strategy.....	17
Search Terms.....	17
Inclusion/Exclusion Criteria.....	18
Results.....	19
Group Identification within the Mental Health Literature.....	25
Group Identification within the Learning Disabilities Literature.....	38
When an Individual is Identified by Others as Being a Member of a Stigmatised Group, do they Tend to Identify Themselves as a Member of that Group?.....	46
What is the Relationship between Identification with a Stigmatised Group and Self-Evaluation?.....	49
Is the Relationship between Group Identification, Stigma and Self-Evaluation Different for Mental Health and Learning Disabilities Diagnoses?.....	52
Discussion.....	54
References.....	57
<b>Part Two: Empirical Paper</b> .....	60
Abstract.....	61
Introduction.....	62

Method.....	71
Procedure.....	71
Participants.....	72
Design.....	74
Measures.....	75
Ethical Considerations.....	78
Statistical Analysis.....	78
Results.....	79
Discussion.....	85
Main Findings.....	89
Clinical Implications.....	91
Limitations.....	92
Future Research.....	94
Conclusions.....	96
References.....	97
<b>Part Three: Critical Appraisal.....</b>	<b>102</b>
Introduction.....	103
Literature Review.....	103
Public Stigma and Group Identification.....	104
Empirical Paper.....	105
Internet Recruitment.....	105
Autism Spectrum Condition and Stigma Awareness.....	108
Labelling and Enabling.....	109
Clinical Implications.....	112
Conclusions.....	113
References.....	114

<b>Appendix A: Measures as Presented Online.....</b>	<b>116</b>
<b>Appendix B: Information Sheet and Consent Form: First Page of Survey.....</b>	<b>117</b>
<b>Appendix C: Debrief Sheet.....</b>	<b>120</b>
<b>Appendix D: Ethical Approval Confirmation.....</b>	<b>121</b>

## List of Tables

### Part One: Literature Review

Table 1. Database Search Terms.....	17
Table 2. Journal Articles Exploring the Role of Group Identification (GI) and Stigma in Self-Evaluation of People with Mental Health Diagnoses.....	20
Table 3. Journal Articles Exploring the Role of Group Identification (GI) and Stigma in Self-Evaluation of People with Learning Disabilities.....	23

### Part Two: Empirical Paper

Table 1. Descriptive Characteristics of Adults with ASC Recruited for Current Study N = 223.....	73
Table 2. Differences Between Subsections of Adult ASC Sample on Group Identification, Stigma Resistance, Stereotype Rejection and Self-Esteem....	81
Table 3. Correlations for Age, Years Since Diagnosis, AQ-S Scores and Measures for Model .....	82
Table 4. Mediation Effect of Group Identification (GI) on Self-Esteem (S-E) Through Stereotype Rejection and Stigma Resistance.....	84

## List of Figures

### Part One: Literature Review

Figure 1. Theoretical arguments leading to questions for this review, focusing on two groups: mental health problems ('MHPs') and learning disabilities ('LD').....	16
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### Part Two: Empirical Paper

Figure 1. The Rejection-Identification Model: the mediating effect of group identification on stigma and psychological well-being (Branscombe et al., 1999).....	67
Figure 2. Processes identified as mediating the relationship between group identification and self-esteem (Crabtree et al., 2010).....	70
Figure 3. Relationship identified between Group Identification (GI) and Self-Esteem (S-E) including point estimates for total mediation effect and for each mediator identified.....	85

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## **Part One: Literature Review**

### **Group Identification and Self-Evaluation among Stigmatised Groups: A Review of Mental Health and Learning Disabilities Literature**

## **Abstract**

**Aims:** If an individual receives a diagnosis, this can identify them as a member of a stigmatised group. The aim of this paper is to review the relevant literature in order to address three main questions about group identification. 1) When an individual is identified by others as being a member of a stigmatised group, do they tend to identify themselves as a member of that group? 2) What is the relationship between identification with a stigmatised group and self-evaluation? 3) Is this relationship different for mental health and learning disabilities diagnoses?

**Method:** The academic literature was searched using PsycINFO, Web of Science, Embase, Medline and Google Scholar to identify peer-reviewed articles that explore the relationship between group identification, self-stigma and self-evaluation in the two diagnosed groups: mental health problems and learning disabilities.

**Results:** Sixty-eight studies were identified by systematic search, 13 met criteria for this review. Eight papers focused on mental health and five focused on learning disabilities.

**Conclusions:** There was variation in quality of methodology used, so conclusions are tentative. People tended to identify with their group but variation in level of group identification was found. Identification with the mental health problems group seemed to impact negatively on self-evaluation when the group had little value to the group member and group membership did not aid coping with stigma; if the group was valued and coping resources increased, self-evaluation could be protected. Ingroup, downward comparison to protect self-evaluation was present in both groups, but was more of a focus in the learning disabilities literature; there were no reports of the learning disabilities group being valued by its members. Implications for future research are discussed, including the study of other diagnoses such as Autism Spectrum Condition.

## Introduction

Society's attitudes towards people due to their race, religion, gender, age, sexuality and socio-economic status have been studied by the field of social psychology for decades. More recently, stigmatised views towards people with mental health problems and learning disabilities have received attention in the field. The existence of stigma and prejudice towards people with mental health problems or learning disabilities can present a dilemma within clinical psychology: labelling someone as having a learning disability or mental health problems may provide them and other professionals with an explanation for their difficulties and aid treatment planning, but the label may also affect how they feel about themselves (i.e. their self-evaluation) and leave them vulnerable to stigma and discrimination from others.

Cooley (1902) and Mead (1934) proposed that an individual's sense of self is created through knowing how others perceive them via the 'looking glass' of others' perceptions (Cooley, 1902). This 'looking glass self' theory suggests that views held by others are interpreted by the individual as a true reflection of themselves, which may leave some individuals vulnerable to internalising a negative self-view of themselves owing to the opinions held by society, for example individuals who are stigmatised against. Goffman (1963) described stigma as a social process whereby individuals who possess attributes that are devalued in society are discriminated against and socially rejected. Goffman reasoned that those individuals who are devalued and discriminated against will become aware of a 'spoiled identity' of the self. In line with the theories proposed by Cooley (1902) and Mead (1934) that one internalises the views of others when constructing one's own identity, Goffman (1963) suggested that an awareness of the stigmatised views of others can result in an individual feeling ambivalent towards his or herself. In support of this, Wahl (1999)

found evidence that the stigmatizing label of having mental health problems was associated with negative experiences such as being treated as less competent and being socially rejected, and that these experiences of stigma could lead to low self-esteem. There is evidence to suggest that low self-esteem as a result of stigma can impact on important areas of an individual's life, and it has been found that people with mental health problems are less likely to apply for jobs or to pursue intimate relationships due to fear of rejection (Link, Cullen, Struening, Shrout & Dohrenwend, 1989).

This relationship between stigma, poor self-evaluation and poor quality of life is further perpetuated by existing public discrimination: people labelled with mental health problems have difficulty finding employment when they do apply for jobs (Link & Phelan, 2001), which in turn is likely to impact negatively on quality of life and self-evaluation. Within the learning disabilities field, there is evidence that people are also subject to discriminating behaviours such as social rejection and even violence from others (Mencap, 1997). However, there appear to have been no studies to date examining how these experiences impact on quality of life, rates of job applications or pursuit of relationships within this population. It may be the case that if stigma experienced by people with learning disabilities leads to poor self-evaluation, then quality of life will be impacted upon in a similar way to that found with people with mental health problems (Link & Phelan, 2001).

The relationship between identification with a stigmatised group and self-evaluation may not be as simple as the 'looking glass self' suggested by the early models of Cooley (1902) and Mead (1934) however. There may be important factors affecting this relationship such as the characteristics of the group to which an individual belongs. For example, whether an individual can voluntarily leave their

group or hide their membership at any stage may have important implications for the relationship between identification with that group and self-evaluation. Social Identity Theory (Tajfel & Turner, 1979) suggests that the self-evaluation of an individual depends on how the group they belong to is perceived by society and on their ability to leave a stigmatised group if they wish to by, for example, hiding their membership. It may be possible for some individuals to hide their religious or political views when they wish to, but it is more difficult to hide one's gender or race. If individuals do not have the option to hide their group membership, as with gender and race, then that group is described by Social Identity Theory as having no 'permeability': individuals cannot hide their membership and cross over to another group. Chronic conditions such as learning disabilities and long-term mental health problems could possibly have little permeability as groups, given the life-long nature and severity of the conditions. For these individuals who cannot easily hide their group membership, Social Identity Theory would predict that that applying stigmatised views to the self cannot be avoided and self-evaluation will suffer as a result: i.e. the stigma will be internalised.

It may not be the case that membership to impermeable, stigmatised groups automatically results in poor self-evaluation, however. Crocker and Major (1989) examined the effects of stigma on the self-esteem of individuals from a range of impermeable, stigmatised groups such as people from ethnic minorities, people with facial disfigurements, people with physical disabilities and people with learning disabilities. In their review of the evidence they found that members of these groups did not automatically experience low self-esteem. They proposed that this was due to a number of social mechanisms: group members attributed the negative views of others to stigma and so these were seen as invalid, they used ingroup comparison

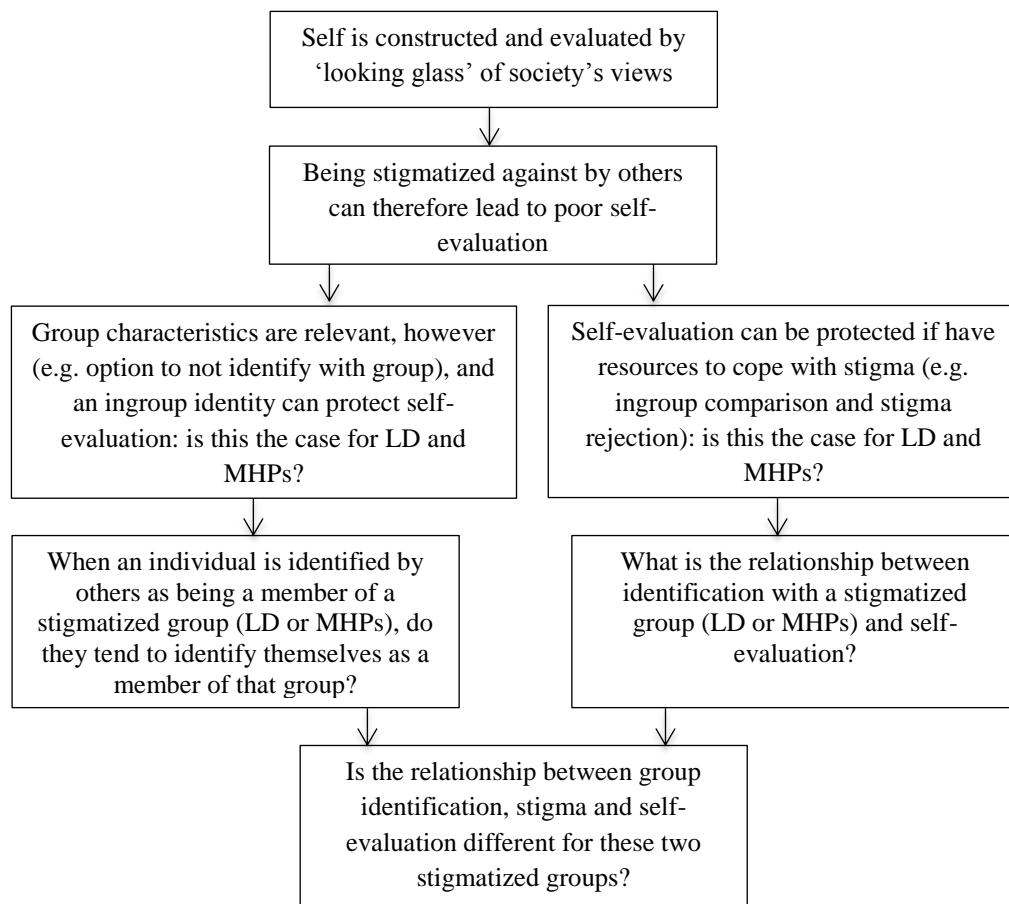
rather than outgroup comparison to boost positive self-evaluations, and they valued the dimensions in which their group performed well and devalued those in which the group performed poorly. Engaging in these coping behaviours seemed to protect positive self-evaluation, despite an awareness that the 'looking glass' views of others were negative due to stigma.

Branscombe, Schmitt and Harvey (1999) suggested a model that supports findings that self-evaluation can be protected amongst people belonging to stigmatised groups. They found that being a member of a stigmatised group, in this case being African American, led to social rejection by the outgroup, but the negative impact that this discrimination had on self-evaluation was mediated by certain factors. Feelings of belonging to an ingroup and having a strong sense of identity as a member of that group protected self-evaluation despite feeling stigmatised against. Their 'rejection identification' model adds to the argument that the development of the self and self-evaluation is not as simple as internalising the negative views of others held towards one's social group, as a 'looking glass self' model would suggest.

There is an assumption within all of the models mentioned, however, that when an individual is given a label by others they will invariably identify themselves as belonging to that labelled group; this may be due to the fact that the findings are based on truly impermeable groups such as being African American. However there may still be some variability between individuals in the extent to which they identify with their group labels. It could be assumed that people with lifelong conditions such as learning disabilities and very severe mental health problems would strongly identify with their group owing to the unlikelihood of being able to leave that group. However the level of identification may vary depending on how easily hidden their

condition is. It seems important, therefore, to establish whether group identification varies among group members and whether some individuals choose not to identify with their label, or to hide it, in order to protect self-evaluation. This is one of the areas that this review hopes to investigate further.

Branscombe et al.'s (1999) model suggests that poor self-evaluation is not an inevitable outcome for stigmatised group members, if they foster a sense of identity that helps protect self-esteem. It is not known whether such a positive ingroup identity is fostered among people with learning disabilities or mental health problems. Crocker and Major's (1989) findings suggest that there may be coping strategies available to these groups, but it is not known whether people with learning disabilities or mental health problems gain a positive self-identity through being part of an ingroup, as suggested by Branscombe et al. (1999). The relationship between level of group identification, perception of stigma and self-evaluation within these two groups needs further examination. It will also be important to establish if there are any differences between these groups in terms of this relationship, and if so whether this is due to factors such as group permeability. These areas are explored within this review, and three main questions have been developed for this review through understanding previous theory (see Figure 1).



*Figure 1.* Theoretical arguments leading to questions for this review, focusing on two groups: mental health problems (‘MHPs’) and learning disabilities (‘LD’).

As above, the three questions this review hopes to answer are:

- 1) When an individual is identified by others as being a member of a stigmatised group, do they tend to identify themselves as a member of that group?
- 2) What is the relationship between identification with a stigmatised group and self-evaluation?
- 3) Is the relationship between group identification, stigma and self-evaluation different for mental health and learning disabilities diagnoses?



## Method

### Search Strategy

The literature was systematically searched to identify studies that had focussed on the relationship between group identification, stigma and self-evaluation in people with mental health problems and people with learning disabilities. The electronic databases PsycINFO, Web of Science, Medline, Embase and Google Scholar were searched for the period of January 1992 to September 2012 to encompass a 20 year period to date.

### Search Terms

The search terms focused on four domains: self-evaluation, stigma, group identification and clinical population presented below in Table 1.

Table 1

#### *Database Search Terms*

Self-evaluation	Stigma	Group identification	Clinical population
Self-esteem	Stigma*	(Group or collective)	Mental health
Self esteem	Self-stigma*	adj (ident* or memb*)	Mental* ill*
Self-belief	Intern* stigma*	Social ident*	Psych* dis*
Self belief	Prejudice*		
Self-efficacy	Discriminat*		Learning dis*
Self efficacy	Social* stigma*		Learning diff*
Well being			Mental* retard*
Well-being			Intellectual*
Wellbeing			dis*
Self concept			Intellectual*
Self-concept			impair*
Self-worth			
Self worth			

\* truncates words so that endings for that term are found.

Keyword searches self-esteem, stigma, group identity, mental health and learning disabilities were exploded on each database so that all variations of the keyword were included in the search. For example when exploded in the search, 'mental health' would include papers on 'depression', 'schizophrenia', 'bipolar' etc. Self-evaluation, stigma and group identity domains were combined for each search, and then combined with either mental health or learning disability domains.

### **Inclusion and Exclusion Criteria**

Articles found in the search were evaluated against criteria to determine suitability for this review:

#### **Inclusion Criteria.**

- English publication in a peer-reviewed journal.
- Published between January 1992 and September 2012, to cover the last 20 years of research plus any papers published in the months leading up to the time of the search.
- Describe a study that looks at group identification and self-evaluation, focused on an adult population (18 years old or above).
- Be empirically based, including quantitative or qualitative methodologies.

#### **Exclusion Criteria.**

- Focused on the experiences of relatives or carers rather the diagnosed individuals themselves.
- Focused only on public attitudes and stigma, not the experience of the stigmatised individuals.
- Presented theoretical models or review articles rather than empirical evidence.

Reference lists of the studies found were hand searched for possible additional papers and the same inclusion and exclusion criteria were applied to

determine the suitability of these papers. All studies were selected for review by reading the abstract or full article when the abstract did not provide enough detail.

### **Results**

The search terms produced a total of 68 papers. When the inclusion and exclusion criteria were applied to these papers, 13 papers remained. One more was found via the reference list of those identified.

The results of the search are summarised in Table 2 and Table 3, followed by a detailed review of the literature. A quality checklist was not used for this review as there is a wide range of methodologies included and the focus of this review is to examine theories raised in the literature rather than clinical interventions. However, methodologies of the studies are critiqued and each study is considered in terms of its methodological strength when discussing its findings.

Table 2

*Journal Articles Exploring the Role of Group Identification (GI) and Stigma in Self-Evaluation of People with Mental Health Diagnoses*

Researchers	Country	Sample	Qualitative or Quantitative Design	Relevant Measures	Was Group Identification (GI) Found to Exist in This Population?	Was a Relationship Between GI and Self-Evaluation Found?	Other Findings?	Limitations
Camp, Finlay & Lyons (2002)	UK	$N = 10$	Qualitative	None	Yes	Yes, GI linked with sense of capability.	Downward, ingroup comparison improved sense of capability.	Small $N$ , sampling bias: all regular attendees of day centre, may affect generalizability of results.
Corrigan, Morris, Larson, Rafacz, Wassel, Michaels, Wilkniss et al. (2010)	USA	$N = 85$	Quantitative	GI, perceived discrimination, 'coming out', stigma coping, quality of life interview	Yes	Yes, GI assoc with less use of secrecy of label to deal with stigma. Secrecy did not promote positive self-esteem.	Strategies to deal with stigma differed among group members.	Coming Out with Mental Illness Scale was adapted from measure used for coming out as homosexual, not previously tested on MHPs population.
Crabtree, Haslam & Postmes (2010)	UK	$N = 73$	Quantitative	GI, self-esteem, stereotype rejection, stigma resistance, perceived social support	Yes	Yes, GI predicted low and high self- esteem depending on mediating factors.	Stigma resistance, stereotype rejection, social support mediated relationship between GI and self-esteem.	Small $N$ for structural equation modelling.  May be alternative causal relationships suggested in SEM model.

Researchers	Country	Sample	Qualitative or Quantitative Design	Relevant Measures	Was Group Identification (GI) Found to Exist in This Population?	Was a Relationship Between GI and Self-Evaluation Found?	Other Findings?	Limitations
Rüsch, Lieb, Bohus & Corrigan (2006)	Germany & Switzerland	<i>N</i> = 90	Quantitative	GI, perceived stigma, self-esteem, empowerment, perceived legitimacy of discrimination, depression	Yes	No	Low perceived discrim. & low perceived legitimacy of discrim. predicted high self-esteem and empowerment.	Two groups only: borderline personality disorder and social phobia. Cannot generalize to other mental health disorders.
Rüsch, Corrigan, Wassel, Michaels, Olschewski, Wilkness & Batia (2009a)	USA	<i>N</i> = 85	Quantitative	GI, group value, stigma as harmful, coping with stigma, perceived discrimination, perceived legitimacy of discrimination, depression, social cue recognition	Yes	Yes, GI assoc with perceived harm due to stigma and perceived coping with stigma.	Perceiving stigma as unfair assoc with more perceived harm. High group value assoc with perceived coping resources.	No measure for stigma stress in response to threatening situations, only measured as a trait.
Rüsch, Corrigan, Powell, Rajah, Olschewski, Wilkness & Batia (2009b)	USA	<i>N</i> = 85	Quantitative	Ingroup comparison (used as GI measure), social anxiety, management of stigma, devaluing domains, self-esteem, hopelessness, social competence test, seating distance, social role-plays	Yes	Yes, ingroup comparisons was associated with poor social performance and increased seating distance from outgroup members.	More ingroup comparison in SZ sample. Stigma stress assoc with social anxiety and shame. Coping styles not assoc with self-esteem, but devaluing group was assoc with hopelessness.	No measure for stigma stress in response to threatening situations, only measured as a trait.

Researchers	Country	Sample	Qualitative or Quantitative Design	Relevant Measures	Was Group Identification (GI) Found to Exist in This Population?	Was a Relationship Between GI and Self-Evaluation Found?	Other Findings?	Limitations
Rüsch, Corrigan, Wassel, Michaels, Olschewski, Wilkniss & Batia (2009c)	USA	<i>N</i> = 85	Quantitative	GI, group entativity (cohesiveness), perceived value of the group, perceived discrimination, perceived legitimacy of discrimination, depression, positive stigma behaviour, negative stigma behaviour, hopelessness, social competence test, social role-plays	Yes	Yes, low GI assoc with good social performance when group value was low.	GI assoc with group value and group entativity. People with MHPs valued MHP group more than public did. Both groups perceived similar levels of discrimination against people with MHPs, but people with MHPs thought discrimination more unfair.	Sample size
Watson, Corrigan, Larson & Sells (2007)	USA	<i>N</i> = 71	Quantitative	GI, self-stigma of mental illness, stereotype awareness, self-efficacy, self-esteem, perceived legitimacy of discrimination	Yes	Yes, GI assoc with self-stigma. Stereotype agreement mediated this relationship.	High awareness of stigma assoc with lower perceived legitimacy of stigma. Stigma awareness: precursor to both agreeing and disagreeing with stigma.	Sample size means effect sizes had to be large to reach significance – some correlations may have been missed.

Table 3

*Journal Articles Exploring the Role of Group Identification (GI) and Stigma in Self-Evaluation of People with Learning Disabilities*

Researchers	Country	Sample	Qualitative or Quantitative Design	Measures	Was Group Identification (GI) Found to Exist in This Population?	Was a Relationship Between GI and Self-Evaluation Found?	Other Findings?	Limitations
Dagnan & Waring (2004)	UK	$N = 39$	Quantitative	Social comparison scale (inc. GI items), stigma, evaluative beliefs	Yes	No, group belonging was not associated with negative evaluative beliefs.	Stigma and social comparison was mediated by negative evaluative beliefs.	Internal validity of social comparison measure (inc. GI) was low – may be why no correlations found between social comparison and negative evaluative beliefs or stigma.
Finlay & Lyons (1998)	UK	$N = 28$	Mixed methods	GI, group evaluation, self-esteem	No	No, GI was not assoc with self-evaluation.	Rejecting the LD label altogether assoc with higher feelings of self-competence.	GI measure: two items only and asked about having LD rather than group belonging. Self-esteem measure had not been previously tested on LD population
Finlay & Lyons (2000)	UK	$N = 33$	Qualitative	None (qualitative)	No	No, label was rejected. But downward, ingroup comparisons protected self-esteem.	Lateral comparisons with public (on similarities) also protected self-esteem.	LD with and without phys. disability is mentioned as a factor but phys. disability is not referenced in demographics and is not inc. in the interview.

Researchers	Country	Sample	Qualitative or Quantitative Design	Measures	Was Group Identification (GI) Found to Exist in This Population?	Was a Relationship Between GI and Self-Evaluation Found?	Other Findings?	Limitations
Jahoda & Markova (2004)	UK	<i>N</i> = 28	Qualitative	None (qualitative)	Yes	Yes, GI linked to feeling like an 'outsider' and 'rejected', but also linked to rejecting stigma.	Rejection of stigma by distancing selves from stigmatising services found.	Groups inc. people in assisted living or those being discharged from hospital. People just admitted were not inc. in sample, so small sample bias.
Paterson, McKenzie & Lindsay (2012)	UK	<i>N</i> = 43	Quantitative	Social comparison (inc. GI items), stigma, self-esteem scale	Yes	Yes, GI was assoc with positive self-esteem.	Negative social comparisons assoc with low self-esteem.	Adapted self-esteem measure inc. social comparison items which may have affected the relationship found between these two variables.



As Table 3 shows, only five of the 13 papers that met criteria focussed on people with learning disabilities. All five of these studies were UK based, which means that generalizability to the wider learning disabilities population cannot be assumed. Of the papers found on mental health problems (see Table 2) there was more variability in country of origin, but all were Western studies. This means that generalizability can only be assumed within the Western, developed world. Three of the papers used the same sample (Rüsch et al., 2009a, 2009b and 2009c).

None of the studies examined differences across time as all of them were cross-sectional. They examined one population only except for one study that reported findings for a control group (Rüsch et al., 2009c). None of the studies included a wide range of impairment; all of the learning disabilities studies had a sample of high functioning people owing to the requirement of adequate communication skills to answer research questions, and none of the participants with mental health problems were currently inpatients.

None of the learning disabilities papers included differences in physical markers of disability in their analysis, so it is not known whether there is a difference in experience of stigma between people with physical signs of a learning disability and people without.

Only four papers reported the ethnicity of participants (Corrigan et al., 2010; Rüsch et al., 2009a, 2009c; Watson et al., 2007), however these details were not included in analysis. All of these papers were from the USA and focused on mental health. There were no reports of ethnicity in any of the learning disabilities papers.

### **Group Identification within the Mental Health Literature**

Camp et al. (2002) examined the impact of being labelled with mental health problems among 10 women in their qualitative study. Through content analysis they

identified that while the women were aware of society's stigma towards mental health problems, they did not accept these representations as valid and rejected them as applicable to themselves. None of the women rejected their mental health problem label and four actively accepted theirs. There was no formal group identification measure used, however there was evidence of comparisons being made between participants and other day centre members on characteristics such as level of care needed, and ingroup comparisons on group-based characteristics can be viewed as a marker of group identification (Hinkle & Brown, 1990). The comparisons made were both lateral (comparison with others who are seen as 'equal' , eight of the ten women made these) and downward (comparing oneself to those less able or less well, four out of the ten women made these); two women made both lateral and downward comparisons. This use of ingroup comparison mirrors Major and Crocker's (1989) findings that downward comparisons are made when group identification with a stigmatised group occurs, in an effort to promote positive self-evaluation.

When asked specifically about labels, there were differences found in the sample as to their usefulness versus their harm. Six of the women named 'personality disorder' as a label that they felt uncomfortable identifying with and one rejected it entirely owing to the stigma attached to it. 'Depression' was named as a more socially accepted mental health label.

The strengths of this study lie in the richness of themes that emerged through open-ended questions and that differences between distinct diagnostic labels were examined, even within this small sample. The small sample and the sampling bias of high functioning women only, from just one drop-in centre, mean that generalizability to other groups cannot be assumed: however generalizability was not the main aim of the study. Group identification and self-evaluation measures would

have enabled more conclusions to be drawn about this relationship within this population, and could be an area to pursue when considering further research in this area.

In their quantitative study Corrigan et al. (2010) investigated openly admitting to having mental health problems as a strategy for coping with self-stigma ( $N = 85$ ). They call this 'coming out'. Self-stigma can be described as the internalisation of the stigmatised views of others (i.e. the 'looking glass self' concept), such that an individual can feel devalued, demoralized, and may experience lowered self-esteem and social adaptation (Link & Phelan, 2001; Ritscher & Phelan, 2004). Corrigan et al. (2010) hypothesised that coming out as having a mental health problem would mediate the effects of self-stigma on quality of life. They found two factors in the analysis of the 'coming out' scale: benefits of being out and reasons for staying in. The former factor was associated with self-stigma having less of an impact on quality of life, and with two coping strategies from the 'managing stigma' measure: affirming strategies (facing stigma through action) and becoming aloof (not acknowledging stigma as personally relevant). Unsurprisingly no relationship was found between benefits of being out and the third coping strategy, keeping one's diagnosis a secret.

No relationship was found between the reasons for staying in factor and quality of life, self-stigma or coping strategies. This may be due to one of the study's weaknesses: sampling bias. As 75% of their sample was 'out' about their diagnosis, this meant that the 'in' population were not well represented and so it may be expected that the reasons for staying in factor did not have sufficient power to detect associated relationships to coping strategies. The study did not report the mean average for level of group identification, however, group identification was found to

positively correlate with the coping strategies associated with the factor ‘benefits of being out’, for example, addressing stigma in society through action. This makes theoretical sense as one would expect that the people who so positively address stigma on behalf of their group would be the individuals who feel closely identified with it. It is worth noting that due to the very nature of research recruitment in this area, the ‘out’ members may be more likely to answer questions about their mental health; if one is hiding one’s mental health diagnosis, then participating in a study related to it seems unlikely. A sampling bias such as this could mean that studies may be presenting an exaggerated picture of the extent to which people with a diagnosis do identify with their group.

The strengths of this study include the large sample and the use of several validated measures. While the sampling bias meant that no relationship could be detected between the ‘staying in’ factor and styles of coping with stigma, it did enable sufficient power for relationships between the ‘benefits of being out’ factor and styles of coping with stigma to be detected. A weakness of the study may lie with the *Coming Out with Mental Illness* (Corrigan et al., 2010) measure, however, as it had not been piloted on a relevant group of participants and was adapted directly from a sexuality questionnaire (as mentioned in Table 2).

As causality cannot be inferred from this observational and cross-sectional design, it is not known if high group identification leads to adaptive stigma responses or whether one’s attitude to stigma affects how much one identifies with the group. If an individual feels ashamed of their diagnosis, then keeping it a secret may be protective and by keeping it a secret they may deny being identified as a member of that group. An additional possible variable that was not accounted for was the different diagnoses identified amongst participants. It may be interesting to know if

different labels and previous experiences, for example, number of times hospitalised, led to different levels of group identification and its associated variables.

Crabtree et al. (2010) investigated the hypothesis that identification with a stigmatised group can protect people from the negative effects of stigma via coping resources similar to Crocker and Major's (1989) finding: that of rejecting negative stereotypes of the group as stigma, and the social support that such a group may provide. Their sample ( $N = 73$ ) was taken from support groups and the group identification measure focused on the support group itself, rather than the population identified with mental illness used in the other studies. They found high levels of group identification with this measure (a mean average group identification response score of 4.42 in a scale where 1 is the lowest and 5 is the highest possible score) and that group identification was associated with both positive and negative self-evaluation. Using structural equation modelling, they were able to propose a model that sought to explain the mechanisms underlying these different outcomes. If someone identified with the ingroup, and could reject the stigmatised views held about the group and feel an increase in perceived social support, then this was associated with positive self-evaluation. Group identification without these mediating factors was associated with negative self-evaluation. Despite several papers suggesting the use of structural equation modelling, this is the only study that used it to offer a potential explanation for the causal links between group identification and positive or negative self-evaluation.

A weakness of the study is the generalizability of these results: participants were recruited from support groups and were asked about identification with the support group they attended, rather than with the wider, more abstract group of 'other

people with mental illness'<sup>1</sup>. This means that their findings may not be applicable to the wider population of people with diagnosed mental health problems and makes direct comparison with the other studies difficult, as the other quantitative studies measured identification with 'other people with mental illness'. The sample size is also relatively small for structural equation modelling, but the correlations reached significance, suggesting the study had sufficient power for the model. A further weakness of the study, however, is that there may be alternative pathways that are not presented as this is one of the characteristics of structural equation modelling.

Rüsch et al. (2006) investigated differences between people with mental health problems in terms of the extent to which they self-stigmatise and experience poor self-evaluation as a result. They hypothesized that a high level of perceived discrimination, where the discrimination was perceived to be legitimate, and high group identification would lead to high self-stigma. They found in their correlational study ( $N = 90$ ) that people diagnosed with borderline personality disorder ( $n = 60$ ) scored significantly higher on the group identification measure (a mean average of 4.6 out of a possible 7) than people with social phobia ( $n = 30$ ) did (a mean average of 3.3 out of a possible 7). However, group identification was not found to predict self-stigma or self-evaluation, positive or negative, in either group. They did find that low levels of perceived discrimination and low perceived legitimacy of discrimination predicted positive self-evaluation, which mirrors the coping strategy of rejecting stigma as invalid, as outlined in Crocker and Major's (1989) study. This finding suggests that group identification alone will not predict negative or positive self-evaluation, but that one's reaction to stigma, for example agreeing stigma

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<sup>1</sup> Unless otherwise stated, the mental health studies under review used 'other people with mental illness' for the Group Identification measure.

against the group is legitimate, will impact on self-evaluation. This finding is different to Crabtree et al.'s (2010) model that suggests that group identification without stigma-coping responses will lead to negative self-evaluation, and this may be due to the different group labels being investigated. The study also detected that people with social phobia scored significantly higher on their self-evaluation measures (empowerment and self-esteem) than people with a diagnosis of borderline personality disorder. However, as group identification was not found to predict either of these variables and there was no difference in perceived discrimination between the two groups, it may be that this difference was due to a confounding factor such as how the two types of mental health problem affect self-evaluation before stigma is even considered.

A strength of this study's design is that it was the only one identified in this review that compared diagnoses as part of their analysis. Their relatively large sample size for regression analysis suggests that their results are likely to be robust. The significant difference between the two groups on 'mental illness' group identification may suggest that being diagnosed as having a mental health problem does not mean that an individual necessarily identifies with that group. It is likely that particular diagnoses lend themselves more to an individual identifying with such the 'mental illness' group, but more research would be needed to ascertain why people with borderline personality disorder identify with the 'mental illness' group more than people with social phobia.

One weakness of the study is that the groups were not asked about group identification within their own diagnosis, as it would be clearer then whether people with social phobia do not identify with any mental health group at all or whether this is unique to the umbrella term 'mental illness'. Furthermore, the sample was made up

of women only, so generalizability to men labelled with different mental health problems cannot be made.

Rüsch et al. (2009a) tested the hypothesis that group identification, group value, group 'entitativity' (a sense that the group has a shared, cohesive identity), level of perceived discrimination and legitimacy thereof, would predict appraisal of stigma as a stressor. They found that group identification was present among their sample of people with schizophrenia, schizo-affective and affective disorders ( $N = 85$ ). However, they did not report the mean average score for these groups in this paper, so it is not known if group identification differed between the groups. Group identification was found to correlate with both seeing stigma as harmful; i.e. stigma is a stressor, and perceived resources to cope; i.e. stigma can be coped with. They identified perceived group value as a mediator between group identification and appraisal of stigma that could explain these different findings. As such, group identification can be associated with coping with stigma if one values the group one is identified with, but it can also be associated with stigma being seen as harmful if the group has little value to the member.

They also found that group entitativity was found to be associated with group identity and both 'harm from stigma' and 'resources to cope' appraisals. This suggests that if one feels attached to a group that has a cohesive, shared identity then this will either be felt to be a resource or a threat depending on how highly one values the group. These findings that group identification can have a positive or negative impact on self-evaluation depending on whether the group enables better coping with stigma echo the model described in Crabtree et al.'s (2010) paper.

Strengths of the study include the high number of measures investigating the intricate properties of group identification, as this offers insight into a variety of



group processes at play, such as group value. Their relatively large sample size is sufficient for the t-test and regression analyses used. One weakness of the study is the stigma stress appraisal measure itself, as mentioned in Table 2, as it does not take into account the situational factors involved in stress responses so seeing stigma as a stressor or not may change within an individual depending on these factors.

However, the sample size may be powerful enough to account for these individual differences. It is also not known if measures were taken to avoid type I error in the correlational analysis of so many measures, which may be a further weakness of the study and means that the conclusions drawn should be tentative.

Using the same sample as Rüsç et al. (2009a), Rüsç et al. (2009b) hypothesised that stigma will be a stressor if the perceived stigma-related harm outweighs the three coping resources outlined by Crocker and Major (1989): devaluing the domains at which the group performs poorly, attributing stigma to the prejudice of others and making ingroup comparisons on the basis of capability or wellness. They did not report mean average scores for group identification in this paper, however these can be found in Rüsç et al. (2009c). However, they did find that group identification was present within the different mental health problems groups and that individuals with a diagnosis of schizophrenia used ingroup comparisons significantly more than those with a diagnosis of bipolar disorder, which by Crocker and Major's (1989) definition may suggest higher identification with the group. Greater levels of ingroup comparison were associated with the study's two behavioural measures: poorer social performance and increased seating distance from people without mental health problems. Their analysis detected no significant difference in levels of hopelessness between these two diagnostic groups,

however, and found no relationship between any of the coping responses and self-esteem once social anxiety was controlled for.

The sample of this study was not large enough or varied enough in terms of diagnosis to accurately control for social anxiety as part of the symptomology of the individuals' diagnoses. It is difficult, therefore, to draw conclusions about the impact of stigma on self-esteem with this sample, as the mediating social anxiety cannot be reliably accounted for. This major weakness of the study makes it difficult to draw conclusions about the other social anxiety related measure: seating distance.

The mixed methods of measurement reported is a strength of this paper, as using self-report measures and behavioural measures diminish the potential bias effect of including self-report measures only. Their sample size ( $N = 85$ ) was large enough for their analysis to detect relationships between the variables. As with their other paper reporting these findings (Rüsch et al., 2009a), a weakness of the study is the lack of a measure for stigma stress in response to threatening situations – measuring as a trait only means that the potential impact of level of group identification on self-evaluation is unclear.

In their third paper, Rüsch et al. (2009c) report the quantitative measures used to investigate whether the way in which people with mental health problems perceive their ingroup, (group value, group identification and entitativity), affects how they react to stigma. They report a reasonably high group identification score (a mean average score of 5 out of a possible 7) among people with mental health problems. A strength of their study is that it included a control group ( $n = 50$ ) and they found that people with no diagnosed mental health problems did not identify as highly with the 'mental illness' group (a mean average score of 2.4 out of 7 for the control group). This provides a useful comparison when considering the validity of this

measure. People with mental health problems also scored significantly higher than the control group on group entitativity and group value measures, suggesting that being a part of the group engendered feelings of the group being cohesive and was in some way rewarding to belong to.

Those with a diagnosed mental health problem scored lower on perceived legitimacy of discrimination than the control group; i.e. how deserved are some stereotypes and stigmatised views about people with mental health problems, such as them deserving less status in society. This was not due to a lack of awareness among the control group in regards to the level of stigma faced by people with mental health problems, as there was no significant difference between the two groups' scores on perceived level of discrimination against people with mental health problems. This suggests that both groups were equally aware of the stigma and discrimination that exists against this population, but people without mental health problems saw this stigma as more legitimate.

Another key finding in this paper was that high group identification when group value is low was associated with poor social performance; poor social performance was predicted by high perceived legitimacy of discrimination. They also found that if group entitativity is high and perceived legitimacy of stigma as low, then this predicted the support of anti-stigma initiatives. These findings suggest that group value is paramount to social performance, and perhaps believing one's group has no value engenders negative self-evaluation and social anxiety such that the individual struggles to perform socially. However, the lack of a self-evaluation measure in this study means that only assumptions can be made about this relationship rather than conclusions drawn. They found, however, that when an individual feels positively towards their group, and the group has a cohesive identity

(‘entitativity’) with which they identify, then individuals are more likely to actively support anti-stigma campaigns. This suggests that seeing one’s group as a cohesive whole may encourage what Corrigan et al. (2010) term ‘affirming’ stigma strategies, but only if one’s perception of the group is positive.

In addition to the inclusion of a control group, a strength of Rüsçh et al.’s (2009c) study is the inclusion of depression as a variable to control for a possible effect of low mood on self-evaluation. One major limitation of the study is that there is no inclusion of reported self-evaluation, in contrast to the other papers from the same study studies (Rüsçh et al., 2006, 2009a, 2009b). Instead the impact of group identification and perceived legitimacy of stigma on self-evaluation is assumed by measuring social performance, with the suggestion that poor social performance indicates low self-evaluation due to the internalisation of stigma. While it is a reasonable assumption that poor self-evaluation caused by self-stigma may result in poorer social performance, it may not be enough to measure social performance alone, especially as social anxiety may be part of the symptomology of mental health problems, as discussed in the critique of their other paper (Rüsçh et al., 2009b).

As with the other papers reporting on this study, the cross-sectional nature of the design means that no causal relationships can be determined; it may be that reactions to stigma could themselves impact on perception of (or sensitivity to) stigma, but this cannot be determined. The researchers suggest repeating the study using structural equation modelling to hypothesise causal directions within the relationships. A further potential weakness of the study is that they do not differentiate diagnostic groups, despite the researchers finding this to be a factor in group identification in previous research (Rüsçh et al., 2006).

Watson et al. (2007) used a correlational design to examine the relationships between group identification, stigma awareness, stereotype agreement, perceived legitimacy of discrimination and self-stigma. They found fairly high rates of group identification within their sample ( $N = 71$ ) of people from outpatient mental health services (a mean average response of 6.07 out of a possible 9). They found no association between group identification and stigma awareness or between stigma awareness and stigma agreement. This means that in their sample there was no relationship found between the degree to which individuals identified with their group and their awareness of public stigma; this seems to echo Rüscher et al.'s (2009c) finding that there was no difference between the control group and the 'mental illness' group in awareness of stigma; i.e. group identification does not affect awareness of stigma, only one's response to it.

There was evidence of a negative correlation between perceived legitimacy of stigma and stigma awareness, such that greater stigma awareness was associated with lower perceived legitimacy scores. This suggests that the less aware one is that unfair stereotypes exist against their group the more likely one is to perceive stigmatised attitudes as legitimate. They found that group identification and perceived legitimacy were associated with self-stigma, and there was a strong positive correlation between group identification and self-efficacy. This suggests there may be a protective role that group identification plays on self-evaluation, but if stigma is perceived as legitimate then group identification will instead lead to self-stigma and poor self-evaluation as a result. The potential protective role of group identification is also suggested by the finding that low group identification on its own was associated with higher self-stigma, which may suggest that higher levels of group identification can increase access to the type of coping resources that help an individual avoid self-

stigma. These findings echo those found in Crabtree et al.'s (2010), Corrigan et al. (2010) and Rüsçh et al. (2009a).

Strengths of this study lie in the use of validated measures, however a weakness is that the small sample size meant that large effect sizes were needed to reach significance, and there may have been some relationships present that were not detected; for example, the correlation between perceived legitimacy and self-efficacy was close to significance. It may also be the case that by using a mediational analysis that infers mediation (the study used Baron and Kenny's (1986) mediational analysis approach) rather than an analysis that identifies mediation through a more robust multiple mediator model (Preacher & Hayes, 2004) affected relationships found. Owing to previous research (Corrigan et al., 2006) that demonstrated self-stigma explained a unique variance in self-esteem and self-efficacy when depression was controlled for, depression was not controlled for in this study. This may be a weakness of the study, however, when considering the relationships that may not have been detected: perhaps depression had an effect on some of the relationships tested, but this was not detected owing to its absence as a measure. A control group for comparison may also have improved validity of the results within this study.

### **Group Identification within the Learning Disabilities Literature**

Dagnan and Waring (2004) explored the roles of negative self-evaluation and 'feeling different' on self-stigma in people with learning disabilities. They found in their correlational study ( $N = 39$ ) that negative self-evaluative beliefs were associated with feeling different; negative self-evaluations were also associated with poor self-rated social attractiveness. They found moderate levels of group identification among their sample of people with learning disabilities that attended a day centre (a mean average score of 2.26 out of a possible 4), however their group

identification measure was flawed: when asking individuals if they felt the same or different to other members of a group, the group was not specified. This meant that participants were not rating how similar or different they felt to other people with learning disabilities specifically, but were instead comparing themselves to 'other people'. It could be argued that this lack of a specified group renders this learning disabilities group identification measure meaningless and makes it difficult to draw any conclusions about group identification among this sample. Their study identified a difference among people from different housing situations, however, such that people living in staffed housing experienced a greater degree of self-stigma than those living independently. This relationship was fully mediated by level of verbal ability: people with mild learning disabilities (and therefore lived independently) experienced less self-stigma than people with more severe learning disabilities (who lived in supported housing due their severity of impairment). This suggests that those with more severe learning disabilities were either more stigmatised against or were more prone to internalizing this stigma, perhaps due to lack of coping resources. It is not possible to extrapolate a difference between these two causes from the findings of this study.

One of the strengths of the study was the use of visual analogue scales as a response method for the measures, which enhances the validity of the results as it limits the opportunity for 'last choice responding' that can occur within a learning disabilities population when using measures with multiple choice options (Heal & Sigelman, 1995). However, as previously mentioned, the group identification measure is not specific enough to be considered as a valid tool for measuring identification with other people with learning disabilities. They also did not include a depression measure which means that the impact of depression on negative self-

evaluation was not accounted for in their findings, and cannot be excluded as a possible factor. Drawing reliable conclusions from this study is difficult due to these methodological weaknesses.

Finlay and Lyons (1998) investigated the significance of the label 'learning difficulties' when examining self-evaluation in their mixed methods study ( $N = 28$ ). Two-thirds of their sample admitted having the 'learning difficulties' label when asked directly, but the label was not used spontaneously in self-descriptions. Whether or not a participant admitted to having the label was the sole group identification measure in this study, which means that any relationships found with this measure were relationships with label rejection or acceptance. Label acceptance may be qualitatively different to group identification which includes several other factors such as whether the individual believes there to be a group of people compared to whom they feel more similar than compared to the outgroup (Tajfel & Turner, 1979; Rüscher et al., 2009b).

They found no association between self-evaluation and group evaluation, whether the individual accepted their label or not: people who valued the group poorly did not report feeling more negatively about themselves even when they accepted the label 'learning difficulties', and those that accepted the label did not evaluate it any more positively than those that rejected it. This suggests that group value was not an important component to self-evaluation within this sample, even when they accepted the label. Direct comparisons to the mental health literature on this finding are difficult to make as the studies investigating group value did not include a self-evaluation measure. However, they did find that high group value was associated with perceived resources to cope with stigma and low group value was associated with increased levels of hopelessness (Rüscher et al., 2009a, 2009c). This



may suggest that group value has less of an impact on self-evaluation among people with learning disabilities than people with mental health problems, perhaps owing to less group identification among people with learning disabilities. However the methodological differences, especially in terms of group identification measure, make it impossible to draw firm conclusions.

Compared to the extensive detail provided on group identification by Rüschi et al. (2009b), the focus on the label alone within this study does not seem sufficient. This highlights a difficulty in comparing the two groups, however, as it may be necessary to simplify measures for the learning disabilities population and in doing so aspects of a particular construct will be omitted. The question with the current paper may be whether or not label rejection was the most appropriate construct to choose, compared to more group-focused items such as similarity to other group members.

The small sample size for quantitative measures may also have implications for the conclusions drawn from this study. They conclude that group evaluation is not associated with self-evaluation, whether appraisal of the group is positive or negative, but their sample of 28 may not have sufficient power to detect any relationship that may exist between these variables. A strength of this study is the use of mixed methods analysis which means that findings on the validated self-esteem measure are strengthened by the verbal reports of how participants felt about themselves, but the methodological issues of power and the group identification measure affect the reliability of their findings.

Finlay and Lyons (2000) investigated how sense of self is constructed by through social comparisons. In their qualitative study ( $N = 33$ ) they found that participants made downward ingroup comparisons based on level of capability and

behaviour, for example challenging behaviour, and downward outgroup comparisons based on morality and behaviour, for example people without learning disabilities who steal. They found within their sample that people select the dimensions by which to compare themselves to others in order to promote positive self-evaluation. This reflects the coping strategy identified by Major and Crocker (1989) of being selective in the domains one chooses to value. However, Finlay and Lyons (2000) did not find that participants devalued domains that the group performed poorly at, but instead they would choose domains for comparison at which they outperformed other people with learning disabilities (for example, those with more severe cognitive impairment). This would suggest that instead of identifying with the group and devaluing domains the group performs poorly at to improve self-evaluation, self-evaluation was instead protected by distancing oneself from individuals within the same group who performed less well on those domains.

Group identification was assumed to be present by the researchers if participants engaged in upward comparison with others using attributes relevant to their group. As upward comparisons were rarely made, they assume that group identification was not found. Indeed, their findings suggest that participants made more allusions to being similar to people without learning disabilities than people with learning disabilities, again suggesting an attempt to distance oneself from the group rather than identify with it.

However, as mentioned previously in this review, it may be that comparing oneself to the ingroup on group-based, stigmatised characteristics such as capability and independence is in itself some indication of recognising that one belongs to that group (Hinkle & Brown, 1990). Downward, ingroup comparison present within this

study suggests that some sense of group identification existed, but in the context of individuals wishing to distance themselves from more stigmatised group members.

A strength of this study is the large sample size for a qualitative design, meaning that more individuals' experiences are included so more themes can be identified. However a more robust way of identifying group identification and self-evaluation would improve the reliability of their findings.

Jahoda and Markova (2004) investigated the impact of stigma on self-evaluation of people with learning disabilities living independently compared to those living in hospital accommodation. In their qualitative study ( $N = 28$ ), they found that participants were aware of stigma and had different views about themselves in terms of this stigma. The main findings identified by the researchers were that participants regarded themselves as part of a minority group who rejected prejudice, but also tried to distance themselves from other people with learning disabilities due to the associated stigma. There are examples in the paper of people with learning disabilities rejecting the label due to its associated stigma and feeling it is not personally applicable.

Differences between housing groups and level of independence was found and seem to echo Dagnan and Waring's (2004) findings that people living more independently experience less self-stigma than those in more supported, more stigmatizing accommodation. In Jahoda and Markova's (2004) paper, they found that people in supported housing felt rejected by non-learning disabled peers and that this was a stressor, however the group who resided in hospital spoke of greater feelings of shame than the independent living group due to being visibly defined as an inpatient (via hospital tags). The hospital group admitted to a desire to hide the fact they lived at the hospital due to feeling stigmatised which mirrors Social Identity

Theory's (Tajfel & Turner, 1979) notion that belonging to a visible, impermeable group will engender stronger feelings of self-stigma, owing to the fact that one cannot hide one's group membership.

The study did not measure verbal ability so its role in the relationship between level of supported living and self-evaluation cannot be explored in the same way as Dagnan and Waring's (2004) study, however some residents of the supported housing scheme spoke of being in hospital in the past, which suggests that verbal ability may not account for the relationship with stigma entirely as several participants experienced both settings.

A strength of this study is the large sample size for qualitative analysis and the inclusion of two groups for comparison, including some members that have experience of belonging to both groups. However, as with all of the learning disabilities studies, the sampling bias of people with mild learning disabilities means that the themes generated in their research may only be relevant to this population, and it is not known how long people were in hospital, for what reason specifically and how this may have impacted upon feelings of stigma and self-evaluation.

Paterson et al. (2012) investigated social comparison as a mediator for perception of stigma and self-evaluation within a learning disabilities sample ( $N = 43$ ). They found in their correlational design that negative social comparisons with both the ingroup and the outgroup were associated with low self-evaluation. The mean average ingroup identification was high (3.83 out of a possible score of 5), however their identification with the outgroup was only slightly lower (3.67 out of a possible 5) and this difference was found to be non-significant. This suggests that people with learning disabilities did not identify more with their ingroup than with the outgroup. However, participants who reported identification with the ingroup felt

more capable compared to other members of the ingroup by engaging in downward comparisons and reported positive self-evaluation, whereas no relationship between identification with the outgroup and self-evaluation was found. This suggests that belonging to the ingroup may be protective of self-evaluation, but only if downward comparison with other members are utilised. This finding mirrors other studies within this review (Finlay & Lyons, 2000; Jahoda & Markova, 2004).

A strength of this study is the use of validated measures, however the self-report nature of these measures meant that the sampling bias of only high functioning individuals was present as with the other studies in this review. A further weakness of the study is that their group identification measure was one construct only: 'do you feel the same or different as other service users/other people in the local community?' While this could be considered a more useful, group-based construct than the label acceptance or rejection construct used in Finlay and Lyons' (1998) study, being the same or different as other group members is only one component to group identification. A strength of their group identification is that they specify similarity to other service users, compared to Dagnan and Waring's (2004) more ambiguous measure. Perhaps the addition of Dagnan and Waring's (2004) second group identification item, 'part of a group or alone', would have further strengthened the validity of their group identification measure.

A further weakness of their study is that 43 is a small sample size when trying to detect mediating factors, meaning that some relationships between factors may have gone undetected.

## **When an Individual is Identified by Others as Being a Member of a Stigmatised Group, do they Tend to Identify Themselves as a Member of that Group?**

Some degree of group identification was found within each study, however levels of group identification varied. Within the mental health literature, identification with the ‘mental illness’ group varied among people with different diagnoses (Rüsch et al., 2006), suggesting that group identification may happen more with certain diagnostic labels, but also that certain symptomologies may lend themselves more to identification with the label. Crabtree et al. (2010) investigated group identification with mental health support groups, rather than ‘other people with mental illness’ and found higher levels of group identification (mean average of 4.42 out of a possible 5) than the other studies (Rüsch et al., 2006; Rüsch et al., 2009c; Watson et al., 2007). This suggests that in addition to diagnostic label being an important factor, the specificity of the group will also impact upon identification: perhaps people will identify more with smaller, more specific groups than larger, more abstract populations. More research is needed to confirm this hypothesis and whether it has any bearing on people’s experience of stigma and self-evaluation.

The quantitative studies that reported a mean average score for level of identification with the ‘mental illness’ group (Rüsch et al., 2006; Rüsch et al., 2009c; Watson et al., 2007) all detected some group identification among their sample, but the levels varied. Camp et al.’s (2002) qualitative study described how four of the ten participants accepted the ‘mental illness’ label, but six described feeling uncomfortable with certain diagnostic labels (one example was ‘borderline personality disorder’). As discussed when examining Finlay and Lyons’ (1998) study with people with learning disabilities, there may be more to the group identification process than label acceptance or rejection alone, however the presence of label

rejection may suggest that, for some participants, this is a strategy for coping with the possible negative effects of identifying with a stigmatizing label.

Paterson et al. (2012) included a group identification measure focusing on similarity with others and found a high average level of identification with other service users with learning disabilities (3.83 out of a possible 5 on the group identification measure), which seems to be a more group-based measure than label rejection or acceptance. However, their high average for identification with the ingroup was not significantly different to levels of identification with the outgroup (3.67 out of 5). While it is difficult to draw conclusions about group identification based on one item, however the results of their 'similarity to others' construct may suggest that in order to protect self-evaluation it is necessary for some groups to emphasise their similarities with the outgroup. The presence of similar scores for ingroup and outgroup identification is at odds with the Branscombe et al. (1999) model that suggests a strong sense of an ingroup identity will be fostered and utilised to promote positive self-evaluation. It seems that there is in fact little evidence of a strong ingroup identity being fostered among the learning disabilities population, which raises questions about why this might be. While there is evidence of people with mental health problems denying their label and identification with their group (Corrigan et al., 2010), there are some examples within the literature of people feeling positively towards their label (Camp et al., 2002) and their group (Rüsch et al., 2009a; 2009b). It could be hypothesised that denying group identification is more prevalent in people with learning disabilities because it is more difficult to foster to positive group identity, possibly due to greater stigma or due to the impermeable nature of the group owing to the lifelong nature learning disabilities. However, the scarcity of literature on group identity among people with learning disabilities and

the methodological issues identified of measuring this construct make this hypothesis difficult to prove. This therefore may be an important area for future research.

Levels of group identification amongst diagnosed individuals may vary even further than these studies can capture, as people who do not identify with their group may be less inclined to participate in a study recruiting members of that group. In relation to this, when considering group identification there may be an issue of whether an individual has the option of keeping their diagnosis private. In Corrigan et al.'s (2010) study, they investigated differences between being publicly open about one's mental health problems ('being out') and keeping them a secret ('staying in'), and found that being 'out' was associated with positive coping strategies. However, their study only had sufficient power to analyse the results of those who were 'out' ( $n = 64$ ), due to the fact that their sample of people who were 'in' was too low ( $n = 21$ ). It may not be possible for all people to hide their label and perhaps being 'in' or 'out' is less of an option afforded to people with learning disabilities, especially those who require assistance with living or are an inpatient. The relevance of being 'visible' as a stigmatised group member was raised in Jahoda and Markova's (2004) study, when participants made reference to feeling ashamed when they could be identified as a hospital patient via their hospital tags. In line with Social Identity Theory (Tajfel & Turner, 1979), it may be less possible for people with learning disabilities to hide their label, their group is less permeable as a result, and label rejection and distancing from other group members is therefore used to protect self-evaluation. It may be difficult to prove this hypothesis among people who can hide their label when they wish to, however, as recruitment to research of this kind requires some willingness to admit a label as applicable to self.



In summary, it seems that people with mental health diagnoses do tend to identify with their group. However, sampling bias within the studies means that people who do not identify with their group may not have been included. Within the learning disabilities research, identification varied but was generally lower or similar to the outgroup, and label rejection and distancing from other group members was identified. The highest levels of group identification were found with a small, specific group (Crabtree et al., 2010) and this may be a factor when considering group identification.

### **What is the Relationship between Identification with a Stigmatised Group and Self-Evaluation?**

It appears that there may be several steps between being identified as a member of a socially defined group and one's self-evaluation. There are a number of important factors not included in Branscombe et al.'s (1999) model that seem important to this relationship. As described in the section above, first one must identify with their group label or reject it, and then decide whether they feel they belong to this group of people and are similar to other members in some way. A finding among the learning disabilities literature (Paterson et al., 2012; Jahoda & Markova, 2004; Finlay & Lyons, 2000) was that seeing oneself as the same or different as other group members had an impact on self-evaluation. These papers detected that downward comparison with other ingroup members was used to protect self-evaluation, which served as an effective strategy for those more able members of the group. When group identification was present, downward comparisons were used to try and distance the individual from other, less able, more stigmatised individuals. This mirrors Crocker and Major's (1989) findings that people belonging to impermeable, stigmatised groups may use downward comparisons to protect self-

esteem. This raises important questions for the self-evaluation of those individuals who have more severe forms of learning disabilities and subsequently are the ones being used for comparison; due to the nature of the research, only people with mild learning disabilities were included in these studies, so it is not known what strategies are being used by people with more severe impairments, how aware they are of stigma or how they protect self-evaluation.

The coping mechanism identified by Crocker and Major (1989) of attributing negative views of others to stigma was identified within the mental health literature in terms of people rating perceived discrimination as not being legitimate (Rüsch et al., 2009c). Indeed, Rüsch et al. (2009c) identified that people with mental health problems perceived discrimination as less legitimate than did the control group of people without a diagnosed mental health problem, suggesting both that people in the outgroup discriminate against the ingroup more than members of the ingroup, and that the coping strategy of attributing negative views of others to stigma was found among people with mental health problems. In order for an individual to reject stigmatised views as legitimate, however, it may be necessary for them to have a positive view of their ingroup. In turn, the mental health literature suggests that the degree to which the ingroup is valued by the individual affects self-evaluation (Rüsch et al., 2009a; Rüsch et al., 2009c; Watson et al., 2007). Rüsch et al. (2009a) found that identifying with a group will impact on how an individual responds to stigma depending on group value: if an individual feels attached to a group that they perceive to have high value, then this group membership is associated with feelings of being able to cope with stigma, however if they feel attached to a group that has little value then this membership is associated to feelings of increased vulnerability to the harm of stigma.

Therefore, group identification can be a resource to help one cope with public stigma or group identification can be seen as a threat to self-evaluation, depending on the stigma associated with it and how an individual copes. By comparison, no association was found between group evaluation (group value) and self-evaluation among the learning disabilities population (Finlay & Lyons, 1998), even when participants accepted the label. While this may suggest that the relationship between group identification, group value and self-evaluation are different for the two populations, the differences in measures used, sample size and methodological strength of these studies make it difficult to draw conclusions.

In summary, group identification can have a negative or a positive influence on self-evaluation, depending on the group's perceived value and the resources it may provide to cope with stigma. If the group is seen as having little value but an individual identifies with it, then self-evaluation may suffer, especially if that individual is at the less competent or independent end of the group's spectrum and has no effective strategies for coping with stigma such as downward comparison. If the individual is more competent and independent than other members, then the group membership is likely to improve self-esteem by making downward comparisons, especially within the learning disabilities group. Within the mental health literature there was some evidence that the group and its members can be viewed positively, rather than serving as a platform for downward comparisons, and this can be protective for self-evaluation when group identification is present. However the same positive group value was not detected within the learning disabilities literature. It seems that while people who identify with the mental health problems group can experience protected self-esteem against stigma when they see the group as having value, the same positive group value was not identified among

people with learning disabilities; instead, downward comparison to distance oneself from less independent members of the group was the main coping mechanism found.

There are sampling issues in terms of a bias in recruiting people who are ‘out’ about their diagnosis, which may inflate findings related to level of identification, coping with stigma and positive self-evaluation among this sample. There may also be a key difference between the mental health group samples and the learning disabilities samples in terms of who sought the diagnosis and when this was obtained: people with a learning disabilities may have had their diagnosis for much longer than people with mental health problems, and people with mental health problems may be more likely to seek a diagnosis themselves than people with learning disabilities. This may have some impact on level of group identity, historic experiences of stigma and current self-esteem; it is not possible to establish whether this is the case from the papers included in this review, however, and it is recommended that this be examined in future research.

### **Is the Relationship between Group Identification, Stigma and Self-Evaluation Different for Mental Health and Learning Disabilities Diagnoses?**

There are similarities between the groups in terms of both populations being aware of stigma, but there may be some differences between the groups in how self-evaluation is protected. There is evidence in the mental health studies that group members can view their group positively which can help in the rejection of stigma, and that group membership can be associated with increased perceived social support which also protects self-esteem (Crabtree et al., 2010; Rüscher et al., 2009a; Watson et al., 2007). This contrasts with the findings from the learning disabilities literature, which found that people tend to try and distance themselves from other group members, whether physically (Jahoda & Markova, 2004) or through downward

comparison (Jahoda & Markova, 2004; Finlay & Lyons, 2000; Paterson et al., 2012), suggesting that the group itself is not valued among its members. Group value was not measured in any of the learning disabilities literature and further research is needed to confirm differences between the groups on this.

Due to the differences in methodology and number of papers found, no clear conclusions can be drawn from the literature, especially in regards to differing levels of group identification between the two populations. However, this review has highlighted potential themes emerging from the literature. It seems possible for some people with mental health problems to value their group and to use it as a resource to address stigma within society: i.e. there exists a belief within some that the negative views of others are not valid and can be altered through action. There was no evidence of such a positive group image within the learning disabilities population, and perhaps this is the reason why downward comparison and label rejection were found more commonly within this population. Owing to the small number of studies identified, more research is needed so that the relationship between group value, stigma and self-evaluation can be examined within the learning disabilities population. No studies investigating group identification, rejection of stigma and self-evaluation among people with learning disabilities were found.

In summary, differences may lie between these two populations in terms of group permeability, label acceptance versus label rejection, strategies for coping with stigma, and whether one can view one's ingroup positively or not. However, firm conclusions cannot be drawn owing to the methodological issues previously mentioned and the scarcity of a learning disabilities literature.

## Discussion

This review has highlighted that group identification varies among individuals with a diagnosis and the relationship between group identification and self-evaluation may not be as straightforward as earlier theories suggest (Cooley, 1902; Mead, 1934). Branscombe et al.'s (1999) rejection-identification model could also be expanded upon to incorporate the group processes that occur within impermeable, stigmatised groups in an effort to protect self-evaluation. Ways in which group identification may aid coping with stigma or hinder it have been identified within these papers, and seem to echo some of Crocker and Major's (1989) findings with a variety of stigmatised groups; downward comparisons seemed particularly pertinent to the learning disabilities population, and attributing negative views to stigma was a strategy found more within the mental health problems group. Methodological weaknesses and limited literature make any conclusions tentative; however it seems to be the case that within the mental health population, group identification can have a positive influence on self-evaluation if adaptive means of coping with stigma are accessible. Within the learning disabilities literature, high group value was not found and affirmative action against stigma was not identified as a theme; instead themes emerged around individuals wanting to distance themselves from the label and from other group members. This may be indicative of there being greater felt stigma among people with learning disabilities or a greater absence of any positive ingroup image for this population. This raises questions about, for example, whether enough is being done within the public arena to alter people's perceptions of people with learning disabilities, and whether more could be done to encourage a positive ingroup image for this population

When considering this review's findings, its weaknesses need to be acknowledged. All of the studies included in this search are in the English language and so some papers from other countries may have been missed. This means that this review presents an Anglocentric view of group identity and self-evaluation among these populations. Also, the variety of sample sizes, methodology and group identification measures found, make it difficult to make firm conclusions or provide a coherent synthesis of the evidence.

The finding that self-evaluation can be protected if coping resources are accessed suggests that if coping resources can be made more accessible for members of stigmatised groups, then more people can benefit from positive self-evaluation. This presents an important potential role for clinical psychologists, therefore, such as providing opportunities for support groups focusing on effective ways to challenge stigma and promote positive self-evaluation. It may also be important to work on a public awareness level, and increase public understanding of people with mental health problems or learning disabilities and on the impact that stigma can have on people. It is recommended that future research focuses on better understanding of the group identification to self-evaluation relationship among people with learning disabilities and that these findings are used to improve self-evaluation among this population. It is also important to evaluate the relationship between group identification and self-evaluation among other impermeable, stigmatised groups. As several of the studies mentioned the social aspect of this relationship, for example feeling part of a group, this raises questions regarding the experience that people with the lifelong, stigmatised social and communication condition Autism Spectrum Condition (ASC) may have of group identification and self-evaluation. It is not known what role the social aspects of group identification would play with a

population for whom difficulties with social interaction defines their condition. It is therefore also recommended that future research examines the relationship between group identification, coping with stigma and self-evaluation among the ASC population.



## References

- Baron, R., & Kenny, D. (1986). The moderator-mediator variable distinction in social psychological research: Conceptual, strategic and statistical considerations. *Journal of Personality and Social Psychology, 51*, 1173-1182.
- Branscombe, N., Schmitt, M., & Harvey, R. (1999). Perceiving pervasive discrimination among African-Americans: Implications for group identification and well being. *Journal of Personality and Social Psychology, 77*, 135 – 149.
- Camp, D., Finlay, W., & Lyons, E. (2002). Is low self-esteem an inevitable consequence of stigma? An example from women with chronic mental health problems. *Social Science and Medicine, 55*, 823-834.
- Cooley, C., (1902). *Human nature and the social order*. In C.H. Cooley, *Two major works: Social organization and human nature and the social order*. Glencoe: Free Press.
- Corrigan, P., Morris, S., Larson, J., Rafacz, J., Wassel, A., Michaels, P.,... Rüsçh, N. (2010). Self-stigma and coming out about one's mental illness. *Journal of Community Psychology, 38*, 259-275.
- Corrigan, P., Watson, A., & Barr, L. (2006). The self-stigma of mental illness: Implications for self-esteem and self-efficacy. *Journal of Social Clinical Psychology, 25*, 875–884.
- Crabtree, J., Haslam, S., Postmes, T., & Haslam, C. (2010). Mental health support groups, stigma and self-esteem: Positive and negative implications of group identification. *Journal of Social Issues, 66*, 553-569.
- Crocker, J., & Major, B. (1989). Social stigma and self-esteem: The self-protective properties of stigma. *Psychological Review, 96*, 608-630.
- Dagnan, D., & Waring, M. (2004). Linking stigma to psychological distress: testing a social-cognitive model of the experience of people with intellectual disabilities. *Clinical Psychology and Psychotherapy, 11*, 247-254.
- Finlay, M., & Lyons, E. (1998). Social identity and people with learning difficulties: Implications for self-advocacy groups. *Disability and Society, 13*, 37-51.

- Finlay, M., & Lyons, E. (2000). Social categorizations, social comparisons and stigma: Presentations of self in people with learning difficulties. *British Journal of Social Psychology*, 39, 129-146.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. New Jersey: Prentice-Hall.
- Heal, L., & Sigelman, C. (1995). Response biases in interviews of individuals of limited mental ability. *Journal of Intellectual Disability Research*, 39, 331-340.
- Hinkle, S., & Brown, R. (1990). Intergroup comparisons and social identity : Some links and lacunae. In D. Abrams & M. A. Hogg (Eds.), *Social identity theory: Constructive and critical advances* (pp. 48-70). New York: Harvester Wheatsheaf.
- Jahoda, A., & Markova, I. (2004). Coping with social stigma: People with intellectual disabilities moving from institutions and family home. *Journal of Intellectual Disability Research*, 48, 719-729.
- Link, B., Cullen, F., Struening, E., Shrout, P. & Dohrenwend, B. (1989). A modified labeling theory approach to mental disorders: An empirical assessment. *American Sociological Review*, 54, 400-23.
- Link, B., & Phelan, J. (2001). Conceptualizing stigma. *Annual Review of Sociology*, 27, 363-385.
- Mead, G. (1934). *Mind, self and society from the standpoint of a social behaviourist*. Chicago: University of Chicago Press.
- Mencap. (1997). *Barriers to justice: A Mencap study into how the criminal justice system treats people with learning disabilities*. London: Mencap.
- Paterson, L., McKenzie, K., & Lindsay, B. (2012). Stigma, social comparison and self-esteem in adults with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 25, 166-176.
- Preacher, K., & Hayes, A. (2004). SPSS and SAS procedures for estimating indirect effects in simple mediation models. *Behavior Research Methods, Instruments, and Computers*, 36, 717-731.

- Rüsch, N., Corrigan, P., Powell, K., Rajah, A., Olschewski, M., Wilkniss, S., & Batia, K. (2009b). A stress-coping model of mental illness stigma: II. Stress responses, coping behavior and outcome. *Schizophrenia Research, 110*, 65-71.
- Rüsch, N., Corrigan, P., Wassel, A., Michaels, P., Olschewski, M., Wilkness, S., & Batia, K. (2009a). A stress-coping model of mental illness stigma: I. Predictors of cognitive stress appraisal. *Schizophrenia Research, 110*, 59-64.
- Rüsch, N., Corrigan, P., Wassel, A., Michaels, P., Olschewski, M., Wilkniss, S., & Batia, K. (2009c). Ingroup perception and responses to stigma among persons with mental illness. *Acta Psychiatrica Scandinavica, 120*, 320-328.
- Rüsch, N., Lieb, K., Bohus, M., & Corrigan, P.W. (2006). Self-stigma, empowerment and perceived legitimacy of discrimination among women with mental illness. *Psychiatric Services, 57*, 399-402.
- 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.
- Wahl, O. (1999). Mental health consumers experience of stigma. *Schizophrenia Bulletin, 25*, 467-478.
- Watson, A., Corrigan, P., Larson, J., & Sells, M. (2007). Self-stigma in people with mental illness. *Schizophrenia Bulletin, 33*, 1312-1318.

## **Part Two: Empirical Paper**

### **Autism Spectrum Condition (ASC) and Social Group Identity: Can an ASC Diagnosis Protect Self-Esteem?**

## **Abstract**

**Aims:** The aims of this paper were to examine the relationship between group identification and self-esteem among adults with an Autism Spectrum Condition (ASC). We tested whether this relationship was mediated by the internal coping processes of stereotype rejection and stigma resistance.

**Methods:** Adults who self-reported as having ASC were recruited via online forums and 200 participants completed an online questionnaire. The questionnaire included demographic items, an ASC screening tool (the Autism Quotient-Short) and measures of group identification, coping strategies for stigma and self-esteem. A multiple mediator model (Preacher & Hayes, 2008) bootstrapped in 10,000 samples was used to test the hypothesised mediation relationships.

**Results:** High group identification was found to predict positive self-esteem. This relationship was fully mediated by stigma resistance and stereotype rejection: group identification's direct effect on self-esteem became non-significant when the mediators were added to the model.

**Conclusions:** Identification with the ASC community was associated with positive self-esteem; this positive relationship was accounted for by the effects of stereotype rejection and stigma resistance. Group identification can therefore be considered protective for self-esteem with members of the ASC community when it is associated with strategies for coping with stigma; lower levels of group identification were associated with lower self-esteem. Limitations of this research and the clinical implications of its findings are discussed.

## **Introduction**

This study aimed to investigate how the diagnosis of an Autism Spectrum Condition (ASC) affected the self-esteem of diagnosed adults. The relationship between identification with this stigmatised group and the self-esteem of its members was examined including the possible mediating effects of coping with stigma. While the current study's focus was to examine the extent to which group identification can impact upon self-esteem, it must be acknowledged that many other factors contribute to self-esteem that were not included within the scope of this study.

### **Autism Spectrum Condition: A Stigmatised Diagnosis**

Autism Spectrum Condition is a neurodevelopmental condition characterised by a social interaction and communication impairment which can lead to difficulties with social relationships (Wing & Gould, 1979) as well as difficulties with flexibility of thought, sensory issues and repetitive patterns of behaviour (*Diagnostic and Statistical Manual of Mental Disorders*, 5th ed., text rev.; American Psychiatric Association [APA], 2013). It affects approximately 1% of the adult population (Brugha et al., 2011) and is diagnosed more commonly among males than females by a ratio of approximately 4:1 (Ehlers & Gillberg, 1993). Despite a growing emphasis on early diagnosis for this population (Moore & Goodson, 2003; Landa, Holman & Garrett-Mayer, 2007), there has been a paucity of literature on the stigma surrounding ASC and on the impact that the diagnosis can have on self-esteem. The limited research so far that has investigated experiences of stigma among people with ASC has found that adolescents (Shtayermman, 2007, 2009) and adults (Punshon, Skirrow & Murphy, 2009) with the diagnosis had experiences of being bullied and

socially rejected due to their ASC and attributed these experiences to stigma around the condition. In addition, Ruiz Calzada, Pistrang and Mandy (2012) discovered that many young people with ASC themselves hold negative stereotypes about the condition, and report feeling shame about their 'autism' or Asperger's label.

There is some evidence of this stigma being portrayed at the public media level, with the recent reporting in British newspapers of the term 'autistic' being used in a derogatory fashion. The Guardian newspaper reported that the son of jailed politician Chris Huhne told his father upon his arrest that he was an 'an autistic piece of s\*\*\*' (Davies, 2013). Whether or not the details of this story are accurate it is an example of 'autistic' being portrayed as an insulting adjective, suggesting negative views of the condition exist. Comedian Stephen Merchant recently offered an apology to The Sun newspaper following a complaint from an ASC campaigner when he described his character in an upcoming film as a 'socially autistic nerd' (Crick, 2013). There were no complaints from other members of the public, indicating that using the term 'autistic' pejoratively is socially accepted to the degree that it does not warrant widespread complaint.

Both of these examples, and the above mentioned empirical studies, suggest that ASC is now a condition that the public is aware of and is often viewed in a negative way. However, the limited empirical research conducted so far in this area found that despite being aware of such negative views towards the condition, a diagnosis of ASC did not lead to negative self-evaluations (Shtayermman, 2007, 2009; Punshon et al., 2009). The participants in these studies described a positive self-identity as a person with ASC and described diagnosis leading to an alternative identity that made sense to them, counteracting the feeling of being different and an 'outsider' in society before diagnosis (Shtayermman, 2007, 2009; Punshon et al.,

2009). Owing to the methodology used in these studies, the strength of the relationship between diagnosis-led group identification and self-esteem is not known, and it is not clear to what extent self-esteem was protected or how such a stigmatised group identity came to be protective. The phenomenon of being labelled as a member of a stigmatised group yet experiencing positive self-esteem shall be examined in the current study. In order to understand this phenomenon it is necessary to first consider how one's perception of self and self-esteem is influenced by the stigmatised views of others.

### **Stigma and Self-Concept**

Stigma can be defined as negative attitudes towards a social group who are devalued in society and therefore socially rejected (Goffman, 1963). The social constructionist approach argues that the individual does not exist in isolation meaning that one's identity and evaluation of oneself (self-esteem) will be informed by the social world. In the early part of the last century, ideas about the construction of the self in a social world began to emerge in social psychology. Cooley's (1902) idea that one's self-identity is the direct product of seeing oneself through the eyes of others, i.e. a 'looking glass' self, was extended by Mead (1934) who described the self being defined by the social context. They both argued that individuals internalise the opinions others have of them and it is through this internalisation that a self-identity is developed. The social psychology field has continued to develop these theories to consider the mechanisms that may underlie this process.

Social identity theory (Tajfel & Turner, 1979) extended the concept of the social self to include the social groups within which individuals exist, such as gender and ethnicity groups. Tajfel and Turner (1979) hypothesised, in a similar way to Cooley and Mead, that individuals' self-image and self-esteem is heavily influenced



by the positive or negative views that society has of their group. Social identity theory predicts that members of a minority group will form their own 'ingroup' identity based on the marginalizing of their group by the 'outgroup' majority. It has been further suggested that these minority groups are often stigmatised by the majority owing to the imbalance of power between the ingroup and the outgroup (Link & Phelan, 2001). Therefore social identity theory suggests that if ingroup members are aware of the negative views others have of their group, then these views will negatively impact on how they see themselves.

As a result, stigma can leave marginalised group members vulnerable to low self-esteem and it may be the case that group members attempt to hide their membership to their group in order to protect self-esteem (Tajfel & Turner, 1979). This may only be possible for some groups, however. Tajfel and Turner (1979) described the degree to which one's group can be left in order to join the majority as the group's 'permeability': if an individual can hide their group membership to join the majority, their group would be said to be permeable. Therefore, according to the ideas of Tajfel and Turner (1979), people who belong to impermeable groups such as those based on gender or ethnicity will be more vulnerable to stigma and experiences of discrimination than those who can hide their membership. The theory predicts that members of impermeable, stigmatised groups will identify more highly with their group as a result of not being able to leave it and will experience poor self-esteem due to stigmatised views held against their inescapable group identity. This would suggest that people diagnosed with ASC, an impermeable group due to its presentation in a range of social contexts and the lifelong nature of the condition, should experience higher identification with the ASC group and lower self-esteem as a result of stigma.

However, as suggested by Punshon et al.'s (2009) findings that individuals with ASC experience their group label positively, the relationship between identification with the ASC group and self-esteem may not be so straightforward. Indeed, as a development of social identity theory, Crocker and Major (1989) reviewed the literature on marginalised 'impermeable' groups and found that there was not as much evidence of the low self-esteem that social identity theory would predict. They found that people belonging to impermeable stigmatised groups employed a number of strategies to mitigate the negative impact of this stigma on their self-esteem: attributing the negative views of others to stigma to reduce the legitimacy of those views, using ingroup members as a base for social comparison rather than members of the social majority, and devaluing the domains at which the group performs poorly. In doing so, Crocker and Major (1989) concluded that stigmatised group members were able to protect their self-esteem from the negative impact of stigma as it enabled them to reject it as untrue.

### **Protection against Stigma**

It seems then, that the rejection of stigma identified by Crocker and Major (1989) may protect group members from the harmful impact of 'internalising' stigmatised views as true of the group and themselves. Corrigan (1998) described internalising stigma as incorporating stigmatised views into one's self-image, leading to shame about one's group identity and suffering poor self-esteem as a result. Internalisation of stigma represents a model of stigma's impact on the self that is similar to Cooley (1902) and Mead's (1934) 'looking glass' self. Crocker and Major's (1989) findings suggest, however, that internalisation of stigma was not an inevitable outcome of being a member of a stigmatised group. While Crocker and Major's (1989) findings provide some insight into how group members cope with

stigma, they do not entirely explain how stigmatised group membership comes to be associated with this coping with stigma and protected self-esteem. Branscombe, Schmitt and Harvey (1999) designed a study to explore the relationship between group identity and how it relates to coping with stigma and self-esteem.

Branscombe et al. (1999) hypothesised that for members of impermeable, stigmatised groups, attributing social rejection and prejudiced actions of others to stigma will not protect self-esteem alone. However, if the awareness of stigma that one gains from experiences of prejudice leads to a heightened identification with the ingroup, then this sense of group identification can protect self-esteem. They used structural equation modelling to find evidence for their model (Figure 1) with a sample of African Americans living in a society dominated by White Americans.

*Figure 1.* The Rejection-Identification Model: the mediating effect of group identification on stigma and psychological well-being (Branscombe et al., 1999).

Branscombe et al.'s (1999) model highlights the important role that having a shared group identity can have on self-esteem, even when the group is stigmatised. Belonging to a group with other marginalised individuals is necessary for awareness

of stigma to have a positive impact on self-esteem. Branscombe et al.'s (1999) model provides a framework for an ethnic minority group, but it may also be applicable to groups who share an identity based on diagnosis. In order to establish whether such a model would be applicable to people with ASC, it is necessary to consider the research already conducted among groups defined by stigmatised diagnoses.

As mentioned in the literature review in part one of this thesis, there is some evidence that group identification as a means to coping with stigma can be found amongst people diagnosed with mental health problems. Despite evidence that the stigmatizing label of mental health problems can be associated with being treated as less competent and more socially rejected (Wahl, 1999), there is evidence of people with mental health problems holding a positive view of their group identity (Camp, Finlay & Lyons, 2002; Crabtree, Haslam, Postmes & Haslam, 2010; Rüsçh et al., 2009).

Crabtree et al. (2010) explored in more detail the relationship identified by Branscombe et al. (1999) between group identification and self-esteem with a sample of people diagnosed with mental health problems. They found that identification with a mental health support group had a similar relationship with self-esteem as that identified by Branscombe et al. (1999). They found that group identification led to an increase in effective strategies for coping with stigma and this in turn protected self-esteem. They identified two key internal coping responses that mediated the relationship between group identification and self-esteem: stigma resistance and stereotype rejection (Ritsher, Otilingam, & Grajales, 2003).

Stigma resistance is described by Ritsher et al. (2003) as the degree to which one is unaffected by stigma. The items that compile this measure ascertain the degree to which an individual can hold a positive image of themselves despite being aware

of the stigma against the group. It is assumed given the pervasive level of stigma within society against people with diagnoses such as mental health problems and ASC, that stigma resistance is an active process utilised to protect self-esteem. The second identified mediator, stereotype rejection, is the degree to which an individual disagrees with negative stereotypes about the group; the items measure level of agreement with negative stereotypes such as 'people can tell that I have a mental illness by the way I look'. If individuals disagree that the negative stereotypes are true, then they are denying the 'looking glass' of stigma as the truth and score highly on stereotype rejection. Stereotype rejection was found by Crabtree et al. (2010) to protect self-esteem among individuals who identified with the group.

### **Group Identification, Stigma Resistance and Stereotype Rejection**

Crabtree et al. (2010) found that the relationship between group identification and self-esteem was fully mediated by the two variables stigma resistance and stereotype rejection, plus a third variable measuring perceived increase in external social support from friends and family (Figure 2). Their findings suggest that when identification with the support group was high, they experienced greater levels of stigma resistance and stereotype rejection, as well as increased social support; these processes in turn were associated with positive self-esteem. The correlational nature of the relationship identified further suggests that low group identification was associated with poor self-esteem, as it was not associated with coping strategies for stigma.

*Figure 2.* Processes identified as mediating the relationship between group identification and self-esteem (Crabtree et al., 2010).

Crabtree et al.'s (2010) findings show that group identification models like Branscombe et al.'s (1999) can be applied to groups which are marginalised due to diagnostic label as well as ethnicity. However, their model was based on identification with small groups who met regularly. It is not known whether the same process would be true for the much larger, and more abstract, group identity that includes all people sharing a diagnosis. Punshon et al.'s (2009) study alluded to the possibility that such a relationship may exist within the ASC population, with participants describing a shared group identity that alleviated the distress of stigma and social rejection (Punshon et al., 2009). No quantitative research has been conducted to establish whether such a relationship exists for this group, however. Therefore, the current study aimed to investigate whether Crabtree et al.'s (2010) model of identification with a stigmatised group is applicable to the ASC population.

As the current study was not recruiting from a small support group that could influence perceived external support from friends and family, Crabtree et al.'s (2010) third mediator of perceived external social support was excluded. A mediational model was therefore used to test three hypotheses:

- Level of group identification with the ASC population will impact on self-esteem.
- The relationship between group identification and self-esteem will be mediated by stigma resistance.
- The relationship between group identification and self-esteem will be mediated by stereotype rejection.

## **Method**

### **Procedure**

The group identification, coping with stigma and self-esteem measures used by Crabtree et al. (2010) were adapted to suit the ASC population where necessary for the current study. The measures were piloted with an ASC support group who suggested minor changes to the explanation of the group identity measure; these changes were made and the survey was re-piloted with five additional members of the ASC support group who confirmed that the explanation of the measure was clear. Demographic information items were added, as was an abridged Autism Spectrum Quotient to measure severity of ASC (Hoekstra et al., 2011). A patient information sheet, consent and debrief forms were added. The survey was made available for online participation using UCL Opinio 6.6.3 software (<http://www.objectplanet.com/opinio>).

Eight online forums were contacted requesting permission to post the link to the online survey and four allowed the link to be published. The posts were commented on several times a week by the researcher to ensure that they remained on the front page to aid recruitment. The link was also posted on the social website Twitter on an account set up specifically for recruitment purposes. Any queries that arose from participants were answered in a timely and professional manner.

Each participant ticked a consent box at the bottom of the information page at the beginning of the questionnaire (Appendix B). Once they had ticked the consent box they could enter the survey. The information sheet explained that they could withdraw at any time and that their responses were anonymous. The debrief (Appendix C) explained that a summary of the results would be available to participants but individual scores for measures would not be. The option of leaving an email addresses for entry into a prize draw was given, and it was explained that these email addresses would not be included in analysis or be stored with their responses to ensure anonymity.

## **Participants**

Participants were recruited from ASC forums and through Twitter. A total of 238 participants opened the survey, fifteen of whom did not complete any of the questions leaving a sample of 223 participants. Of these 223 participants, 200 completed all of the measures, giving a response rate of 84%. The demographic results can be seen in Table 1.



Table 1

*Descriptive Characteristics of Adults with ASC Recruited for Current Study N = 223*

	%		%
<i>Gender</i>		<i>Type of Diagnosis</i>	
Male	45.3	Asperger's Syndrome	57.4
Female	51.6	High Functioning Autism	4.5
Other	2.4	ASD	4.0
Not stated	0.4	Autistic Disorder	2.2
		PDD-NOS <sup>†</sup>	2.2
<i>Relationship Status</i>		Not stated	23.3
Single	47.9	<i>Age at diagnosis</i>	
In a relationship/married	45.3	≤10yrs old	5.8
Separated/divorced	5.4	11-20yrs old	16.6
Other (long distance/estranged)	1.3	21-30yrs old	20.2
Not stated	0	31-40yrs old	10.8
<i>Ethnicity*</i>		41-50yrs old	10.8
White British	56.1	51-60yrs old	4.9
Any other white background	40.5	≥61yrs old	1.3
Asian	1.9	Not stated	27.8
Mixed race	4.4	<i>Who sought diagnosis?</i>	
Other/Not stated	1.9	Myself	43.5
<i>Employment Status</i>		Someone else	29.6
Employed (part time or full time)	49.1	Not stated	26
Voluntary work	10.8	<i>Who diagnosed you?</i>	
Unemployed but worked in the past	31.8	Clin. Psychologist (UK)	33.2
Unemployed, never worked	7.6	Psychiatrist (UK)	18.8
Not stated	0.4	Adult CMHT	4.9
<i>Education level</i>		CAMHS	3.1
Degree/postgraduate/further training	57.8	Paediatrician	2.7
Secondary school only	40.5	Neuropsychologist	1.8
Other (SEN/Residential school)	1.3	Psychiatrist (USA/Canada)	1.8
Not stated	0.4	Autism Specialist/Team	0.9
<i>Diagnosis</i>		Family/friends/internet	1.3
Formal ASC diagnosis	75.8	Child Dev. Team	0.9
No formal diagnosis	20.2	GP	0.9
Not sure	4.0	'Doctors'	0.9
Not stated	0	University	0.9
		Not stated	26.5
		<i>AQ-S Scores</i>	
		≤64 (below threshold)	1.9
		65-84	31.1
		85-104	61.8
		105-112	4.2
		Not stated	0

\* Ethnicities collapsed as several options available such as 'Black British' were not selected

<sup>†</sup> Pervasive Developmental Disorder-Not Otherwise Specified

As can be seen from Table 1, the majority of participants were White, just over half being White British; of those who recorded their ethnicity as ‘White other’ and opted to describe their ethnicity ( $n = 6$ ), three were ‘White American’ and three were ‘White European’. The sample was fairly evenly split between males and females (45.3% male, 51.6% female). Two participants described themselves as ‘agender’ and one described themselves as transgender. Almost half of the sample was single and almost half were in a relationship. All participants were aged 18 years or over and the mean age was 34.8 years ( $SD = 12.4$ ).

The nature of the questionnaire format meant that the participants in this study were of a high level of functioning, which is reflected in the education and employment sections of Table 1. The range of scores given for the Autism Quotient-Short (AQ-S) in Table 1 are not official cut off points recommended by the authors of the measure (Hoekstra et al., 2011), as the only recommendation given is that 65 is a useful threshold when using the measure as a screening tool for queried ASC. The ranges are provided by the current researcher as an indication of the different levels of severity of ASC within this sample; 67% of participants scored 85 or above. Four participants (1.9%) did not reach the threshold of 65 on this measure, however this was not an exclusion criteria for this study as the focus was to identify people who saw themselves as having ASC which could occur without meeting threshold. The four participants in question achieved a score within 15 points of the clinical threshold of 65.

## **Design**

This was a cross-sectional, correlational, non-experimental design testing mediational models. Mediational analysis using bootstrap methods was used to test

the hypothesis that a relationship exists between group identification and self-esteem and that this is mediated by stigma resistance and stereotype rejection. It was important to establish whether the sample size of the current study was powerful enough to detect relationships within the model. Friz and McKinnon (2007) describe in their comprehensive analysis of sample sizes required for mediational analysis, that a sample size of 200 participants will detect medium to large mediation effects (0.26 to 0.59) when using bootstrap methods. Mediation effect sizes of 0.14 or smaller are unlikely to be detected in a sample smaller than 400.

## **Measures**

The measures included in this study are outlined below and can be found in Appendix A. Apart from the AQ-S, all measures were adapted for the current study, for use with an ASC population.

**Autism Spectrum Quotient.** The abridged Autism Spectrum Quotient (AQ-S) has been found to have acceptable to good internal validity ( $\alpha$  between .77 and .86) and was found to have strong reliability with the current study's sample ( $\alpha = .83$ ). It correlates highly with the full version of the AQ ( $r$  between .93 and .95). Using a cut off score of 65, the measure has a sensitivity of .97 and a specificity of .82 of distinguishing people with a clinical diagnosis of ASC from a control group of people without ASC. It is scored using a Likert scale of four items from 'definitely agree' to 'strongly disagree', each answer giving a possible score between 1 and 4; a typical item is "I prefer to do things the same way, over and over again". Higher scores on this measure indicate a greater incidence of ASC traits.

**Self Esteem.** The Rosenberg self-esteem scale (Rosenberg, 1965) is a well-established measure and has been used with an ASC population previously (Mawhood & Howlin, 1999). It is a widely used, ten-item measure designed to

assess global self-esteem ( $\alpha = .88$ , Rosenberg, 1986). Traditionally it uses a Likert scale of four items from 'strongly agree' to 'strongly disagree'; an additional midpoint option of 'neither agree nor disagree' was added for the current study such that each answer obtained a possible score of between 1 and 5. The addition of the midpoint avoided forced responding and enabled identification of items that did not work for this sample: if an item scored 'neither agree nor disagree' more than 50% of the time, it would have been omitted from analysis as it was likely to have been a confusing or irrelevant item. No item on the self-esteem measure provided scores similar to this, so no items were omitted for analysis. A typical item on the self-esteem measure is "On the whole, I am satisfied with myself". Higher scores on this measure indicate more positive self-esteem. Chronbach's alpha for this measure with the current sample was found to be good ( $\alpha = .89$ ).

**Group Identification.** The group identification measure was based on Crabtree et al.'s (2010) measure to assess identification with a mental health group. It is a 10 item measure with good internal validity ( $\alpha = .81$ ). It uses a five point Likert scale scoring from 'never' to 'very often' and a typical item is "I am a person who sees myself belonging to (name of group)". Due to the flexible nature of the question structure, it was feasible that it could be applied to an ASC population as the space for the name of the support group could be replaced with 'ASC community'. Chronbach's alpha for the current sample was found to be good following the change ( $\alpha = .77$ ) from the name of the support group to 'ASC community'. 'Autism Spectrum Condition' was used in place of 'Autism Spectrum Disorder' following consultation with forum users on their preference of label. Thirteen people responded to the forum post: five people preferred the term 'disorder' but did not object to the term 'condition', five people preferred 'condition' and three people reported feeling

indifferent to the distinction. ‘Autism Spectrum Condition’ was chosen by the researcher owing to the feedback by some participants that it was less stigmatizing than ‘Autism Spectrum Disorder’ and that the change from ‘disorder’ to ‘condition’ was not objected to by those who referred to themselves as having ASD. An example of an adapted item is “I am a person who sees myself as belonging to the ASC community”. Higher scores on this measure indicate greater levels of group identification with the ASC community.

**Stereotype Rejection and Stigma Resistance.** Two of the five subscales from Ritsher et al.’s (2003) Internalisation of Stigma measure were used to test the mediation hypotheses in the current study: Stereotype Rejection and Stigma Resistance.

Stereotype Rejection has seven items ( $\alpha = .63$  for the current sample). Typical items include “I can’t contribute anything to society because I have ASC”. These items were reverse scored to provide a ‘Stereotype Rejection’ total. Higher scores indicate greater disagreement with stereotypes about people with ASC. Stigma Resistance has 5 items ( $\alpha = .67$  for this sample). Typical items include “People with ASC make important contributions to society”. Higher scores indicate being less negatively affected by stigma against people with ASC.

All items of these measures were adapted for this study by replacing ‘mental illness’ with ‘ASC’. Aside from this, questions were changed as little as possible so that reliability and validity were not adversely affected. The Chronbach’s alpha shows that for this sample, the measure has satisfactory internal consistency following these changes. The Ritsher et al. (2003) Internalisation of Stigma measure uses a four point Likert from ‘strongly agree’ to ‘strongly disagree’; the current study added the midpoint option of ‘neither agree nor disagree’ so that there were no

forced responses, as with the self-esteem measure. Scores therefore ranged from 1 to 5 for each item. As with the self-esteem measure, if any item scored ‘neither agree nor disagree’ more than 50% of the time it would be removed for analysis. No item on either the stigma resistance or stereotype rejection measures needed to be removed based on this criterion.

### **Ethical considerations**

This study was approved by the UCL ethics committee on July 19<sup>th</sup>, 2012, Project ID number: CEHP/2012/019 (see Appendix D). Anonymity of participants was maintained by asking for no identifiable information other than the option to leave their email address. Consent was mandatory in order to complete this survey. Within the survey information was given regarding which organisations to contact, should participants feel they need information or support with their ASC (Appendix C). An email address as a point of contact for the researcher was given for any questions that may have arisen from participating in the study.

### **Statistical analysis**

The data were analysed using SPSS version 19. Internal consistencies were examined by the calculation of Cronbach’s alpha to investigate the reliability of these measures in the current population. All showed satisfactory reliability or better and were deemed eligible for inclusion in analysis. All measures were converted into Z scores so that coefficients in the mediation analysis were standardised and comparable. A series of t-tests were conducted to identify significant differences between subgroups that emerged within the data. To address the three hypotheses, a multiple mediator model (Hayes, 2013) was used. This was chosen instead of Baron and Kenny’s (1986) approach to testing mediators as it can test the size as well as the

presence of a specific mediator, whilst controlling for other hypothesised mediation effects. To ensure robustness of parameter estimates the model was bootstrapped in 10,000 samples. This allowed empirically-based 95% confidence intervals to be calculated (the equivalent of  $p < .05$ ) and avoided the need for the normality-based assumption.

## Results

All results below are for  $n = 200$ . All measures were tested for normality of distribution; while some proved significant on the Kolmogorov-Smirnov test for normality, indicating a deviation from normality, this test is extremely sensitive for large sample sizes (Parikh, Li & Ramanathan, 1999) and in such cases normality of distribution can be better established through examining graphical representations of the data. These appeared normal for all measures, as confirmed by a second and third party. Furthermore, the use of bootstrap models with empirical 95% confidence intervals, protected analyses from yielding biased parameters that could have arisen from non-normal variables.

Table 2 shows how different subgroups of the sample compared on the group identification, stigma resistance, stereotype rejection and self-esteem measures. Subgroups that were too unevenly divided could not be included in statistical analysis, for example within the subgroup 'type of diagnosis', 128 of the 160 people who reported a diagnosis selected Asperger's syndrome, with the second largest diagnosis group comprising only  $n = 10$ . This meant that meaningful comparisons between diagnostic groups could not be made. All demographic information that could not be included for t-test analyses can be found in Table 1. The data in Table 2 and Table 3 provide descriptive information of the data set; they did not inform conclusions regarding the hypotheses so significance tests have not

been corrected for type I error. Conclusions from the tables' findings should therefore be conservative.

The t-test analyses presented in Table 2 show a significant difference between males and females on group identification and stereotype rejection measures, with females obtaining higher scores in both measures than males. This suggests that females identified with the group more and were more rejecting of negative stereotypes towards the group than males; however no difference was found between the genders in self-esteem. People who reported having sought their own diagnosis scored higher on stigma resistance, stereotype rejection and self-esteem than people whose diagnosis was sought by someone else. Those who were in paid employment scored higher on stigma resistance, stereotype rejection and self-esteem than those who were volunteering or unemployed, suggesting that people with paid jobs were more able to reject negative stereotypes of the group, felt less affected by stigma and had higher self-esteem than people not in paid work. People in a relationship scored higher than those not in a relationship on stigma resistance, but no differences were found with the other measures.

As well as the data shown in Table 2 there was a significant difference in age found between males and females ( $t = -3.217, p = .002$ ), such that males ( $\bar{x} = 37.40, SD 13.59$ ) were older than females ( $\bar{x} = 31.80, SD 10.49$ ) in this sample.



Table 2

*Differences Between Subsections of Adult ASC Sample on Group Identification, Stigma Resistance, Stereotype Rejection and Self-Esteem*

	<u>Group Identification</u>			<u>Stigma Resistance</u>			<u>Stereotype Rejection</u>			<u>Self-Esteem</u> <sup>c</sup>		
	<i>M</i>	<i>SD</i>	Statistic	<i>M</i>	<i>SD</i>	Statistic	<i>M</i>	<i>SD</i>	Statistic	<i>M</i>	<i>SD</i>	Statistic
<u>Gender</u>			t=-2.64**			t=-.92			t=-2.90**			t=1.22
Male <i>n</i> =95	34.69	6.54		18.31	3.91		22.97	3.77		29.53	29.53	
Female <i>n</i> =106	37.14	6.60		18.78	3.22		24.47	3.47		28.11	28.11	
<u>Who Sought Diagnosis?</u>			t=1.41			t=-2.91**			t=-2.76**			t=-2.66**
Myself <i>n</i> =95	35.57	6.50		19.30	3.40		24.52	3.97		30.61	30.61	
Someone else <i>n</i> =63	37.11	6.92		17.64	3.50		22.78	3.48		26.87	26.87	
<u>Education Level</u>			t=.25			t=1.36			t=-1.69			t=-1.04
Secondary school only <i>n</i> =86	35.98	6.90		18.13	3.70		23.17	3.81		28.08	28.08	
Degree/postgrad/ further training <i>n</i> =110	35.74	6.28		18.22	3.30		24.08	3.61		29.28	29.28	
<u>Employment Status</u>			t=1.62			t=-2.17*			t=-3.45**			t=-2.27*
Volunteer/Unemployed <i>n</i> =105	36.73	6.83		18.01	3.61		22.83	4.01		27.56	27.56	
Paid employed <i>n</i> =103	35.25	6.27		19.08	3.40		24.58	3.08		30.12	30.12	
<u>Relationship status</u>			t=1.23			t=-2.67**			t=-1.36			t=.34
In a relationship <i>n</i> =96	35.55	6.51		19.24	3.43		24.07	3.89		29.43	29.43	
Not in a relationship <i>n</i> =111	36.58	6.66		17.93	3.52		23.37	3.47		28.31	28.31	

Note \* $p < 0.05$  (two-tailed), \*\* $p < 0.01$  (two-tailed)

Table 3

*Correlations for Age, Years Since Diagnosis, AQ-S Scores and Measures for Model*

	Self-esteem	AQ-S	GI	Stigma Resistance	Stereotype Rejection	Age
AQ-S	-.22**					
GI	.17**	.08				
Stigma Resistance	.56**	-.05	.42**			
Stereotype Rejection	.38**	-.05	.28**	.39**		
Age	.17*	.12	.03	.19	-.06	
Years since diagnosis	-.03	-.23**	-.08	-.05	-.06	.03

Note \* $p < 0.05$  (two-tailed), \*\* $p < 0.01$  (two-tailed)

Table 3 shows correlations between the four measures included in the mediational model and ASC traits, age and years since diagnosis. Table 3 shows a negative correlation between AQ-S scores and self-esteem, suggesting that greater levels of ASC traits were significantly correlated with lower levels of self-esteem. Table 3 also shows that both of the mediating variables were positively correlated with group identification and self-esteem, confirming the presence of an association between group identification, coping with stigma and self-esteem. In order to directly test the study's hypotheses and establish whether a mediated relationship between group identification ( $M = 3.6$ ,  $SD = 0.7$ ) and self-esteem ( $M = 2.9$ ,  $SD = 0.8$ ) existed, and to discover the extent to which stigma resistance ( $M = 3.7$ ,  $SD = 0.7$ ) and stereotype rejection ( $M = 3.9$ ,  $SD = 0.6$ ) accounted for this mediation, bias-controlled and accelerated bootstrapping analysis was conducted.

When using bootstrap analysis, an effect is deemed significant when the 95% bootstrap lower and upper confidence intervals (CIs) do not cross zero: both are positive numbers or both are negative numbers. One negative and one positive number would indicate that the confidence intervals cross zero, suggesting that confidence cannot be gained that the effect found is different from zero. As 95% CIs indicate that the effect found is significant 95% of the time, not crossing zero is the equivalent to obtaining a  $p$  value of  $<.05$ . Therefore any CIs that do not cross zero could be considered to have a point estimate  $p$  value below  $.05$ . As Table 4 shows, when the two stigma mediators were not included in the model, there was a significant direct relationship between group identification and self-esteem, with CIs both positive. When the mediators were included in the model, as shown in Table 4, the direct relationship between group identification and self-esteem became non-significant, with CIs crossing zero. As the direct relationship between group identification and self-esteem became non-significant when the mediators were included in analysis, this indicates that the relationship was fully mediated. This suggests that when group identification levels were high, it was associated with higher self-esteem due to the mediating factors of stigma resistance and stereotype rejection, to which high group identification provided access.

Table 4

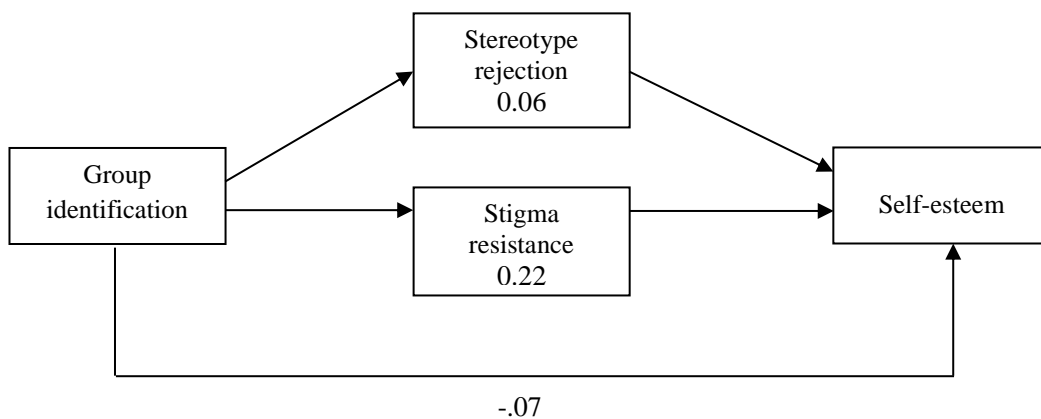
*Mediation Effect of Group Identification (GI) on Self-Esteem (S-E) Through  
Stereotype Rejection and Stigma Resistance*

	Effect	Boot SE	Bootstrapping Bias Controlled 95% CI	
			Lower	Upper
Total Mediation Effect of GI on S-E	0.21	0.08	0.06	0.36
Direct effect of GI on S-E	-0.07	0.07	-0.21	0.07
Stereotype Rejection	0.06	0.02	0.02	0.11
Stigma Resistance	0.22	0.04	0.14	0.31
	Contrasts			
Stigma Resistance – Stereotype Rejection	0.16	0.05	0.08	0.26

The next stage to the analysis was to consider each mediator in turn (MacKinnon, 2000; Shrout & Bolger, 2002). Both stereotype rejection and stigma resistance were found to independently mediate the relationship between group identification and self-esteem, as shown by their CIs not crossing zero. In order to establish whether there was a significant difference between stigma resistance and stereotype rejection in magnitude of mediation effect, contrast effects were included as part of the analysis. Using the same principle of determining significance by examining the bootstrap CI intervals, Table 4 shows that contrast effects confirm a

significant difference existing between the mediation effect of stigma resistance and of stereotype rejection. This suggests that stigma resistance had more of a mediating effect on the relationship than did stereotype rejection.

In summary, a significant relationship was found between group identification and self-esteem such that higher group identification was associated with higher self-esteem and lower group identification was associated with lower self-esteem. This relationship was fully mediated by stigma resistance and stereotype rejection (Figure 3). All associations found within this relationship reached significance at the 95% confidence interval level (or  $p < .05$ ).



*Figure 3.* Relationship identified between Group Identification (GI) and Self-Esteem (S-E) including point estimates for total mediation effect and for each mediator identified.

## Discussion

The current study aimed to investigate whether identification with a stigmatised group, the ‘ASC community’, impacted upon the self-esteem of adults with this diagnosis, and whether this relationship was mediated by internal coping responses to stigma. As mentioned previously, group identification and internal

responses to stigma cannot account for all variance found levels of self-esteem among this sample, as demonstrated by the small total mediation effect of this model on self-esteem 0.21 (Table 4). Various other factors may influence the self-esteem of participants including employment, education and mental health problems, however the current study's focus examined group identification and responses to stigma only. With this focus in mind, a mediational model was found and in line with previous research on stigmatised groups (Crabtree et al., 2010; Branscombe et al., 1999) adults with ASC were found to identify with the group and higher levels of group identification were associated with higher self-esteem. This was mediated by greater levels of stigma resistance (being unaffected by stigma) and negative stereotype rejection, in line with Crabtree et al.'s (2010) findings. Before considering the study's hypotheses in light of these findings, issues of generalizability need to be addressed.

The current sample was self-selecting and recruited from forums for people who identified themselves as having ASC, meaning that participants were likely to identify highly with their group. It is less likely that people who did not identify strongly with the ASC group would have self-selected for a study about having the label. This means that while variation in levels of group identification was present within the data, care must be taken when generalizing these findings to the wider ASC community, such as to those individuals with a diagnosis who do not engage with the idea of belonging to a shared group identity. While it would have been useful for the current study to have a sample including people with ASC who do not strongly identify with the group, to recruit individuals for a self-selecting study on ASC identity when they do not identify with this group presents too great a challenge for the current study.

There is also a possibility that some of the participants in this study would not reach diagnostic criteria for ASC, but identified strongly enough with the ASC community that they took part in the study and over-rated their scores on the self-report ASC screening tool. As discussed later in this section, a weakness of using online recruitment and self-report only measures is the limited control that the researcher has in ensuring that participants do not falsify their responses. While the large sample size may serve as some protection against false or inflated responses from some participants, it is not possible to altogether control for these responses and further supports the argument that generalizability of these findings must be conservative. Indeed, one viewpoint may be that the findings of this study are generalizable only to an online ASC community of high functioning adults who strongly identify with their label.

With the above caveats in mind, it is interesting that social processes such as being aware of a group identity, perceiving oneself as belonging to that group and being aware of stereotypes against the group were found among this population of people with social and communication difficulties. It may be expected that difficulties with theory of mind (Happé, et al., 1996; Beaumont & Newcombe, 2006) would interfere with stereotype awareness and rejection, and that the concept of a ‘group’ with which to identify would be difficult for people for whom social relationships and social understanding can be problematic (APA, 2013). This further suggests that the sample of individuals found in the current study were of a high functioning level within the Autism Spectrum and that the findings are generalizable to this subsection of the ASC population only. The relationship between group identification and self-esteem may be different for individuals who do not possess the ability to engage with these processes.

An important positive outcome of the study in terms of generalizability is the high number of females recruited. Epidemiological studies suggest that the rate of males with diagnosable ASC outweighs the rate of females by a significant degree (Brugha et al., 2011), however it has been suggested that this difference in numbers may be smaller than first thought. The presentation of ASC in females has been found to differ when compared to males, and this may be responsible for some under-diagnosis amongst the female population (Attwood, 2006; Ehlers & Gillberg, 1993; Gould & Ashton-Smith, 2011). As such, while the rates of ASC may not be equal between the genders, there may be higher proportion of females with the condition than suggested by previous studies. The increasing awareness of this difference in presentation means that females may be more likely to obtain a correct ASC diagnosis now than in the past. As rates of diagnosed women increase, so will the need for studies to include them in their research. It is therefore an unexpected strength of the current study to have recruited a high number of females with ASC.

A similar inclusion of overlooked ethnic minority groups was not found in the current study. The bias towards being White represents the same bias found in previous research and seems representative of the lower rates of ASC diagnosis among non-White, ethnic minority groups (Zaroff & Uhm, 2012). This means that the results may only be generalizable to people from White ethnic backgrounds, as with most ASC studies. A useful area for future research would be to investigate the impact of diagnosis on self-esteem among socially rejected ethnic minority groups and whether identification with the ASC group is as protective for individuals who may be marginalised for reasons additional to their ASC. The clinical implications of such biases in sampling are considered later in this discussion.



In summary, the current study's findings should be generalized to high functioning adults with ASC, and are especially useful for providing insights into females on the autism spectrum. However, its conclusions may be less applicable to people with intellectual disabilities or people who engage less with the online ASC community. Also, it remains a question for future investigations whether the current findings extend beyond the predominantly White population of people with ASC who participated in this study.

### **Main Findings**

A weakness of Crabtree et al.'s (2010) model was that their findings could only be generalized to identification with support groups who met on a regular basis. The current study aimed to address this issue by investigating identification with the diagnostic group 'ASC community' in order to establish whether the wider group identity based on diagnosis alone existed for this population and whether Crabtree et al.'s (2010) model could be applied to this larger, more abstract social entity. The 'ASC community' was identified with and the more this diagnostic group was identified with, the higher the self-esteem scores. These findings suggest that the diagnostic label ASC can provide individuals with a shared identity and belonging to this group can protect self-esteem.

The findings suggest that the null hypothesis that group identification would not significantly impact upon self-esteem can be rejected. Group identification was found to have a positive relationship with self-esteem such that greater identification with the ASC community promoted positive self-esteem. The converse is also true: lower levels of identification with the group were associated with lower levels of self-esteem. This finding replicates the model identified by Branscombe et al. (1999) in their study with African American minority groups and supports the theory that

identifying with the ASC group would be protective of self-esteem, and that not identifying with the group could leave group members vulnerable to lower self-esteem (Branscombe et al., 1999).

The null hypothesis that stigma resistance does not significantly mediate the relationship between group identification and self-esteem can also be rejected. Stigma resistance was found to be the most powerful mediator of this relationship, such that a strong ingroup identity was associated with stigma resistance, which was associated with higher levels of self-esteem. These findings replicate those found by Crabtree et al. (2010) with their sample of mental health support groups. The stigma resistance measure included items on stigma towards other people with ASC, for example, 'I feel comfortable being seen with an obviously ASC person'. The strong mediation effect of this measure therefore is supportive of the hypothesis, based on theory and previous studies (Crabtree et al., 2010), that strong identification with the group is associated with feeling less affected by stigma, subsequently protected self-esteem.

The null hypothesis that stereotype rejection does not significantly mediate the relationship between group identification and self-esteem can also be rejected. Stereotype rejection's mediation effect was smaller than stigma resistance, however it still reached significance. This suggests that in a similar way to stigma resistance, when group identification was high, it could promote rejection of negative stereotypes which in turn was associated with higher self-esteem. These findings replicate the relationships found in Crabtree et al.'s (2010) model.

In line with Branscombe et al.'s (1999) model, group identification had a positive impact upon self-esteem despite group members' experience of stigma. This

develops the argument that earlier theories of a ‘looking glass’ process (Cooley, 1902; Mead, 1934) that leads to internalising the stigma of others (Corrigan, 1998) when part of a marginalised ingroup (Tajfel & Turner, 1979) is too simplistic and often not the case. Instead, the current study found that an ingroup identity of ASC protects self-esteem through rejection of stigma, supporting the qualitative findings of Punshon et al. (2009).

### **Clinical Implications**

The relationship identified in this study has important clinical implications. The potential positive impact that correct diagnosis and associated group identification could have for some people with ASC is notable. While the sample was not obtained in clinical settings, the findings suggest that establishing ways to enhance identification with the ASC group could be beneficial to many individuals following diagnosis, and this could influence clinical practice. Perhaps through psycho-education about ASC and the ASC community, facilitating ASC support groups and signposting to online forums could help individuals interested in their shared group discover their ASC community and enhance self-esteem as a result. Crabtree et al.’s (2010) sample of members of a support group suggests that attending a group was protective of self-esteem owing to its group identification properties, and the current study suggests that people with ASC may benefit from similar, tailored, group identification interventions.

The current study did not recruit people from a range of ethnic backgrounds and this may be indicative of the bias towards diagnosing White individuals with ASC more commonly than people from other backgrounds (Zaroff & Uhm, 2012). The potential impact of receiving a diagnosis that provides a shared group identity for people already marginalised on the basis of ethnicity are therefore not known,

and neither is whether the relationship between identification with the ASC community and self-esteem would differ for members of different ethnic minority groups. It is important, therefore, that more research is conducted into the factors which influence the lower diagnosis rates of ethnic minority groups and whether a group identity for such marginalised people could be as protective as the current study suggests.

The findings of the current study provide an alternative message to the one delivered in a recent publication from the Division of Clinical Psychology (DCP, 2013). This recent statement urged psychiatry and clinical psychology to move away from the diagnosis-led model as they conclude that diagnosis leads only to discrimination, stigmatization, disempowerment, marginalisation and low self-esteem. The current study's findings suggest that this message may not be applicable to all diagnoses. For some individuals with ASC, diagnosis can allow for identification with a group which improves resources to cope with stigma and discrimination and protects self-esteem rather than lower it.

### **Limitations**

By using a sample of people actively engaged with ASC forums, a bias towards high group identification was likely. This meant that while assumptions could be made about the relationship between low group identification and low self-esteem, the subsection of the community for whom group identification is very low were not included in the sample. As such, the results of this study may only be generalizable to people with ASC who identify highly with their diagnostic group.

There may also be limitations in using online sampling, as outlined in the British Psychological Society's (BPS) guidelines on internet research (BPS, 2007).

The BPS cites reduced control over participants' responding behaviours as one of the limitations of internet recruitment. It is possible, for example, that some participants answered the measures twice in order to increase the likelihood of winning the prize draw. One duplicated email address was identified and hence one set of their responses deleted, but it is possible that people entered different email addresses to participate more than once.

The measures used for this study had not been used for this population before except for the self-esteem measure and the AQ-S. As such, while reliability was found to be satisfactory to good for all measures with this sample, it is possible that tailoring the stereotype rejection measure to include more specific stereotypes to ASC could have enhanced our findings. The group identification measure was adapted from a mental health group measure and the term 'ASC community' was devised by the researcher. This measure was piloted and deemed understandable by the pilot group, however a larger scale validation of this measure with this population would be advised. The stigma measures were also adapted from mental health measures and a validation of the newly adapted measures would be a useful area for possible research.

A further limitation of the research was that it is possible that a reverse relationship exists between group identification and self-esteem, but the study's cross-sectional design does not allow for this reverse relationship to be adequately investigated. It could be the case that individuals with positive self-esteem are more likely to feel comfortable identifying with their group label, rejecting negative stereotypes and resisting stigma. Investigating the external factors that impacted upon the self-esteem of participants across a lifetime that may have in turn been associated with group identification was beyond the remit of this study, however the

small effect that group identification had on self-esteem ( $r = .17$ ) suggests that several other factors impact upon the self-esteem of people with ASC.

One such possible factor not accounted for in the current study is mental health. It may be that mental health moderates the relationship between group identification and self-esteem owing to the impact that mental health problems can have on self-esteem, and the addition of depression and anxiety measures may have provided the study with useful data in this regard. However, the current study excluded such measures in the interest of reducing drop-out rates that could have occurred as a result of including too many measures. Perhaps if a higher number of measures had been included, the potential drop-out rates could have reduced the likelihood of obtaining the necessary data to prove the existence of the main relationship under investigation.

### **Future Research**

As previously mentioned, future research should focus on investigating the current model within a wider ASC sample that includes people who do not identify highly with the group and people from a variety of ethnic backgrounds. Future research may wish to conduct a large-scale diagnostic study to investigate whether potential rates of diagnosable ASC are equal among the ethnic groups, and whether a label would be as useful for all groups as it was for the current study's sample or whether differences lie across cultures.

The current study accounts for a small number of factors that influence the self-esteem of adults with ASC, and future research should examine in more detail other possible factors that could promote positive self-esteem such as employment and the sense of agency in obtaining one's own diagnosis as suggested in Table 2.

Mental health could also be a factor impacting upon the self-esteem of people ASC, and future research may wish to investigate whether mental health problems and receiving co-morbid diagnoses impact on self-esteem and the group identification and self-esteem relationship.

It is also recommended that a longitudinal study is conducted to examine factors that contribute to self-esteem over the lifetime of people with ASC, and to establish any significant differences in self-esteem before and after receiving a diagnosis. Only through a longitudinal design could causality of the relationship between group identification and self-esteem be truly determined, as the causality of the relationship postulated in the current study is based on theory but cannot be proved with a cross-sectional design. It may be the case also that a longitudinal study could determine some of the reasons underlying the significant differences found between subgroups in Table 2. For example, as some gender differences were identified in the t-test analyses (Table 2), future research may wish to investigate these differences further within a longitudinal design.

Future research should also aim to validate the adapted measures used within this sample. The findings suggest that they are reliable for use with this population, but a validated tool for ASC group identification and stigma would be beneficial for research and clinical purposes.

## **Conclusions**

This study discovered that an ASC diagnosis can serve an important protective function for self-esteem, as it enables identification with a label and an associated ingroup that help diagnosed individuals reject stigma. Diagnosis plays a crucial role in promoting positive self-esteem among this stigmatised group. Females and people from ethnic minorities are underrepresented in the prevalence rates of

diagnoses, and the current study suggests that this may have serious implications for the self-esteem of these individuals.



## References

- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders*, (5<sup>th</sup> ed.). Washington DC: American Psychiatric Association.
- Attwood, T. (2006). The pattern of abilities and development of girls with Asperger's syndrome. In *Asperger's and girls* (pp. 1-7). Arlington, TX: Future Horizons.
- Baron, R., & Kenny, D. (1986). The moderator-mediator variable distinction in social psychological research: Conceptual, strategic and statistical considerations. *Journal of Personality and Social Psychology*, *51*, 1173-1182.
- Bazelon, E. (2007, August 5). What autistic girls are made of. *The New York Times*. Retrieved from <http://www.nytimes.com/2007/08/05/magazine/05autism-t.html?pagewanted=all>
- Beaumont, R., & Newcombe, P. (2006). Theory of mind and central coherence in adults with high-functioning autism or Asperger syndrome. *Autism*, *10*, 365-382.
- Branscombe, N., Schmitt, M., & Harvey, R. (1999). Perceiving pervasive discrimination among African-Americans: Implications for group identification and well-being. *Journal of Personality and Social Psychology*, *77*, 135-149.
- British Psychological Society. (2007). Report of the working party on conducting research on the internet: Guidelines for ethical practice in psychological research online. *The British Psychological Society*. Retrieved from: [http://www.bps.org.uk/sites/default/file/documents/conducting\\_research\\_on\\_the\\_internet-guidelines\\_for\\_ethical\\_practice\\_in\\_psychological\\_research\\_online.pdf](http://www.bps.org.uk/sites/default/file/documents/conducting_research_on_the_internet-guidelines_for_ethical_practice_in_psychological_research_online.pdf)
- Brugha, T., McManus, S., Bankart, J., Scott, F., Purdon, S., Smith, J., Bebbington, P., Jenkins, R., & Meltzer, H. (2011). Epidemiology of Autism Spectrum Disorders in Adults in the Community in England. *Archives of General Psychiatry*, *68*, 459-466.
- Camp, D., Finlay, W., & Lyons, E. (2002). Is low self-esteem an inevitable consequence of stigma? An example from women with chronic mental health problems. *Social Science and Medicine*, *55*, 823-834.

- Cooley, C., (1902). *Human nature and the social order*. In C.H. Cooley, *Two major works: Social organization and human nature and the social order*. Glencoe: Free Press.
- Corrigan, P., (1998). The impact of stigma on severe mental illness. *Cognitive and Behavioural Practice*, 5, 355-366.
- Crabtree, J., Haslam, S., Postmes, T., & Haslam, C. (2010). Mental health support groups, stigma, and self-esteem: Positive and negative implications of group identification. *Journal of Social Issues*, 66, 553–569.
- Crocker, J., & Major, B. (1989). Social stigma and self-esteem: The self-protective properties of stigma. *Psychological Review*, 96, 608-630.
- Crick, A. (2013, January 30). TV Steve in autism ‘jibe’ row. *The Sun*. Retrieved from <http://www.thesun.co.uk/sol/homepage/showbiz/tv/4769474/Ricky-Gervais-pal-Stephen-Merchant-in-autism-jibe-row.html>
- Davies, C. (2013, February 4). Text messages reveal terrible toll on Chris Huhne's relationship with son. *The Guardian*. Retrieved from <http://www.guardian.co.uk/uk/2013/feb/04/messages-toll-chris-huhne-relationship-son>
- Ehlers, S., & Gillberg, C. (1993). The epidemiology of Asperger syndrome: A total population study. *Journal of Child Psychology and Psychiatry*, 34, 1327- 1350.
- Friz, S. & McKinnon, D. (2007). Required sample size to detect the mediated effect. *Psychological Science*, 18, 233-239.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. New Jersey: Prentice-Hall.
- Gould, J. & Ashton-Smith, J. (2011). Missed diagnosis or misdiagnosis? Girls and women on the autism spectrum. *Good Autism Practice*, 12, 34-41.
- Happé, F., Ehlers, S., Fletcher, P., Frith, U., Johansson, M., Gillberg, C,... Frith, C. (1996). 'Theory of mind' in the brain. Evidence from a PET scan study of Asperger syndrome. *Clinical Neuroscience and Neuropathology*, 8, 197-201.

- Hayes, A. (2013). *Introduction to Mediation, Moderation, and Conditional Process Analysis*. New York: Guilford Press.
- Hoekstra R., Vinkhuyzen A., Wheelwright S., Bartels M., Boomsma D., Baron-Cohen S., Posthuma D., & van der Sluis, S. (2011). The construction and validation of an abridged version of the Autism-Spectrum Quotient (AQ-Short). *Journal of Autism and Developmental Disorders*, *41*, 589-596.
- Landa, R., Holman, K., Garrett-Mayer, E. (2007). Social and communication development in toddlers with early and later diagnosis of Autism Spectrum Disorders. *Arch Gen Psychiatry*, *64*, 853-864.
- Link, B., & Phelan, J. (2001). Conceptualising stigma. *Annual Review of Sociology*, *27*, 363-385.
- MacKinnon, D. (2000). Contrasts in multiple mediator models. In J. Rose, L. Chassin, C. Presson, & S. Sherman (Eds.), *Multivariate applications in substance use research: New methods for new questions* (pp. 141–160). Mahwah, NJ: Erlbaum.
- Mak, W. & Kwok, Y. (2010) Internalization of stigma for parents of children with autism spectrum disorder in Hong Kong. *Social Science & Medicine*, *70*, 2045–2051.
- Mawhood, L. & Howlin, P. (1999). The outcome of a supported employment scheme for high-functioning adults with autism or Asperger's syndrome. *Autism*, *3*, 229-254.
- Mead, G. (1934). *Mind, self and society*. Chicago: University of Chicago Press.
- Moore, V. & Goodson, S. (2003). How well does early diagnosis of autism stand the test of time? Follow-up study of children assessed for autism at age 2 and development of an early diagnostic service. *Autism*, *7*, 47-63.
- University College London (2013) UCL Opinio 6.6.3. Retrieved from <http://www.objectplanet.com/opinio>
- Parikh, H., Li, W., Ramanathan, M. (1999). Evaluation of an alternative to the Kolmogorov-Smirnov test for flow cytometric histogram comparisons. *Journal of Immunology Methods*, *29*, 97-105.

- Preacher, K., & Hayes, A. (2004). Asymptotic and resampling strategies for assessing and comparing indirect effects in multiple mediator models. *Behavior Research Methods*, *40*, 879-891.
- Punshon, C., Skirrow, P., & Murphy, G. (2009). The ‘not guilty verdict’: Psychological reactions to a diagnosis of Asperger syndrome in adulthood. *Autism*, *13*, 265-283.
- Ritsher, J., Otilingam, P., & Grajales, M. (2003). Internalised stigma of mental illness: Psychometric properties of a new measure. *Psychiatry Research*, *121*, 31-49.
- Rosenberg, M. (1965). *Society and the adolescent self-image*. Princeton, NJ: Princeton University Press.
- Rosenberg, M. (1986). Self-concept from middle childhood through adolescence. In J. Suls (Ed.), *Psychological perspectives on the self* (Vol. 3, pp. 107-136). Hillsdale, NJ: Erlbaum.
- Rosenblatt, M. (2008) *I exist: The message from adults with autism in England*. London: National Autistic Society.
- Ruiz Calzada, L., Pistrang, N., Mandy, W. (2012). High Functioning Autism and Asperger’s syndrome: Utility and meaning for families. *Journal of Autism and Developmental Disorders*, *42*, 230 – 243.
- Rüsch, N., Corrigan, P., Wassel, A., Michaels, P., Olschewski, M., Wilkness, S., & Batia, K. (2009). A stress-coping model of mental illness stigma: I. Predictors of cognitive stress appraisal. *Schizophrenia Research*, *110*, 59-64.
- Shrout, P., & Bolger, N. (2002). Mediation in Experimental and Nonexperimental Studies: New Procedures and Recommendations. *Psychological Methods*, *7*, 422-445.
- Shtayermman, O. (2009). An exploratory study of the stigma associated with a diagnosis of Asperger’s syndrome: The mental health impact on the adolescents and young adults diagnosed with a disability of a social nature. *Journal of Human Behavior in the Social Environment*, *19*, 298-313.

- Shtayermman, O. (2007). Peer victimisation in adolescents and young persons with Asperger's syndrome: A link to depressive symptomatology, anxiety symptomatology and suicidal ideation. *Issues in Comprehensive Pediatric Nursing, 30*, 87-107.
- Thornicroft, G., Rose, D., Kassam, A., Sartorius, N. (2007) Stigma: Ignorance, prejudice or discrimination? *British Journal of Psychiatry, 190*, 192-193.
- 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.
- Wahl, O. (1999). Mental health consumers experience of stigma. *Schizophrenia Bulletin, 25*, 467-478.
- 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.
- Zaroff, C., & Uhm, S. (2012). Prevalence of autism spectrum disorders and influence of country of measurement and ethnicity. *Social Psychiatry and Psychiatric Epidemiology, 47*, 395-398

### **Part Three: Critical Appraisal**

## **Introduction**

This critical appraisal contains my reflections on conducting research in an area that has hitherto not been investigated thoroughly. It includes my thoughts on my findings in both my literature review and my empirical paper, on internet recruitment and on how this research process has influenced my thinking about diagnostic labelling. I do not include reflections on generalizability of my data or the limitations of my empirical paper, as these issues have been considered in the discussion section of the paper. I conclude with reflections on working with the Autism Spectrum Condition (ASC) online community and what a resource these forums can be to diagnosed individuals.

## **Literature Review**

The initial aim for the literature review was to examine existing findings on stigma and self-esteem amongst people who identified with the ASC label compared to people who identified as having mental health problems. However, due to the lack of studies that had investigated the experiences of adults with ASC thus far, the aim of the literature review was altered to focus on the experiences of group identification and stigma among people with learning disabilities and people with mental health problems.

The literature review highlighted how limited the research on group identification, stigma and self-evaluation has been to date, especially in the field of learning disabilities. While this allowed me to make useful conclusions regarding the need for research in this area, it was difficult to draw firm conclusions about the role that group identification has for people with learning disabilities or whether any meaningful comparisons with people with mental health problems exist. It also highlighted the gap in the literature investigating group identification, stigma and

self-esteem among individuals with an ASC diagnosis, which was subsequently addressed by my empirical paper.

There may be several plausible reasons for there being such little published research investigating the personal experiences of people with learning disabilities and people with ASC. I outlined how the limited research suggests that people with learning disabilities are aware of stigmatized views against them and make attempts to distance themselves from the group as a result (Jahoda & Markova, 2004). None of the studies, however, offer insight into why there is such a lack of research investigating group identification and stigma amongst people with learning disabilities, or why no studies to date had investigated this relationship amongst people with ASC. It could be the case that the paucity of self-report research is related to the difficulty presented to researchers in obtaining this data from participants who have problems with communication. As evidenced by the empirical paper, it may indeed be the case that a very broad spectrum of ability cannot realistically be obtained for self-report research, however insight can be gained into the experiences of the individuals with a higher level of functioning, whom have also been included in very few studies of this kind.

### **Public Stigma and Positive Group Identity**

Within the mental health field there has been an emphasis over recent years to encourage public awareness, understanding and tolerance for people with mental health problems (Corrigan, Markowitz, Watson, Rowan, & Kubiak, 2003). The previous government financially endorsed charities with this main aim in mind, and Time to Change recruited celebrities such as Ruby Wax, Stephen Fry and Frank Bruno to 'come out' about their mental health problems and try and create a shift in the public view (<http://www.time-to-change.org.uk/>). London underground continues



to promote their message via poster campaigns, and I have seen several people carrying bags and wearing t-shirts with the Time to Change logo. This is undoubtedly a positive thing to happen for people with mental health problems as it may be that more people now have the courage to ‘come out’ and actively address stigma (Corrigan et al., 2010). However, as mentioned in the empirical paper, there is currently not the same degree of awareness and promotion of people with ASC in the public media. Perhaps studies like the current one can at least promote the idea of there being a positive group identity among people with ASC, encouraging professionals to signpost diagnosed individuals to resources that will increase identification with the group.

As Thornicroft, Rose, Kassam and Sartorius (2007) outlined, stigmatized views tend to be the result of ignorance and ignorance is the product of a lack of informed knowledge. Group identification can promote active strategies to address stigma (Corrigan et al., 2010). Perhaps enhancing the positive ASC group identity could be both protective for diagnosed individuals and in some way encourage anti-stigma strategies to improve the public’s knowledge and decrease public stigma.

### **Empirical Paper**

My research raised a number of issues which I have touched upon in its discussion, however I shall reflect further upon some of these issues here and consider in more detail how my perceptions of diagnosis have been influenced by my findings.

### **Internet Recruitment**

There are many risks to conducting internet research outlined by the British Psychological Society in their guide to conducting online studies ethically and

reliably (BPS, 2007). One risk is the difference in level of control in being able to observe participants, for example ensuring that they understand the measures, that they can leave the study at any time and ensuring that they do not complete the study more than once. In this regard, online recruitment carries similar risks to using postal questionnaires, however the ease of completing online surveys compared with postal surveys suggests that online recruitment may be preferable as a means to obtain large sample sizes, and in providing an accessible point of contact should any questions about the measures arise. As such, it may be that internet recruitment is no more risky than more traditional forms of recruitment, and some of the risks may be managed more easily and effectively.

The other risk guideline outlined by the BPS (2007) is to ensure participants are aware that they can withdraw at any time, and perhaps one of the benefits of this style of research is that participants can simply close the survey if they do not wish to continue, without the researcher's presence influencing their engagement or choice of responses. The efficiency of completing a study online meant that the process of completing the study was not so long that a high number of participants dropped out without completing the study. Indeed, the response rate of 84% is a testament to this fact, and it may not be the case that such a high response rate could have been obtained through any other means.

It is possible, however, that owing to the anonymous nature of online, questionnaire-based studies, there were dishonest answers and duplicated entries. This is a risk that cannot be altogether accounted for and is the cost of employing anonymous, self-report measures. It seems unlikely that a study like this would have recruited as many willing, adult participants by using face to face recruitment, however. One qualitative study found that people with ASC prefer to live their social

lives online as it lessens the emotional discomfort felt when socialising face to face (Benford & Standen, 2007). As such, perhaps the data obtained in the current study would simply not have been possible without using online recruitment, and by using online recruitment the findings represent exactly how social processes such as group identification take place among a large proportion of this high functioning group: on the internet.

An alternative recruitment strategy would be to investigate clinical settings. However, there are so few clinical services for adults with ASC that increasing appropriate services for this population became part of government legislation (The Autism Act, 2009). As such, it is unlikely that relying on clinical samples would have yielded a sufficient sample size for the study, even if the discomfort of participants being recruited face to face could in some way be abated.

Internet recruitment, therefore, made mediational analysis possible in a way that recruiting via any other means would not have done owing to the sample size obtained, and enabled a group of people for whom interpersonal communication is difficult to take part in a study about their personal experiences.

An interesting consideration is whether the internet has become such a part of life that comparing online recruitment and face to face recruitment as if one were a more valid means to obtain results is unrealistic. Within the wider population recent figures suggest that in the UK people spend almost one day per month online, mostly on social network sites (UK Online Measurement Company, 2010). This suggests that as part of most people's lives are lived on the internet, using the internet to obtain self-report findings seems natural and may open up opportunities to recruit whole populations of people who can only be accessed in this way.

In regards to the other risks of internet research outlined by the BPS (2007), obtaining consent, providing information for further help, full debriefing and data protection were managed as effectively as possible. Consent was mandatory, the study was fully explained and deception was not an issue. Within the personal messages I received from participants, very few contacted me for advice or help and instead communicated how pleased they were to be included in research on ASC as they felt the adult population had been neglected by researchers. It was a rewarding part of the research experience to interact with so many adults with ASC who felt that the study's focus was a refreshing change, and this enabled me to remain enthusiastic about the study's findings throughout the process.

### **Autism Spectrum Condition and Awareness of Stigma**

In my literature search for my empirical paper, I came across studies investigating how to promote self-esteem among adolescents (Shtayermann 2007, 2013) and young people (Punshon et al., 2009) with ASC, but none that recruited people over 25 years old. It occurred to me that perhaps there was either a lack of interest among researchers in the experiences of stigma and self-esteem among adults with an ASC diagnosis or that there was a misconception that people with ASC are either not affected by stigma or their diagnostic label or are not able to communicate effectively their thoughts and feelings about it. It was a pleasure, therefore, to address this gap in knowledge and provide a platform for considering important clinical implications of the findings. Indeed, the study's clinical implications support the focus of the government's Autism Act (2009), which recognised the need for accurate diagnosis and appropriate services for the neglected adult ASC population, thus highlighting the importance of research like this.

## **Labelling and Enabling**

On commencing this study, I had mixed feelings about the diagnosis-led culture of psychiatry and clinical psychology. The literature review alerted me to how stigmatized some individuals can feel when given a diagnosis by professionals. This was particularly pertinent when reading the accounts of people with learning disabilities in hospital settings (Jahoda & Markova, 2004) who described anger at being diagnosed with the learning disabilities label owing to the stigma attached to it. The findings of Finlay and Lyons (1998, 2000) that individuals rejected the label 'learning difficulties' also made me question the usefulness of diagnoses to the individuals in question. While diagnosis can provide a shared language for professionals, my literature searches for both part one and two of this thesis made me consider how infrequently the impact on the individuals receiving the diagnosis is considered.

Diagnosis and its usefulness in psychiatry was recently the topic of one of the Maudsley debates held at the Institute of Psychiatry (<http://www.kcl.ac.uk/iop/news/debates/index.aspx>). Professor Anthony David, Professor of Cognitive Neuropsychiatry from the Institute of Psychiatry, urged for the "rational, careful, respectful and collaborative" approach to diagnosis and emphasised the positive influence that diagnosis can have for individuals when this approach is taken. His sentiments echo my own upon completion of this research. Perhaps the significant difference found in my empirical paper in self-esteem between people who sought their own diagnosis and those who did not is in some way related to the importance of diagnosis feeling collaborative with the individual being diagnosed. The findings within the mental health literature suggested that correct, careful differential diagnosis could lead to positive self-esteem through the group identification

relationship (Rüsch, Lieb, Bohus & Corrigan, 2006; Camp, Finlay & Lyons, 2002) and discovering similar findings to this within the ASC community strengthened my belief that for some people, correct diagnoses can be incredibly beneficial as long as group identification and adaptive coping with stigma are somehow enabled. I was interested to discover that this relationship between diagnosis and self-esteem was not as simple as ‘diagnoses are stigmatizing, so diagnoses are harmful’, and that the benefits of correct diagnosis extended much further than to provide professionals with a shared language.

As mentioned in the discussion of the empirical paper, the current findings offer an alternative view to the statement offered by the Division of Clinical Psychology (DCP, 2013). The suggestion by the DCP (2013) that diagnosis leads to stigmatization and low self-esteem was the primary null hypothesis rejected in light of the current study’s findings. Perhaps then, the DCP’s (2013) broad stroke approach to dismissing diagnosis as a damaging experience for the individual does not account for the evidence to the contrary at least when it comes to the ASC population who identify strongly with their label. Indeed. Indeed, it seems that care must be taken both when considering the accuracy and helpfulness of a diagnosis and when considering the potential harm of not diagnosing.

A recent longitudinal study by Russell, Kelly, Ford and Steer (2012) found that early diagnosis among children with ASC had no significant benefit or harmful impact on pro-social behaviours of individuals with ASC when older. They highlight that not only does this strongly suggest that social behaviours are a stable trait of ASC, but that it contradicts findings (Scheff, 1999; Harris, Millich, Corbitt, Hoover & Brady, 1992; Al-Qabandi, Gorter & Rosenbaum, 2011) that an early diagnosis assigns these individuals to a more damaging social and developmental trajectory

than their undiagnosed peers. The current study suggests that not only may diagnosis do no harm, but it could be protective for some individuals due to the social rejection often faced when one has such a stigmatized condition.

This finding that diagnosis can be beneficial when group identification is encouraged may not be the case for all labels, and I shall be interested to read future research investigating group identification and its impact on self-esteem for other stigmatized conditions. It may be that the collaborative approach is used to enhance client choice in their diagnostic label. For example, noted former president of the World Psychiatric Association, Professor Norman Sartorius, described in the Maudsley debate the relabeling of the term 'schizophrenia' in Greece owing to its direct translation of 'split-brain' offending diagnosed individuals. Professor Sartorius described how the label was changed to the Greek for 'disorder in co-ordination of thinking', which continued to provide a shared language for the condition amongst professionals but, more importantly, provided a more positive label for the diagnosed individuals of their choosing

It would be recommended, given the findings in this thesis, to consider carefully the diagnoses that the clinical psychology and psychiatry professions use and to keep the diagnostic process client-focussed. The current paper suggests that some diagnoses could be an important part of a process that enables many people to feel a part of an ingroup, promoting coping with stigma and protecting self-esteem. The meaning of the diagnosis to the person and the group identity that it could provide should therefore be considered during the diagnostic process, as well as whether the label is an accurate one to be shared among professionals.

## **Clinical Implications**

The literature review's findings suggest that research needs to focus its attention on the subjective experiences of people diagnosed with learning disabilities to ascertain how they feel about their label. People with mental health problems (Crabtree, Haslam, Postmes, & Haslam, 2010), African Americans (Branscombe, Schmitt & Harvey, 1999) and people with ASC (as found in the current study) are all groups of people who have found group identification a powerful way to cope with stigma.

The empirical paper's findings support the government initiatives advocating for an increase in accurate diagnosis of adults with thus far undiagnosed ASC. In addition the current study advocates for adult ASC services to enhance appropriate treatments by including means to increase identification with their group and, if possible, access to the online community. Visiting the online forums for people with ASC in order to recruit volunteers for my study introduced me to a community where adults with ASC spoke openly about feeling positively towards their label, their fellow group members and their spokesperson with ASC. There were videos posted on one site by the site's owner of him actively campaigning around the world for the ASC community to promote a positive ASC group identity.

Watching these videos and interacting with the forum users made me aware of how an ingroup identity can be nurtured and solidified and how online resources like these forums can provide a support network for people who may find support offered in other ways too difficult to manage. These observations and my empirical findings have made me consider how much more we could be doing within clinical settings to provide practical help for people with ASC. Introducing adults with ASC who are unaware of these online communities seems a valuable place to start.



## **Conclusions**

I have learnt during this research process that internet recruitment has its challenges but can be an excellent way to reach a high number of people that may have otherwise remained overlooked in research. I have learnt that a shared group identity can be a source of resilience, even for people with ASC for whom some of the social meaning pertaining to group membership might be difficult, and that it is likely that the nature of the internet itself facilitates these adaptive social processes for coping with stigma. Being an active part of the online ASC community has been an inspiring experience and I would recommend visiting these websites to any clinician wishing to better understand the experiences of adults with ASC, as well as to any adult either diagnosed with ASC or believes they may have it. The current study's findings suggest that identifying with the ASC group via online forums could be beneficial to the self-esteem of these individuals.

## References

- Al-Qabandi, M., Gorter, J., & Rosenbaum, P. (2011). Early autism detection: Are we ready for routine screening? *Pediatrics*, *128*, 211-217.
- Benford, P., & Standen, P. (2009). The internet: A comfortable communication medium for people with Asperger syndrome (AS) and high functioning autism (HFA)? *Journal of Assistive Technologies*, *3*, 44 – 53.
- Branscombe, N., Schmitt, M., & Harvey, R. (1999). Perceiving pervasive discrimination among African-Americans: Implications for group identification and well being. *Journal of Personality and Social Psychology*, *77*, 135 – 149.
- British Psychological Society. (2007). Report of the working party on conducting research on the internet: Guidelines for ethical practice in psychological research online. *The British Psychological Society*. Retrieved from: [http://www.bps.org.uk/sites/default/file/documents/conducting\\_research\\_on\\_the\\_internet-guidelines\\_for\\_ethical\\_practice\\_in\\_psychological\\_research\\_online.pdf](http://www.bps.org.uk/sites/default/file/documents/conducting_research_on_the_internet-guidelines_for_ethical_practice_in_psychological_research_online.pdf)
- Camp, D., Finlay, W., & Lyons, E. (2002). Is low self-esteem an inevitable consequence of stigma? An example from women with chronic mental health problems. *Social Science and Medicine*, *55*, 823-834.
- Corrigan, P., Markowitz, F., Watson, A., Rowan, D., & Kubiak, M.A. (2003). An attribution model of public discrimination towards persons with mental illness. *Journal of Health & Social Behavior*. *44*, 162-79.
- Corrigan, P., Morris, S., Larson, J., Rafacz, J., Wassel, A., Michaels, P.,... Rüsçh, N. (2010). Self-stigma and coming out about one's mental illness. *Journal of Community Psychology*, *38*, 259-275.
- Crabtree, J., Haslam, S., Postmes, T., & Haslam, C. (2010). Mental health support groups, stigma and self-esteem: Positive and negative implications of group identification. *Journal of Social Issues*, *66*, 553-569.
- Finlay, M., & Lyons, E. (1998). Social identity and people with learning difficulties: Implications for self-advocacy groups. *Disability and Society*, *13*, 37-51.

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

Harris, M., Millich, R., Corbitt, E., Hoover, D., & Brady, M. (1992). Self-fulfilling effects of stigmatizing information on children's social interactions. *Journal of Personality and Social Psychology*, 63, 41-50.

Jahoda, A., & Markova, I. (2004). Coping with social stigma: People with intellectual disabilities moving from institutions and family home. *Journal of Intellectual Disability Research*, 48, 719-729.

Kings College London (2013). Maudsley Debates. Retrieved from <http://www.kcl.ac.uk/iop/news/debates/index.aspx>

Rüsch, N., Corrigan, P., Powell, K., Rajah, A., Olschewski, M., Wilkniss, S., & Batia, K. (2009b). A stress-coping model of mental illness stigma: II. Stress responses, coping behavior and outcome. *Schizophrenia Research*, 110, 65-71.

Russell, G., Kelly, S., Ford, T., & Steer, C. (2012). Diagnosis as a social determinant: The development of prosocial behaviour before and after an autism spectrum diagnosis. *Social Science & Medicine*, 75, 1642-1649.

Scheff, T. (1999). *Being mentally ill: A sociological study* (3rd ed.). Piscataway, New Jersey: Aldine Transaction.

The Autism Act (2009). Retrieved from <http://www.legislation.gov.uk/ukpga/2009/15>

Thornicroft, G., Rose, D., Kassam, A., Sartorius, N. (2007) Stigma: Ignorance, prejudice or discrimination? *British Journal of Psychiatry*, 190, 192-193.

Time to Change (2013). Time to Change: Let's end mental health discrimination. Retrieved from <http://www.time-to-change.org.uk/>

UK Online Measurement Company (2010, May). The Online Media Landscape. Retrieved from <http://www.ukom.uk.net>

## **Appendix A: Measures and Scoring Items with Introduction to Measures**

### **Included**

#### **1. AQ-S**

'Most of the questions below ask how much you agree or disagree with a given statement, some questions ask how often you experience a particular feeling. All questions are multiple choice. Please select the option that you feel most appropriate to you. For the purpose of this study, we will be using the term 'ASC' (Autism Spectrum Condition) as opposed to 'ASD' (Autism Spectrum Disorder), but they mean the same thing.'

**Measure Removed Due to Copyright.**

#### **2. Group Identity Measure**

'Now I would like you to rate your agreement with some statements about the 'ASC community'. By 'ASC community' I mean a group or 'community' of people with an Autism Spectrum Condition. The questions will ask how much you feel you belong to such a 'community' and how you feel about it.'

**Measure Removed Due to Copyright.**

#### **3. Stigma Measure**

'Some of the statements in the following section ask about 'stereotypes'. The definition of a stereotype is: 'a widely held but fixed and oversimplified image or idea of a particular type of person or thing'. For example, stereotypes that can be held about people with ASC is that they must be really good at maths, or that they do not want to engage in relationships. There may be other stereotypes about ASC that you are aware of.'

**Measure Removed Due to Copyright.**

## Appendix B: Information Sheet and Consent Form: First Page of Survey



Thank you for participating in this online study looking into self-esteem of adults with an Autism Spectrum Condition. Once you have answered all the questions, you will be invited to leave your email address so that you can be entered into a prize draw for a **£50 Amazon.com** voucher!

Your email address will not be linked in any way with your questionnaire responses, so that all of your answers remain **entirely anonymous**. Before the questionnaire begins, you will be asked to agree your consent for your anonymous responses to be included in analysis. You must be **at least 18 years old** to be included in this study, and you must **tick the 'consent box'** that appears on the next page before clicking **'start'** to begin the study.

Many thanks and best of luck with the vouchers!

Some extra information...

**Title of study:**

An investigation into self-esteem of adults with an ASC diagnosis

**Contact Details of Researcher:**

Hannah Mustard

[ASCstudyucl@gmail.com](mailto:ASCstudyucl@gmail.com)

**Research Supervisors:**

Dr William Mandy, UCL and Dr Jason Crabtree, UCL

This research is being undertaken as part of a doctorate in clinical psychology at UCL. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, please read the following information carefully and discuss it with others if you wish.

**Details of Study:**

This study aims to find out what effect, if any, having an Autism Spectrum Condition (ASC) diagnosis has on self-esteem. Taking part involves completing a questionnaire, which will take about **15 minutes**. The questionnaire explores your strengths and difficulties, your attitudes to ASC and how you feel about yourself as a person with an ASC diagnosis. We aim to recruit around 160 people, and at the end of the study five participants will be randomly selected to receive a prize of £50 Amazon.com vouchers. For this study we are looking for people aged 18 and over and have ASC.

If you decide to take part, please indicate your consent by ticking the box at the bottom of this page (you cannot continue with the study until you have ticked the consent box). If you decide to take part you are still free to withdraw your data from the project at any time up until it has been analysed for use in the final report (**31/12/12**) without giving a reason.

This study has been approved by the

UCL Research Ethics Committee as Project ID Number: CEHP/2012/019

The questionnaires are anonymous and any information provided will be kept confidential. The research may be considered for publication in the near future, all data will remain anonymous and no one will be identifiable through the paper. You may also request a copy of the research paper by contacting me ([ASCstudyucl@gmail.com](mailto:ASCstudyucl@gmail.com)).

### Participant's Statement

I agree that I have:

- read the information.
- understood my rights as a participant and whom to contact for further information.
- understood that the information I have submitted may be published as a report and I can request to be sent a copy. Confidentiality and anonymity will be maintained and it will not be possible to identify me from any publications.
- understood that I am free to withdraw from the study without penalty if I so wish and I consent to the processing of my personal information for the purposes of this study only and that it will not be used for any other purpose.
- understood that all information I provide will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.

**Please tick the box to indicate your consent**

**YOUR ANSWERS CANNOT BE INCLUDED FOR ANALYSIS IN THIS STUDY IF YOU DO NOT TICK THE CONSENT BOX.**

## **Appendix C: Debrief Sheet**

### **ASC study, UCL**

#### **Thank you, all done!**

A summary of the results from this study will be available to all participants: if you found this study on an ASC forum then please check posts from me there this summer. Alternatively please email me at [ASCstudyucl@gmail.com](mailto:ASCstudyucl@gmail.com) for the summary. Unfortunately individual scores for the measures cannot be provided to participants.

If you feel that you need support as a person with ASC, there are a number of services that could help. Your GP can refer you to mental health services if you feel this would be useful, and there are forums and charities for people with ASC to support one another. The National Autistic Society (<http://www.autism.org.uk/>) can provide useful information on a variety of issues related to having ASC, however if you would like more details of other charities and forums please email me.

If you would like to be entered into our prize draw for a £50 Amazon.com book voucher, please **provide your email address** into the box below:

If you are one of the participants chosen at random to receive a voucher, you will be contacted via email to tell you of this. We will draw the winning email addresses once all of the questionnaires have been collected in **December, 2012**.

**Good luck!**



## **Appendix D: Ethical Approval Confirmation**

----- Original Message -----

Subject: ethics approval

From: "Viding, Essi"

Date: Thu, July 19, 2012 9:46 am

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The CEHP Ethics Committee has approved your application:

Researchers: Will Mandy, Hannah Mustard, Jason Crabtree

Number: CEHP/2012/019

Title: ASC and social identity: Does being part of the ASC community protect against stigma and promote self-esteem?

Please do make sure that the data you gather are stored anonymously.

Please remember, in general to observe the Code of ethics and conduct. Leicester: The British Psychological Society, March 2006, and in particular to follow the 'Guidelines for minimum standards of ethical approval in psychological research'. Leicester: The British Psychological Society, July 2004 when conducting your research.

Yours sincerely,

Essi Viding

Chair, CEHP Ethics Committee