

Exploring Experiences of Stigma in Parents of Children with Autism

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D.Clin.Psy thesis (Volume 1), 2020

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**UCL Doctorate in Clinical Psychology**

**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 and referenced.

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Date: 24.06.20

## Overview

This thesis explores the experience of stigma from the perspective of children and young people with intellectual and neurodevelopmental disabilities, and their parents. Part 1 presents a systematic review exploring children and young people with intellectual disabilities experiences of stigma. The review examines research where children and young people had shared their perspective of the impact of stigma, how they make sense of stigma and manage the stigma they experience. There were few studies exploring how children and young people with intellectual disabilities make sense of and manage stigma. Nevertheless, themes emerged around social status and the use of diagnostic labelling, as well as negative and positive coping strategies.

Part 2 reports a qualitative study using constructivist grounded theory to explore the experiences of parents of children with autism. Semi-structured interviews highlighted the range in responses, a theoretical model is presented which offers an understanding of how parents respond to and resist stigma. Responses were altered by two dependent factors; who the stigmatiser was and who was being stigmatised. Four core types of strategies were used to manage stigma; “actively ignoring”, “avoiding”, “challenging” and “actively withdrawing”.

Part 3 offers a critical reflection on the process of conducting this research. It focuses on the benefits of working with experts by experience and some of the challenges faced during this research project. It explores those whose voices were not captured in this research and how future research could address this gap.

## **Impact Statement**

This thesis explores the experiences of stigma for children and young people with intellectual and neurodevelopmental disabilities and their families. It stresses the importance of hearing from children and young people, and their parents about how they manage and respond to stigma. Developing a deeper understanding of those who regularly experience stigma will help direct future research and support the development of interventions for both the stigmatised individual and wider social systems.

On dissemination it can be hoped that the model presented in the empirical paper can be reflected upon with parents of children with autism in clinical settings, for example, post-diagnostic parenting groups. The model presented may help parents see the range of responses and strategies they could use to manage stigma in different contexts.

The information gained in this thesis will be disseminated within the academic community via publication in research journals, as well as being shared with other interested parties, for example, Child and Adolescent Mental Health Services. The research will also be presented to academic working groups to consider the findings, as well as to help to inform and direct future research projects. On a broader level the research findings will be summarised and publicised in other formats on social media and academic blogs, ensuring to share the findings with the charities and the parent support groups who supported with advertisement during recruitment. Moreover, all the participants who took part in the study opted in to receive a copy of the empirical paper, a summary of the findings and the empirical paper will be shared with them.

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## **Acknowledgements**

I am grateful to each of the parents who have taken part in this study, given up their time and shared their experiences with me. I hope that I have been able to capture their experiences in the way that they hoped. I would like to thank my supervisor, Dr Katrina Scior, for her support and guidance. I would like to thank the three experts by experiences who have been an invaluable source of support and knowledge throughout this research project. Finally, thank you to my family and friends for their on-going support and love.



## **Part 1: Literature review**

Experiences of Stigma Among Children and Young People with Intellectual  
Disabilities: A Systematic Review

## **Abstract**

### **Aim**

To review the body of literature on children and young people with intellectual disabilities' first-hand experiences of stigma, focusing on how they are affected by stigma, and make sense of and manage stigma.

### **Method**

Searches were conducted on PsycINFO, Scopus, and ERIC (ProQuest) using search terms and synonyms focusing on: stigma, intellectual disabilities, and children/young people. The 2035 identified studies were screened against the inclusion criteria and quality rated, leading to 16 studies being included in this review.

### **Results**

The reviewed studies highlight the pervasiveness of stigma experienced by children and young people with intellectual disabilities and its deleterious effect on their mental health at different developmental stages. Few studies explored how children and young people with intellectual disabilities make sense of and manage stigma. Positive support, personal values and self-belief were cited by children and young people as key to helping them cope with stigma they experience. Yet, others cited enlisting more negative coping strategies, such as avoidance and being the perpetrator of bullying. Studies also highlighted the discrepancy between parental and the young people's reports of the stigma they experience, emphasising the need to amplify their voice in research.

### **Conclusions**

Further research is required to gain an understanding of how children and young people with intellectual disabilities make sense of and manage different types of stigma throughout childhood and into early adulthood.

## Introduction

Stigma is the process whereby an individual is discredited and discounted by society because their values, characteristics, or practices differ from the social majority (Goffman, 1963). Link and Phelan (2001) proposed that stigma exists when elements of labelling, stereotyping, separating, status loss and discrimination co-occur in a power situation that allows these processes to unfold. Certain groups who are viewed by society to have less power, such as those with intellectual disabilities may, often experience stigma in a range of social contexts in their life (Rüsch et al., 2005).

Intellectual disability is defined as significant deficits in intellectual functioning and deficits in two or more areas of adaptive behaviour which occur before the age of 18 (American Psychiatric Association, 2013). People with intellectual disabilities are a negatively perceived minority within society, resulting in this group experiencing high rates of stigmatisation (McManus et al., 2011). Research highlights that across a range of cultures, the general public has little understanding and awareness of what the label of intellectual disability actually means, often resulting in negative attitudes towards and misconceptions about the capabilities of people with intellectual disabilities (Scior, 2011). A systematic review of how people with intellectual disabilities construct their social identities, in the context of the stigma they experience, was conducted by Logeswaran et al. (2019). They found that people with intellectual disabilities appear aware of the label ascribed to them, or that they are viewed as 'different' by the general public. Nevertheless, many do not perceive their intellectual disability as a key aspect of their identity, despite having experienced negative social interactions due to others viewing the intellectual disability label negatively.

A recent systematic review explored the magnitude and prevalence of victimisation experienced by children and young people with intellectual disabilities (Maiano et al., 2016). The authors concluded that victimisation for children and young

people with intellectual disabilities is a current and worrying problem. The majority of studies reviewed examined parents' views of bullying and victimisation experienced by children and young people with intellectual disabilities. The authors stressed the need to conduct further research into bullying perpetration and victimisation in youth with intellectual disabilities, as well as different forms of victimisation, for example, the impact of physical versus verbal bullying.

A causal mediation analysis was conducted by King et al. (2018) to explore the relationship between disability, bullying, and mental health difficulties in adolescents. Their findings indicate that bullying explains 46% of mental health difficulties in adolescents. Notably, they collected data from parents, teachers, and adolescents, and found discrepancies between the different samples, particularly in the reported frequency and impact of bullying on adolescents. Of note, this study used a broad operationalisation of disability, including participants with either physical health conditions, e.g. speech problems, hearing problems, as well as participants with "difficulty learning or understanding things". Due to this broad definition, it is difficult to draw conclusions from this study for people with intellectual disabilities.

A further systematic review examined the experiences of stigma among families of individuals with intellectual disabilities and autism, i.e. affiliate stigma (Mitter et al., 2019). Affiliate stigma is the process whereby a person associated with a stigmatised person, e.g. a family member, is also subjected to stigma. This associate may then internalise negative beliefs arising from the stigmatising experiences and develop broader beliefs about their own and their family's position in society (Mak & Kwok, 2012). The review by Mitter et al. (2019) and further recent studies (Papadopoulos et al., 2019) highlight that there are several psychosocial variables related to the experience of affiliate stigma, such as caregiving burden, lower self-esteem and increased depressive symptomology. The evidence discussed emphasises the impact that stigma can have on young people with intellectual disabilities and their families.

Researchers have begun to work closely with children and young people with intellectual disabilities to access their perspective on issues that matter to them (Kellett et al., 2010; Scott et al. 2011). Mencap (2007) carried out workshops with 507 children and young people with a range of special educational needs (including dyslexia and intellectual disabilities) to explore their experiences of bullying. The workshops highlighted the importance and ease of working with children and young people with disabilities, as well as the rich qualitative data that can be gained from speaking directly with those being stigmatised.

To my knowledge, there have been no published systematic reviews specifically examining the body of literature on stigma experienced by children and young people with intellectual disabilities, from their perspective. Hence this review aimed to answer the following questions from the perspective of children/young people with intellectual disabilities:

1. How frequently and in what context do they experience stigma?
2. How are they affected by stigma?
3. How do they make sense of stigma?
4. How do they manage stigma?

## **Methods**

### **Search strategy**

A search covering the period from January 1980 to July 2019 was conducted of three electronic databases: PsycINFO, Scopus, and ERIC (ProQuest). The search terms focused on three aspects: stigma, children/young people and intellectual disabilities. Terms relating to these and synonyms were combined using “AND” as the Boolean operator (*Table 1*). The search was conducted on abstracts, key concepts, and title. In addition, reference lists of included studies and relevant reviews were checked for studies that might have been missed.

**Table 1.**  
*Search terms and synonyms*

Stigma	Child/Young Person	Intellectual Disabilities
Stigma*	Child*	Intellectual Disabilit*
Discrimination	Young Person	Disabiliti*
Prejudice	Adolescen*	Developmental
Bullying	Minor	Disabiliti*
Exclusion	Teen*	Retardation
Rejection	School-aged	Learning Disabilit*
Victimisation	Youth	Learning difficult*
Victimization	Paediatric	Mental* retard*
Ostracism		
Cyberbullying		
Marginali*		
Shunned		
Stereotype		
Social Exclusion		

### **Inclusion and exclusion criteria**

Studies were only included if they focused on the experiences of children, adolescents, and young adults with intellectual disabilities, particularly in relation to experiences of stigma or victimisation. Studies were only included if they explicitly collected data from the child, adolescent, or young adult. To capture experiences of stigma that may occur during the transition into adulthood the decision was made to include studies where participants' mean age was  $\leq 25$  years old. Only studies where it was clear that participants had a diagnosis of intellectual disabilities were included (studies using terms used before the DSM-5, e.g. 'mental retardation' were also included). Only studies published in peer-reviewed journals were included. Studies were included if they examined perspectives of more than one group of children, for example, children with a diagnosis of autism and children/young people with intellectual disabilities. However, they were only included if the responses of children/young people with intellectual disabilities were reported separately. The search process is illustrated in Figure 1.

## **Quality assessment and analysis**

The quality of studies identified was assessed using the QualSyst assessment tool (Kmet et al., 2004). This was used due to its suitability for assessing the quality of quantitative and qualitative studies simultaneously. Studies were independently rated by two researchers, with inter-rater reliability averaging 97% (*Table 2, Appendix 1*). A structured questionnaire was used to extract information about the design of each study, sample size, selection of participants, the type of instruments or interviews used, and their reliability and validity (if appropriate), the main findings, generalisability of findings, and key study limitations. The mean assessments of quality must be held in mind when drawing conclusions about these studies' findings.

## **Results**

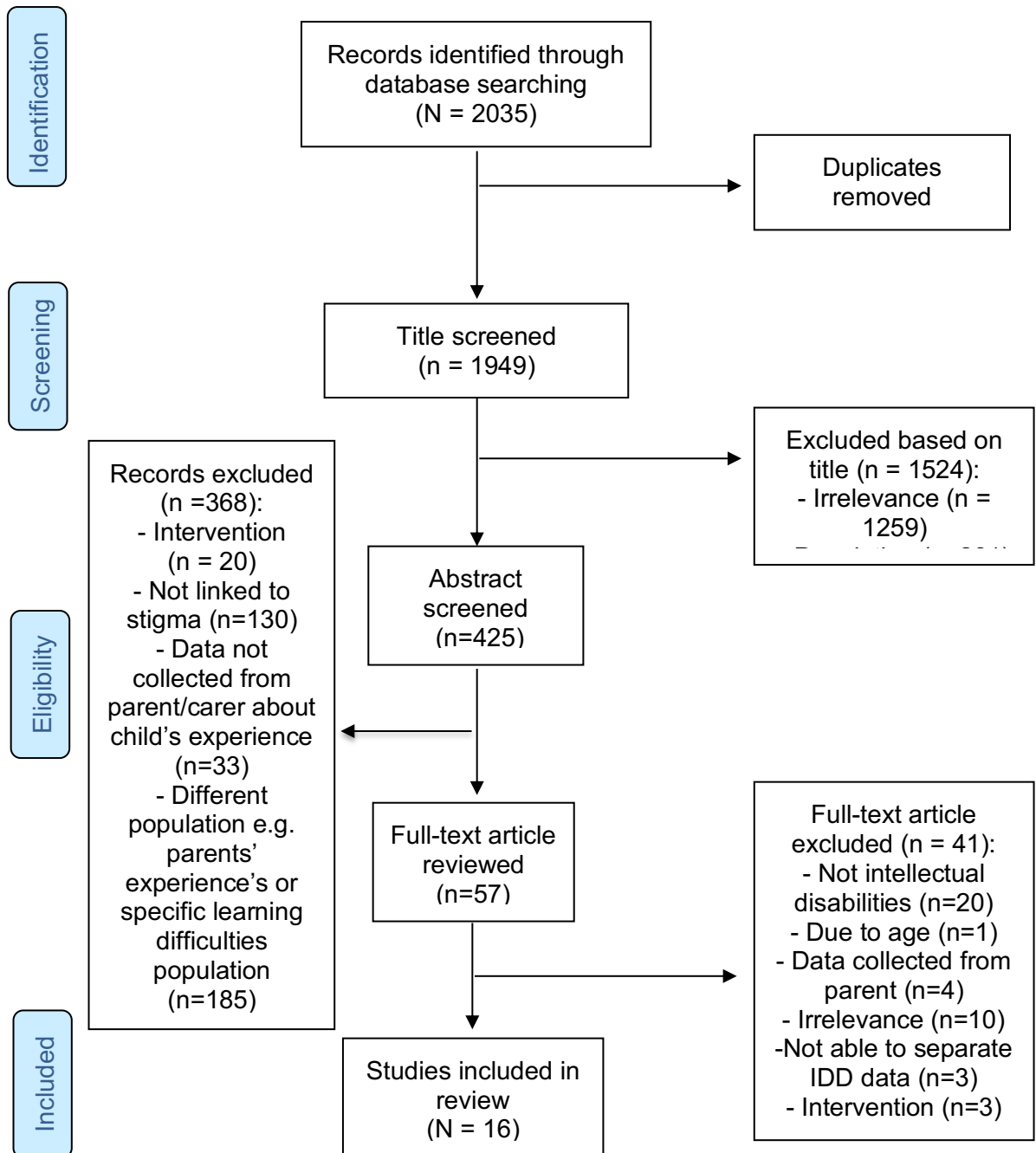
### **Results of search strategy**

*Figure. 1* provides details of the search process and results, as well as reasons for exclusion.

### **Overview of the studies**







A total of 16 papers were included in the review; an overview of these is provided in *Table 3*. A total of 1,583 children and young people with intellectual disabilities took part in the studies presented in the included papers, which explored different aspects of stigma. Eight studies had cross-sectional designs, four used qualitative methods, and four used mixed methods. The majority of the studies were conducted in the USA (n=7), the remaining studies in the UK (n=3), Taiwan (n=2), and one each in Canada, Croatia, Spain and Sweden. In the following sections key themes and findings that emerged from the studies, in relation to the four research questions, are summarised. These studies highlight the frequency of stigma, the various forms it can take, and the effect it has on children and young people with intellectual disabilities' mental health throughout childhood and into early adulthood.







**Figure 1.**  
*Screening procedure, search results, and reasons for exclusion.*





















**Table 3.**  
*Overview of included studies*





No	Study	Design	Sample	Method	Key findings	Limitations	Mean QualSyst Rating
1	Bennett et al. (2017). Canada		21 participants with ID, aged 16-21.	Semi-structured interviews, focused on: social relationships, independent work, school life, and community inclusion. Interviews coded from a critical disability perspective using thematic analysis. 	Key themes; a) Positives of being in special education- linked to less stigma. b) Positive friendships and importance of trust and having someone to 'stick up for you'. c) Close relationships; dependence on parents. d) Importance of maintaining positive experience e) Uncertainty about the future.	IQ not formally assessed, ID identified using administrative definition, e.g. enrolled in special education. The interviews did not explore any negatives for the future. No demographic data.	95%
2	Chen & Shu (2012). Taiwan		14 young people with intellectual disability (Age range 17yrs to 22yrs, 57% male).	Semi-structured interviews, focused on: experiences of stigma in school, their view of the support they received from school, and personal responses to stigma. Data analysed using grounded theory. 	Three key themes; a) Being labelled: the sources of their stigma often resulted from the educational and social welfare systems. b) Perceiving oneself: they viewed themselves as "not good" students, as troublemakers, as sick people and as odd people. c) Living with the labelling: attempting to manage the impression that their intellectual disability had on others by using avoidance, isolation and self-promotion.	Poor generalisability, IQ not specifically reported, ID identified using administrative definition, e.g. enrolled in special education.	100%
3	Chiu et al. (2017). Taiwan		706 adolescents with ID, Age range 12-18yrs (57.2% male).	Online questionnaires: School Bullying Experience Questionnaire- Chinese version (Yen et al., 2012); Symptom Checklist-90 (Derogatis & Unger, 2010); demographics. Participants asked about use of social networking sites, bedtimes and experience of peer relationships. Regression analysis. Parents completed semi-structured interviews. 	70% experienced at least one and 44% at least two types of victimisation. Exclusion (50%) and verbal bullying (70%) most common; these types of victimisation significantly associated with psychological distress. Younger children experienced greater levels of verbal bullying. A good relationship with parents and peers was associated with lower psychological distress and impact on mental health.	Only participants with higher IQ included as self-completed questionnaire. Data from parent interviews not discussed. IQ not formally assessed, ID identified using administrative definition, e.g. government data.	93%

No	Study	Design	Sample	Method	Key findings	Limitations	Mean QualSyst Rating
4	Christensen et al. (2012). USA		137 adolescents and their mothers and children. All adolescents were aged 13yrs. Two groups; ID Group (n= 46, 62.2% male, 48.9% Caucasian) TD Group (n=91, 52.7% male, 59.3% Caucasian)	Semi-structured interviews with mother and adolescent, focusing on significant life events. Mothers also completed; Child Behavioural Checklist (Achenback & Rescorla, 2001). 	ID group reported being victims of bullying more than TD group, but no difference between groups in chronicity and severity. Adolescents with social problems e.g. withdrawal, experienced more bullying. Bullying decreased in early adolescence for all groups. Adolescents reported more experiences of bullying than their mothers, but their mothers reported the bullying as more severe and chronic. Adolescents less likely than their parents to state whether they had bullied other children.	Income and mother's education level significantly lower in ID group, controlled for in analysis; but cannot be controlled for in interviews. Other themes from qualitative interviews not discussed	95%
5	Cooney et al. (2006). UK		60 young people with mild to moderate ID, (mean age= 15yrs, 52% male). 28 participants from mainstream schools and 32 attended special schools. More deprivation in special schools.	Self-report measures completed by participants; Adapted Social Comparison Scale (Allan & Gibert, 1995); Modified Life in School Checklist- Junior school version (Aoroa, 1987); Experience of stigma checklist; Future aspirations checklist (Halpen, 1994). 	Mainstream group reported significant additional stigma at school. Both groups compared themselves positively with more disabled peers and with TD peers. Mainstream pupils had more ambitious work aspirations, both groups felt it equally likely they would achieve future goals. Participants from special schools came from more deprived areas and had lower IQ scores, but no apparent impact on their experience of stigma, social comparisons or future aspirations.	IQ not formally assessed using WISC-IV but interpretation done with the British Picture Vocabulary Scale- Revised. Poor reliability on the Social comparison scale, when comparing to non-disabled peers unclear why.	95%
6	Forte et al. (2011). UK		52 participants, age range (17-20 yrs, mean age= 18yrs). Two groups; ID (n=26, 61.5 % male); TD (n=26, 57.7% male)	Semi-structured interviews explored participants' worries. 12 photographs shown to help facilitate discussion. Participants completed the General Self Efficacy Scale-12 (Woodruff & Cashman, 1993) and Glasgow Anxiety Scale-LD (Mindham & Espie, 2003). 	The ID group's most salient worries (being bullied, losing someone they are dependent upon, failing in life, followed by making and keeping friends) were largely different from TD group (getting a job, followed by not having enough surplus money, failing, and having to make decisions about their future). ID group also reported ruminating more and being more distressed.	Only examined at one-time point. Small sample size. Hard to generalise. Didn't explore how previous experience may have informed current worries.	96%






No	Study	Design	Sample	Method	Key findings	Limitations	Mean QualSyst Rating
7	Hatton et al. (2018). UK		Time point 1: 13/14yrs old; ID (n=472), TD (n=12,067)  Time point 4: 16/17yrs old; ID (n=395), TD (n=10,536)	Secondary data analysis, of the Next Steps- Longitudinal Study of Young People in England from two time points; aged 13-14yrs and 16-17yrs. GHQ-12 (Goldberg, 1978) and self-reported experience of peer victimisation was recorded at each time point.  	ID group more likely than TD group to experience socioeconomic disadvantage and bullying. Strong association between potential MH difficulties for boys with ID aged 13/14 when socially excluded. No significant difference between TD group and ID group in increase of MH incidents over time, as ID group continues to experience MH difficulties across time and experience MH difficulties earlier than TD group.	19% attrition ID group compared to 13% in TD group. Lack of validity of using GHQ-12 with people with ID. IQ not formally assessed, ID identified using administrative definition, e.g. education records.	86%
8	Iglesias et al. (2019) Spain.		181 adolescents, mean age 16 yrs. Three groups; ID (n=45); ASD (n=31); TD (n=105)	Cyber-aggression questionnaire for adolescents (Álvarez-García et al., 2017); Cyber-victimisation Questionnaire for Adolescents (Álvarez-García et al., 2017). A questionnaire on technology usage and social media, developed by authors.  	64.4% of youth with ID experienced cyber-bullying; ASD (51.5%) and TD (62.9%) but no significant difference. Most common type of cyber-victimisation for ID group was verbal abuse e.g. insults via text or WhatsApp.	Different sample sizes; 58% TD. IQ not formally assessed, ID identified using administrative definition, e.g. enrolled in special education.	88%
9	Rose et al. (2015). USA		13,325 students without disabilities and 1,183 students with disabilities (age range 11-18yrs). ID group (n=117).	Participants completed measures on experiences of bullying, in person and online, questions around them bullying others: University of Illinois Scales for fights, bullying and victimisation (Espelage & Holt, 2001); Online Harassment Victimization Scale (Tynes et al., 2010); Relational aggression victimisation/perpetration scales (Crick & Grotpeters, 1995).  	Students with ID reported the highest rates of online victimisation, relational victimisation, being bullied and relational perpetration, and the second highest prevalence rate in fighting. It was also found that they had a high likelihood of being part of the bully-victim dynamic, with 12.8% identifying as bully-victims.	Measures used not validated with ID population. Not able to break down further demographics. IQ not formally assessed, ID identified using administrative definition, e.g. education records.	66%

No	Study	Design	Sample	Method	Key findings	Limitations	Mean QualSyst Rating
10	Sabornie & Kauffman (1987). USA		Two groups; 27 matched peers; TD (n=27) and ID (n=27) Aged range 15-18yrs.	Completed Ohio Social Acceptance Scale (Fordyce et al., 1946), which requires the child to rate their classmates on the closeness of their relationship. 	Participants with ID significantly more accepting of their peers than their peers were of them. Participants with ID were not well known by their TD peers. Participants with ID received more negative classroom ratings. TD participants received high acceptance from their peers and the ID participants.	IQ not formally assessed of either group ID identified using administrative definition, e.g. enrolled in special education. No evidence of reliability in ID pop for OSAS. Specific incidents of bullying weren't recorded.	82%
11	Starke (2011). Sweden		11 young adults with an intellectual disability, age range (18-32yrs, mean=23). All had at least one parent with a similar disability.	Semi-structured interviews focusing on: everyday life, relations in the family, informal and formal networks, and experiences of being parented by a parent with a similar disability. 	Two main themes; positive experiences of family life during their upbringing and experiences of being bullied outside the family context. The study also explored the process of how an individual with ID becomes a bully of others. Some participants described experiences of depression linked to low self-esteem.	Vague demographics; due to identifiability in the area they live. IQ not formally assessed, ID identified using administrative definition, e.g. enrolled in special education.	97%
12	Sullivan et al. (2012). USA		74 adolescents with disabilities (age range; 11 to 16yrs, mean age= 13.2, 95% African American, 61% male). 3 groups; LD group (n=53); ID group (n= 11), Emotional and behavioural difficulties group (n=10).	Twelve problem situations were presented to the adolescents in semi-structured interviews e.g. peer victimisation, conflicts with peers and conflict related to schoolwork. Participants were asked how they would respond. Responses were coded to either be aggressive or non-violent responses. Thematic analysis used to highlight key themes. 	Key themes across groups; How participants managed situations linked to individual characteristics e.g. their own prosocial values or positive self-image Peer factors also influenced responses to the problems, e.g. peer models for non-violent responses and reputation with peers. Adolescents with ID said that peer support and their own prosocial values and beliefs related to when they responded in a non-violent way in situations, that responses did not link to peer role models.	Poor generalisability, no clear measurement of ID and not clear exclusion criteria e.g. dual diagnosis.	80%

No	Study	Design	Sample	Method	Key findings	Limitations	Mean QualSyst Rating
13	Sullivan et al. (2015). USA		74 participants (61% male, 95% African American, age range, 11-16yrs, m=13). 3 groups; LD group (n=53); ID group (n=11); Emotional/behaviour dis. group (n=10); and 35 school staff interviewed.	Students completed the Urban Adolescent School and Peer Problem Situation Scale (Farrell et al., 2006), which assessed problem situation in school and peer contexts, ability to cope, internalising and externalising behaviours and self-worth. Qualitative measures included semi-structured interviews with students and focus groups of school staff. 	82% of ID group felt they were encouraged to fight with others by their peers, yet 73% felt able to manage this situation. 64% of ID group felt they had been blamed for other children spreading rumours at least once a year. 73% of ID group felt that each year someone was 'fake' with them, all participants with ID found this difficult to manage. Unable to separate by disability for qualitative responses from students.	No TD group. Cannot separate the groups for qualitative. IQ not formally assessed, ID identified using administrative definition, e.g. education records.	68%
14	Tipton-Fisler et al. (2018). USA		156 adolescents, aged 15yrs. 3 groups; ASD (n=40, 82% male, 55% Caucasian); ID (n=34, 58.8% male, 41.2% Caucasian); TD (n= 82, 47.6% male, 58.5% Caucasian)	Semi-structured interviews separately with adolescents and mothers on bullying. Content analysis used. Child Behaviour Checklist (Achenback & Rescorla, 2001). - Parent version- compared two time points (same sample - aged 13yrs and current study- aged 15). 	Highest rates of bullying in ASD group. ID group reported the most severe bullying. Longitudinal examination revealed that internalising behaviours at age13 predicted victimisation experiences at age 15 across all groups. In general adolescents with ID or ASD had more internalising and behaviour problems.	Themes quantified before sampling was conducted. Therefore, did not reach saturation, but met power calculations for statistical analysis. Some attrition (n=19)	96%

No	Study	Design	Sample	Method	Key findings	Limitations	Mean QualSys Rating
15	Zeedyk et al. (2014). USA		175 adolescents and their mothers participated in the study. All adolescents were aged 13yrs. Three groups; ASD (n= 44, 88.6% male, 56% Caucasian); ID (n= 39, 53.8% male, 46.2% Caucasian); TD (n=92, 47.8% male, 58.7% Caucasian).	Semi-structured interviews separately with adolescents and mothers; adolescents' relationships with friends and peers, adolescents' experiences of victimisation or bullying others. Parent also completed the Child Behaviour Checklist (Achenback & Rescorla, 2001) and the Social Skills Rating System (Gresham & Elliot, 1990). Content analysis used, composite of bullying variables created, and inter-rater reliability ensured. 	ASD group victimised more frequently than ID or TD group. Higher internalising problems and conflict in friendships found to be significant predictors of victimisation, according to both youth- and mother-reports. Parents reported that children with ID experienced the most physical abuse. ID group expressed the highest level of social, emotional and behavioural impact, but did not rate as highly as the ASD group for internalising these experiences. Parents of children with ID reported more conflict in friendships than their children reported.	Internalising measured only from parental perspective.	76%
16	Zic & Igric (2001). Croatia		40 participants, two groups; ID (n=20); TD (n= 20). Age range 7yrs-10.5yrs old.	Participants completed the Behaviour Rating Profile-Croatian version (Brown & Hammill, 1990). Sociometric analysis conducted based on the nomination technique, whereby students asked to rate peers on range of measures, coded as either accepting or rejecting, averages calculated. 	No significant difference between groups on Student Rating Scale. Sociometric results highlight that children with ID were not accepted by their TD classmates. Peers frequently refuse to study, sit together in class or socialise after class with children with ID. Despite rejection, children with ID had average confidence in their own abilities to form relationships with their peers.	IQ not formally assessed, ID identified using administrative definition, e.g. enrolled in special education. Poor generalizability.	89%

Key:

-  IQ not assessed within this study
-  IQ formally assessed for this study
-  Qualitative methodology
-  Mixed methodology
-  Cross-sectional study

Note: ID = Participants with intellectual disabilities; TD= Typical developing participants; ASD= Participants with autism spectrum disorder; LD= Participants with learning disabilities; IQ= Intelligence quotient.

## **The frequency and types of stigma experienced by children and young people with intellectual disabilities**

Eleven studies directly asked children and young people about the frequency with which they experienced stigma, specifically victimisation and bullying. Three of these studies found that adolescents with intellectual disabilities reported being bullied more than their typically developing peers (Christensen et al., 2012; Hatton et al., 2018; Tipton-Fisler et al., 2018). Of the 13 to 17 years old who took part in these three studies, 28-40% of typically developing participants reporting experiencing bullying, compared to 62-80% of adolescents with intellectual disabilities.

Moreover, two studies compared the severity of bullying experienced by typically developing adolescents, adolescents with Autism Spectrum Disorder (ASD), and adolescents with intellectual disabilities, aged 13 to 15 years old (Tipton-Fisler et al., 2018; Zeedyk et al., 2014). They found that children and parents reported that adolescents with intellectual disabilities experienced the most severe levels of bullying across these three groups. In contrast, Christensen et al. (2012) found no difference in the chronicity and severity of bullying between a typically developing group of 13-year-olds and a group of 13-year-olds with intellectual disabilities. However, it is unclear in these three studies whether the disparity in group sizes was controlled for during analysis of the severity and chronicity of bullying.

Two studies examined social acceptance in schools among children with intellectual disabilities compared to their typically developing peers. These studies compared child ratings of their own social status and confidence in their peer relations (Sabornie & Kauffman, 1987; Zic & Igrić, 2001). Both studies found that children with intellectual disabilities perceive themselves to be of a higher social status and more accepted than their typically developing peers rated them to be. Furthermore, Cooney et al. (2006) investigated whether attending mainstream versus special school affects the amount of stigma a child with intellectual disabilities experiences. They found that children in mainstream education reported experiencing significantly more stigma

within the school environment. However, both groups reported experiencing similarly high levels of stigma in their local area. These findings indicate that children and young people face stigma in a multitude of contexts and often struggle to be accepted by their typically developing peers.

A study conducted by Chiu et al. (2017) explored young people with intellectual disabilities' experiences of victimisation in Taiwan. Of the 706 adolescents with intellectual disabilities who participated in their research, 70% reported at least one and 44% reported at least two types of victimisation. Verbal bullying (70%) and social exclusion (50%) were the most commonly reported types.

Cyber-bullying was explored in two studies, with young people with intellectual disabilities reporting high rates of online victimisation (Iglesias et al., 2019; Rose et al., 2015). Online victimisation was reported by 51% of the 91 American young people with intellectual disabilities aged 11-18 years, who participated in a study conducted by Rose et al. (2015). Similarly, Iglesias et al. (2019) reported that 64% of the 45 Spanish 16-year-olds with intellectual disabilities who took part in their research had experienced cyber-bullying. The most common type of cyber-victimisation for those with intellectual disabilities was verbal abuse, for example, insults via text or WhatsApp (Iglesias et al., 2019).

### **The impact of stigma on the mental health of children and young people with intellectual disabilities**

Social exclusion and verbal bullying of children and young people with intellectual disabilities were shown to be significantly associated with psychological distress and mental health difficulties (Chiu et al., 2017; Hatton et al., 2018; Tipton-Fisler et al., 2018). In particular, Hatton et al. (2018) found a strong association between increased risk of mental health difficulties in boys with intellectual disabilities aged 13 to 14 years when they were socially excluded, in comparison to an age-matched typically developing group.



Young people with intellectual disabilities or autism who have been victimised have been shown to experience a higher level of emotional distress and subsequent behavioural problems, on the Child Behaviour Checklist (Achenback & Rescorla, 2001), compared to typically developing young people (Tipton-Fisler et al., 2018; Zeedyk, et al. 2014). However, Zeedyk et al. (2014) found that despite young people with intellectual disabilities reporting the highest levels of negative social, emotional, and behavioural bullying, they were less likely to internalise these than children with autism. Yet, it is important to note that Zeedyk et al.'s (2014) study was rated as of medium quality (76% on the QualSyst), due to the unclear study design and the analysis of data not being clearly described or systematic. Hence their findings should be viewed with caution.

A qualitative study with 11 young adults with intellectual disabilities emphasised the severity of mental health difficulties that young people with intellectual disabilities may experience due to stigma (Starke, 2011). Some of the young adults described experiences of depression and self-destructive behaviour, as well as attempted suicide which the authors linked to low self-esteem due to internalised stigma. This study highlights the consequences that negative experiences of peer contact and exclusion can have on an individual with intellectual disabilities.

### ***Children and young people's reports on the impact of stigma at different ages***

Four studies comparatively examined the impact of stigma on children and young people with intellectual disabilities at different age points (Chiu et al., 2017; Christensen et al., 2012; Hatton et al., 2018; Tipton-Fisler et al., 2018). They reported that victimisation decreased from middle childhood (8/9 years) through early adolescence (13 years) for all children, including children with intellectual disabilities (Christensen et al., 2012). Chiu et al. (2017) reported that 12-13 year olds in their study in Taiwan reported greater levels of verbal bullying and exclusion than 15- 18 year olds. However, Tipton-Fisler et al. (2018) did not find a difference in bullying

reported by children with intellectual disabilities in the USA at age 13 and 15 years. Moreover, they found that for those children who were bullied at both age 13 and 15, the severity of bullying had increased over time.

A cohort study by Hatton et al., (2018) found that children with intellectual disabilities present with mental health difficulties earlier than their typically developing peers, particularly boys aged 13-14 years. However, there was no significant increase in the percentage of children with intellectual disabilities who experienced mental health difficulties between ages 13 to 14 years and 16 to 17 years. In contrast, typically developing children did experience an increase in mental difficulties across these age ranges. Hatton et al. postulated that this finding might be linked to the wording of the GHQ-12 (Goldberg, 1978), which they used to assess mental health difficulties. This measure focused on newly developed mental health difficulties, not chronic and enduring mental health difficulties which may be more present in those children and young people with intellectual disabilities. Moreover, they noted that there is little research investigating the validity of the GHQ-12 with children and young people with intellectual disabilities.

In regard to future aspirations of young people with intellectual disabilities, Cooney et al. (2006) found that children with intellectual disabilities who had attended mainstream school had more ambitious work-related aspirations at age 15 than their peers who attended special schools. They hypothesised that this might be due to institutional stigma, as children who attended special schools were not exposed to the same career opportunities and possible career paths. Yet, both groups felt it equally likely that they would attain their future goals (Cooney et al., 2006). Forte et al. (2011) reported that many young people with intellectual disabilities experienced anxiety and rumination about future victimisation, failing in life and fears around not being able to make friends and keep friends. Typically developing young people did not express anxiety about these aspects of their future. This emphasises the potential long-term impact that stigma can have on individuals with intellectual disabilities' mental health.

## **How children and young people with intellectual disabilities make sense of stigma**

The following themes emerged from studies that explored how children and young people with intellectual disabilities make sense of stigma; parental perspectives versus child/young people's perspectives of stigma, social status, and experiences of being labelling.

### ***Parental perspectives versus child/young people's perspectives of stigma***

Two studies highlighted contrary views between parents and children/young people with intellectual disabilities, about stigma they experience (Christensen et al., 2012; Zeedyk et al., 2014). Parents reported more conflict in their child's friendships than their children reported (Zeedyk et al., 2014). One could hypothesise various reasons for this difference in opinions. For example, parents might be viewing their child as more vulnerable than their peers, or perhaps the child or young person may not be attuned to subtleties of conflicts within their peer relationships (Zeedyk et al., 2014). Similarly, Christensen et al. (2012) found that adolescents with intellectual disabilities reported experiencing more victimisation than their mothers reported, whilst mothers reported higher levels of severity and chronicity of the victimisation than their children. These studies emphasise the need to conduct research with both parents and children/young people with intellectual disabilities, as without exploring potential differences in opinion, there is a risk of drawing conclusions without taking the full picture into account.

### ***Social status and experiences of being labelled***

Four studies explored how children and young people with intellectual disabilities make sense of their social status. Zic and Igrić (2001) found that in mainstream schools, typically developing children frequently refuse to study with, sit next to or socialise after class with their peers with intellectual disabilities, when compared to typically developing peers. In student ratings on the Behaviour Rating Scale (Brown & Hammill, 1990), children with intellectual disabilities rated themselves

as having average confidence in their own abilities and in the success of their relationships with their peers, despite the high frequency of rejection reported by parents and teachers. Moreover, Cooney et al. (2006), found that children with intellectual disabilities rated themselves more positively than a more disabled peer and a typically developing peer, independently of whether they attended a mainstream school or specialist school. Similarly, Sabornie and Kauffman (1987) reported that participants with intellectual disabilities were more accepting of their typically developing peers than their peers were of them. They used the Ohio Social Acceptance Scale (OSAS) to measure social acceptance, yet the test-retest reliability of the OSAS when used with children with intellectual disabilities is not known (Lorber, 1970). The findings of these studies suggest that there is often a disparity between how a young person with intellectual disabilities perceives their social standing and how their peers view them. Zic and Igrić (2001) hypothesised that although in the short-term holding this belief might improve self-esteem, in the long-term there are risks that it could negatively affect children and young people with intellectual disabilities as they may not be as aware of their social status which might result in more experiences of social exclusion and peer rejection.

Chen and Shu (2012) conducted research in Taiwan to gain an understanding of how young people with intellectual disabilities made sense of their experiences of stigmatisation and how they are perceived by others. Fourteen young people with intellectual disabilities, ranging in age from 17 to 22 years, participated in semi-structured interviews. These focused on experiences of stigmatisation in school, how they made sense of such experiences and how they responded to stigmatisation they experienced. The authors noted that due to being given the 'intellectual disability' label, the young people were instantly put in an othered position and experienced stigma from the educational and social welfare systems. This label and its stigmatising effects led to them often perceiving themselves as "not good" students, as "troublemakers", as "sick people", and as "odd people". In particular, participants

commented on how their self-identity was very strongly linked to great value and social status attached to intellectual ability in Taiwanese culture. They described how they became aware of their academic differences very early on, but often felt confused about why they were viewed so differently from their typically developing peers when they shared many things in common.

### **How children/young people with intellectual disabilities manage stigma**

Eight papers examined how children and young people manage stigmatising situations they experience. The following themes which emerged from these studies will be discussed in more detail: avoidance, importance of support systems, self-belief, and being the bully.

#### ***Avoidance***

Avoidance and isolation are highlighted as two coping strategies that young people with intellectual disabilities use to manage stigma in Taiwan (Chen & Shu, 2012). One of their participants said, "I don't like people in the regular classes... students in the regular classes see us, in strange ways, and they laugh at us. I seldom go there. I always stayed in my class during break time."(p. 247). This study emphasised that one of the key behavioural ways that participants reacted to discriminating and stigmatising treatment was to distance themselves. Often this involved socially isolating themselves or hiding their "handicap card", which is used to identify people with intellectual disabilities in Taiwan.

#### ***Importance of support system***

Bennett et al. (2017) conducted qualitative research to explore the 'Teen Dreams' of young people, aged 16 to 21 years, with intellectual disabilities in Canada. Semi-structured interviews focused on how they were able to manage stigma and pursue their dreams, specifically in social relationships, independent work, school life, and community inclusion. The authors noted that as these participants attended special education, they did not describe many situations of experiencing stigma from peers. Additionally, the authors highlighted the importance of young people having a strong

relationship with their parents. Participants described some dependency on parents to enable them to manage stigma and work toward doing more of the things they enjoy. Similarly, Chiu et al. (2017) found a strong correlation between having a strong relationship with parents and peers and lower levels of psychological distress.

### ***Self-belief***

Children and young people with intellectual disabilities can often be viewed as vulnerable, yet it is important to reflect on their strengths, which help them manage stigma they may experience. Sullivan et al. (2012) presented 12 problem scenarios to adolescents with intellectual disabilities in semi-structured interviews and asked them how they would respond, for example, peer victimisation, conflicts with peers, and conflict related to schoolwork. The authors found that adolescents with intellectual disabilities who had positive peer support and who followed their own prosocial values and beliefs were less likely to respond in a non-violent way to stigmatising encounters. This study emphasises that individual characteristics and values that a person holds affect how they respond to stigma. Sullivan et al. (2015) also examined which stigmatising situations adolescents with intellectual disabilities felt able to manage and which they found overwhelming. Seventy-three per cent of participants felt that every year someone was 'fake' with them and would act as a friend but be mean behind their back; all those affected reported finding such situations difficult to manage. Sixty-four per cent felt that they had been blamed for other children spreading rumours about each other, at least once a year, with all finding it hard to manage such situations. These examples stress the importance of asking individuals with intellectual disabilities what types of stigma they feel able to manage and in what situations they may need further support.

However, both studies were found to have some methodological limitations which must be held in mind when examining their findings. Sullivan et al.'s (2015) mixed methods study was rated at 68% on the QualSyst, due to having a small sample size (N=11), and there was no typically developing control group. Additionally, the

qualitative findings could not be included in this review as it was unclear which themes linked to the group of participants with intellectual disabilities. Sullivan et al.'s (2012) study was rated as of higher quality (80%) but nonetheless had some key limitations, including not stating exclusion criteria, so it was unclear if participants had dual diagnoses, for example, autism and intellectual disabilities.

### ***Being the bully***

Two studies commented on the bully-victim dynamic, where those who have been victims of stigma and bullying become perpetrators of bullying (Rose et al., 2015; Starke, 2011). Rose et al. (2015) found that 13% of children and young people with intellectual disabilities in their study identified as bully-victims. However, these findings must be interpreted with caution, as the study only received a QualSyst score of 66%, due to having an unclear study design, not controlling for co-founding variables, and not using measures validated for a population with intellectual disabilities.

Starke (2011) found that young adults with intellectual disabilities who became the perpetrators of bullying did so as a protective strategy, and to earn respect from others around them. These studies highlight the need to explore further and understand some of the negative coping strategies that children and young adults with intellectual disabilities may use to manage stigma they experience.

### **Limitations of the studies**

Five studies screened participants' intelligence quotient (IQ) to ensure they met DSM-IV criteria for intellectual disabilities, namely a full-scale IQ below 70 in combination with deficits in functional and adaptive skills, both of early-onset (Christensen et al. 2012; Cooney et al. 2006; Forte et al. 2011; Tipton-Fisler et al. 2018; Zeedyk et al. 2014). Of these, four studies screened IQ with the WISC-IV, and one study (Cooney et al., 2006) used the British Picture Vocabulary Scale-Revised, which has been found to be a valid measure to assess IQ with people with intellectual disabilities (Morgan et al., 1997). The remaining 11 studies did not formally assess

participants' functioning and instead used administrative definitions, for example, attendance at special school. It is important to note that one study required participants to complete questionnaires independently without offering support from researchers. This resulted in only participants with higher IQ being able to participate, therefore reducing the ability to generalise their findings to young people with more severe intellectual disabilities (Chiu et al., 2017).

One key limitation of the majority of the studies was a failure to consider the impact that ethnicity and socio-economic status may have on the young people's experiences of stigma. In general, the studies reported that participants with intellectual disabilities often came from less affluent backgrounds (Cooney et al., 2006; Zeedyk et al., 2014). Furthermore, in studies with more than one group, the group of participants with intellectual disabilities had a larger number of participants who identified as belonging to ethnic minorities (Christensen et al., 2012; Sullivan et al., 2015; Tipton-Fisler et al., 2018). Future research should examine the role of socio-economic background and ethnicity when exploring how and why individuals with intellectual disabilities experience stigma, as one cannot rule out that individuals may have also experienced stigma due to other stigmatised attributes.

## **Discussion**

### **Summary of findings**

This systematic review summarises the main findings from primary research on the experiences of stigma among children and young people with intellectual disabilities. Most of the studies included in the review were small qualitative studies, medium scale descriptive cross-sectional studies, or mixed methods studies, which often had unrepresentative samples. In addition, only two studies were conducted in non-Western countries. The majority of the studies explored how different types of stigma affect children and young people with intellectual disabilities. The findings indicate the value of exploring how stigma impacts children and young people with



intellectual disabilities from their perspective, including in relation to cyber-bullying, social exclusion and the effects of stigma on mental health.

Eleven studies confirmed findings from previous research with parents of children with intellectual disabilities, that children and young people with intellectual disabilities experience high levels of stigma. Four studies found that they are more likely to be bullied and excluded than both typically developing peers, and young people with autism (Christensen et al., 2012; Hatton et al., 2018; Tipton-Fisler et al., 2018; Zeedyk, et al. 2014). However, Christensen et al. (2012) found no difference in the chronicity and severity of bullying between a typically developing group of 13-year-olds and an age matched group with intellectual disabilities.

The impact of stigma on mental health was explored in five studies (Chiu et al., 2017; Hatton et al., 2018; Starke, 2011; Tipton-Fisler et al., 2018; Zeedyk et al. 2014). These studies highlight how much psychological distress children and young people with intellectual disabilities can experience due to being stigmatised, particularly due to social exclusion (Chiu et al., 2017; Hatton et al., 2018; Tipton-Fisler et al., 2018). Interestingly, two studies found that victimisation decreased as children with intellectual disabilities approached adolescence (Chiu et al., 2017; Christensen et al., 2012). But this was contradicted by Tipton-Fisler et al. (2018), who found that the frequency of bullying remained stable between 13 and 15 years of age. Moreover, Hatton et al., (2018) noted that children and young people with intellectual disabilities' experiences of mental health difficulties remained high but stable over time.

The discrepancies in these findings raise further questions about the frequency of stigma and its impact on the mental health of children and young people with intellectual disabilities. One could hypothesise that verbal and physical bullying may reduce over time, yet other types of more subtle victimisation may increase, for example, cyberbullying, which may result in a continuous negative impact on mental health. This pattern has been found in typically developing children and young people (Due et al., 2005; Gámez-Guadix et al., 2015; Seals & Young, 2003; Smith et al.,

1999). That is, younger children have not yet acquired the skills to deal effectively with bullying incidents, therefore verbal and physical bullying only begins to reduce in adolescence. However, by adolescence, many have access to technology, resulting in an increase in cyberbullying, which is less easily monitored by adults. This finding highlights the potential for continual experiences of bullying in adolescence and the subsequent effect on adolescents' mental health. The changes in the type of bullying experienced over time was not assessed in the studies examined in this review. This highlights the need for more detailed longitudinal research of the frequency and type of victimisation experienced by children and young people with intellectual disabilities and how they affect mental health.

This review found some clear gaps in the literature; very little research to date has looked at how children and young people make sense of stigma they experience, or compared parents' and young people's perspectives of stigma, social status and labelling. The review highlights the importance of hearing from young people and children themselves, particularly as two studies noted a discrepancy between parents' and their children's views of stigma (Christensen et al., 2012; Zeedyk et al., 2014). This finding mirrors King et al.'s (2018) results; they found discrepancies in the accounts of parents, teachers, and adolescents with a range of disabilities, particularly in the reported frequency and impact of bullying on adolescents.

Three studies also noted a disparity between how young people and children with intellectual disabilities perceive their social standing and how their peers view them. Only one study in Taiwan focused on how young people make sense of and experience being given the diagnosis of intellectual disabilities and how it can link to stigma (Chen & Shu, 2012). Positive support from family and friends was described by children and young people with intellectual disabilities as helping them cope with stigma (Bennett et al., 2017; Chiu et al., 2017). Furthermore, personal values and self-belief were shown to be key factors in helping children and young people with intellectual disabilities manage stigma in the moment (Sullivan et al., 2012, 2015).

Similarly, to Logeswaran et al's (2019) findings, this review can hypothesise that children and young people with intellectual disabilities may go on to develop a positive self-identity if they have positive relationships with family and friends, have self-belief and stand by their own personal values. These findings stress the importance of asking children and young people with intellectual disabilities themselves what resources and strategies that they already use to manage stigma and what they believe will help them feel empowered to overcome and resist stigma. Two potentially negative coping strategies also came to light in this review: avoidance and becoming a perpetrator of bullying (Chen & Shu, 2012; Rose et al., 2015; Starke, 2011). These two strategies to managing stigma have potential costs for an individual's wellbeing, for example, further social isolation, and negative peer interactions. More research is needed to explore what the potential implications may be for children and young people with intellectual disabilities who use these more negative coping strategies, to ensure that appropriate support and advice can be given.

### **Limitations**

This review has several limitations. Firstly, it did not include studies that were not in English, conference reports or proceedings, or grey literature such as dissertations. Secondly, the review included studies that had not formally assessed intellectual disabilities, as well as including some studies without clear exclusion criteria. Studies were included where participants may have had a dual diagnosis, for example, autism and intellectual disabilities. By including these studies, the conclusions which can be drawn are more ambiguous, as it is unclear which experiences of stigma are pertinent to those with a diagnosis of intellectual disability, in comparison to individuals with co-morbid diagnoses. Moreover, some of the studies included did not control for socio-demographic factors or consider the role of ethnicity and intersectionality when drawing conclusions. It can be assumed that such factors may have an impact on how children and young people with intellectual disabilities experience stigma, and unfortunately this has not been explored nor represented in

this review. Finally, this review analysed and drew conclusions on 16 studies with very different methodologies; qualitative (4), mixed-methods (4) and cross-sectional (8), combining these types of study designs may have impacted the validity of the conclusions that can be drawn. However, due to the limited research in this field, it was deemed that the 16 studies could be reviewed together, as they offer rich and interesting findings which contribute to a more detailed understanding of children and young people with learning disabilities experience of stigma. Yet, it is important to hold in mind the variability in the studies designs and regard the conclusions drawn as tentative and a guide to highlight areas for future research.

### **Potential areas for further research**

Research has begun to explore the first-hand experiences of children and young people with intellectual disabilities. Although some research has been conducted into the impact of stigma on this population, there is a need for more longitudinal research into the frequency of stigma, types of stigma and how this impacts mental health across time. Additionally, only one study explored the difference in experiences of stigma depending on whether the child or young person with intellectual disabilities attended a mainstream or special school. This study by Cooney et al. (2006) found that children with intellectual disabilities in mainstream education reported experiencing significantly more stigma at school than those who attended a special school. Yet, more research is needed to assess the relationship between frequency, severity and chronicity of bullying in mainstream versus special school. For example, it would be helpful to compare across different populations, such as children with autism attending mainstream or special school.

Further research is also required to look into how children and young people make sense of and manage the stigma they experience. Very little is known about how they understand their additional needs and how these are viewed by others. Moreover, research is needed to understand how children and young people respond to stigma in the moment. In particular, research should examine the potential

implications for children and young people with intellectual disabilities who use negative coping strategies, for example, avoidance and becoming perpetrators of bullying. It is important for future studies to ensure that they hold in mind the impact of ethnicity and socio-economic status, as the majority of studies included in this review did not adequately reflect on the potential intersectionality of stigma experiences.

### **Clinical Implications**

The findings from this review highlight key clinical implications for local and national services, charities, and government authorities to consider when planning and implementing support and interventions for children and young people with intellectual disabilities. This review notes that children and young people with intellectual disabilities experience stigma and subsequent mental health difficulties; therefore it is imperative that they have access to specialist psychological support (Chiu et al., 2017; Hatton et al., 2018; Starke, 2011; Tipton-Fisler et al., 2018; Zeedyk et al. 2014). Moreover, children and young people with ID may be experiencing mental health difficulties at an earlier age than typically developing peers due to the stigma they experience (Hatton et al., 2018). In light of this, mental health services, charities, schools, local authorities, and families, would benefit from psychoeducation around noticing signs of mental health difficulties in children and young people with intellectual disabilities, including being aware of potential negative coping strategies, for example, avoidance and “being the bully” (Chen & Shu, 2012; Rose et al., 2015; Starke, 2011). Interventions may benefit from promoting the positive coping strategies identified in this review such as developing strong support networks and fostering self-belief (Bennett et al., 2017; Chiu et al., 2017, Sullivan et al., 2012, 2015). There is also the potential for national policy to consider how to reduce the stigma of children and young people with intellectual disability, for example; national school education programmes around difference, neurodiversity and inclusivity. Finally, it is also important for services to ensure that they hear from not only parents of children with

intellectual disability but also from the children and young people themselves, as this review and King et al.'s (2018) review, highlight that parents and children can offer have differing views on the frequency and severity of stigma and its impact on their mental health (Christensen et al., 2012; Zeedyk et al., 2014).

## **Conclusion**

Stigma affects children and young people with intellectual disabilities in various ways. Most of the research conducted in this area has focused on the perspectives of parents. Further research is required to gain a more detailed understanding of how children and young people with intellectual disabilities make sense of and manage different types of stigma over time. The studies reviewed emphasise that children and young people with intellectual disabilities have a voice and a valuable perspective that needs to be heard.

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## **Part 2: Empirical Paper**

Exploring Experiences of Stigma in Parents of Children with Autism

## **Abstract**

### **Aims**

This study aimed to develop a theoretical model to understand how parents of children with autism manage and respond to stigma they may experience.

### **Method**

Twelve parents of children with a diagnosis of autism, aged 10 and under, completed semi-structured interviews about their experiences of stigma and how they respond to stigmatising encounters. A constructivist grounded theory approach was taken to examine parents' narratives and develop theoretical codes.

### **Results**

A theoretical model is proposed to understand how parents of children with autism manage and respond to stigma. Two variables are highlighted in this model - parents' responses were dependent on who the stigmatiser was and who was being stigmatised. Four core responses to stigma were identified: 'actively ignoring,' 'actively withdrawing,' 'avoiding' and 'challenging.' Parents' narratives illustrated the context those responses would be used in.

### **Conclusions**

Whilst the results show the on-going challenges that parents of children with autism face, they also illustrate the skills and resilience such parents have often developed to manage stigma.

## Introduction

Individuals with autism spectrum disorder (also referred to as ASD or autism) and their families experience stigma, prejudice, and discrimination in their everyday lives (Mazumder & Thompson-Hodgetts, 2019; Mitter et al., 2018, 2019). Stigma was defined by Goffman (1963) as the process whereby an individual who possesses an attribute that is seen as deeply discrediting is viewed by society as “tainted and discounted” (p. 3). Link and Phelan (2001) built upon this definition, noting that the individual is identified and labelled by society as ‘different’ and as possessing an undesirable attribute. If these differences occur in a group of individuals, then a stereotype is developed, then they are viewed as a stereotyped group by wider society. Discrimination and prejudice may then be enacted due to imbalances in power or social status between stigmatised groups and the wider population (Corrigan, 2000; Scior & Werner, 2016). Individuals can be stigmatised based on attributes such as mental health difficulties, ethnicity, drug use, physical disability, intellectual disability or atypical neurodevelopment (Corrigan, 2000; Goffman, 1963; Link & Phelan, 2001; Scior & Werner, 2016).

Four different types of stigma have been identified in the literature: ‘public stigma’ is conceptualised as the general attitudes held by society towards a stigmatised individual. Whilst ‘institutional stigma’ relates to how attitudes within society are reflected in legislation and public policy reducing the rights and choices of a person who is stigmatised (Bos et al., 2013; Link & Phelan, 2001). The concept of ‘self-stigma’ focuses on how a stigmatised person becomes aware of, endorses and internalises public and institutional stigma (Bos et al., 2013; Mitter et al., 2018). Yet, it is important to hold in mind that stigmatisation does not only affect the individual who possesses a discredited attribute but also those who the stigmatised person associates with, for example, family members or friends (Goffman, 1963; Manago et

al., 2017). The term 'family stigma', also called 'courtesy stigma' or 'associative stigma', refers to how family members and others that associate with an individual who is stigmatised can, in turn, be stigmatised by proxy (Corrigan et al., 2006; Goffman, 1963; Mehta & Farina, 1998). Related to this is the construct of 'affiliate stigma', which refers to instances when stigmatising attitudes and beliefs are internalised by a stigmatised individual's associates (Mak & Kwok, 2010; Mitter et al., 2018; Werner & Shulman, 2013).

Children and young people with autism spectrum disorder may experience a range of presenting difficulties often characterised by deficits in social development and communication, as well as repetitive and restricted behaviours (American Psychiatric Association, 2013). These difficulties in development often result in children and young people with autism experiencing stigma and victimisation (Sreckovic et al., 2014; Zeedyk et al., 2014). Prevalence studies estimate that approximately 44% of children and young people with autism experience victimisation during their school life (Falla & Ortega-Ruiz, 2019; Maiano et al. 2016; Schroeder et al. 2014; Sreckovic et al., 2014). Mazumder and Thompson-Hodgetts (2019) conducted a scoping study to examine the existing literature related to the stigmatisation experienced by children and adolescents with autism and their families. They noted that the invisible nature of autism can create further stigma due to public misconceptions and stereotyped portrayals of autism, and that individuals with autism and their families on occasion internalise stigmatising views.

Parents of children with autism often experience associative stigma due to societal views that deem parents responsible for their child's difficulties, particularly 'challenging behaviour' (Blum, 2015; Davis & Manago, 2016; Gray, 2002, 2006; Green, 2003; Manago et al., 2017; Ryan, 2010). Recent research has started to explore the impact that affiliate stigma can have on parents of children with autism (Mak & Kwok, 2010; Papadopoulos et al., 2019; Saini et al., 2015; Werner & Shulman, 2015). A systematic review by Mitter et al. (2019) focused on stigma experienced by



the families of individuals with autism, as well as intellectual disabilities. They concluded that most family caregivers experienced associative and affiliate stigma, but the extent and form in which these manifest can vary across cultures. Moreover, this review noted that family members report being marginalised by not only their own families and communities, but also by professionals.

Mitter et al. (2018) suggest that there may be three aspects that contribute to affiliate stigma among family members of individuals with autism. Firstly, a family member may experience the cognitive aspects of affiliate stigma, such as having thoughts that they themselves are somehow to blame for their child's difficulties. Secondly, they may experience negative emotions associated with experiences of stigma, defined as the affective dimension of affiliate stigma. Lastly, this can result in them engaging in the behavioural dimension of affiliate stigma, such as actively avoiding social situations in which they may be confronted with others' negative attitudes.

The concept of 'stigma resistance' has emerged relatively recently (Emler et al., 2004, Thoits, 2011). The latter author suggests that stigma resistance can take two forms: 'deflecting' or 'challenging'. 'Deflecting' of stigma is defined as cognitively separating from the experience of the self and the stigmatising label, while ultimately maintaining stigmatising beliefs (Thoits, 2011). Stigma 'challenging' is defined as the individual actively confronting stigmatising individuals and institutions (Thoits, 2011). Both methods are resistant to the stigmatising experience but vary in the level that they disrupt social interactions. Firmin et al. (2017) explored Thoits' definition of stigma resistance with individuals who experience mental health difficulties. They found that participants tended to use 'challenging' or 'deflection' depending on whether the stigmatisation occurred at a 'person-level' (e.g. self-stigma), 'peer-level' or at a 'public-level'. Furthermore, they noted that in contrast to Thoits' model, which presents deflection as a primarily cognitive response, participants in their research described stigma resistance at the personal level that involved additional responses,

such as education and taking steps to develop a more meaningful sense of identity and purpose. Furthermore, the majority of their participants did not agree with the term 'deflection', as they felt it had connotations of passivity to stigma. Instead, they described acts of resisting stigma at three different levels of experience: the personal, public and peer level. Patterns of successful stigma resistance in their study were linked to a strong sense of identity, empowerment and acceptance that stigma resistance is an on-going process.

Stigma resistance in parents of children with autism has only just begun to be researched (Farrugia, 2009). Harandi and Fischbach (2016) explored how parents of children with autism responded to stigma directed towards their child from the general public. Their descriptive analysis of 502 structured surveys conducted with parents of children with autism revealed that they used five different responses to strangers stigmatising their child: 'active response', including educating the stigmatiser or telling them they had been offended; 'passive response', including ignoring the stigmatisers or avoiding situations where they could anticipate stigma; 'support-seeking' where parents turned to others for support; 'preparing their child'- including preparing their child with distractions before facing situations in which stigma could be anticipated; 'reducing stress', including parents seeking to reduce personal stress after experiencing stigma.

This study also found that neither the frequency of the child's autism-associated behaviours nor the specific stigmatising words used by strangers affected parental responses. However, due to the uneven proportion of parents using the same responses, the researchers could only conduct analysis on the differences between the most frequently used responses: 'active response strategies' or 'passive response strategies'.

They found that parents using 'passive response strategies' expressed high levels of caregiver burden in raising a child with autism, and spoke about experiencing more difficulties managing stigma, in comparison to parents who used 'active

response strategies'. They proposed that this linked to parents who used 'active response strategies' presenting as more accommodating of their child's behaviours and proactively educating stigmatisers.

Harandi and Fischbach's (2016) study has highlighted the importance of exploring in more detail how parents respond to stigma in the moment. However, they did not explore how parents managed and resisted stigma from other people located within different social systems in the children's and parents' lives, for example, family, friends and the child's school. Moreover, they did not focus on associative stigma or affiliate stigma that parents themselves experience, which has been found to have long-term negative consequences for parental wellbeing (Papadopoulos et al., 2019). Harandi and Fischbach's (2016) study highlights a gap in the literature and a need to further explore stigmatising experiences of parents of children with autism.

Manago et al. (2017) explored how parents of children with a range of disabilities, used Thoits' responses of 'deflection' and 'challenging' in relation to either holding a medical or a social narrative around their child's disability. They found that challenging and deflecting did not map clearly onto either a social or medical narrative. Instead, they found that parents used these responses in diverse ways, sometimes using a medical label to challenge stigma, and at other times recognising disabling social structures, whilst still deflecting stigma.

In light of the research conducted by Manago et al. (2017), Firmin et al. (2017) and Harandi and Fischbach (2016), the present study set out to explore how parents of children with autism manage and respond to stigma from different social systems, and how they engage in different ways of stigma resistance. In this endeavour, both Thoits' and Firmin et al.'s models of stigma resistance were held in mind and drawn on in developing a model to understand parents' experiences and actions. The study sought to explore the question: how do parents of children with autism respond to and manage the stigma that they experience? By exploring this question, it was hoped that a deeper understanding of stigma resistance would be developed and help

promote and inform interventions to build stigma resistance among parents of youngsters with stigmatised attributes or conditions.

## **Methods**

### **Design**

A qualitative approach was chosen to allow for a deep level of exploration of parents' experiences of and responses to stigma. Grounded theory was chosen as it offers a bottom-up inductive approach to understanding and developing theory, particularly around abstract theoretical explanations of social processes (Glaser & Strauss, 1967). This approach encourages iterative strategies of going back and forth between data and analysis, ensuring that researchers continue to actively review their data before settling on an emergent interpretive theory (Charmaz, 2014; Glaser & Strauss, 1967). However, critics have argued that grounded theory as originally conceived did not consider sufficiently that both the researcher and participant bring their own constructs of the world to research encounters, and that these influence the theoretical conclusions that can be drawn (Clarke, 2007; Seale, 1999). Charmaz (2000) sought to do justice to a constructivist view of research in developing 'constructivist grounded theory.' This approach emphasises the importance of acknowledging the researcher's context, as it is through the position of the researcher that categories and theoretical conclusions are arrived at. Therefore, the researcher's values, priorities, and actions affect the material and findings presented.

The decision to adopt a constructivist ground theory approach was based on the view that stigma is a social and cultural construct. This approach enabled a deep exploration of individuals' experiences and actions in relation to stigma, while paying attention to the influence of underlying social and cultural processes and constructs. Constructivist grounded theory encourages data comparison both within individual participants' accounts but also across participants (Charmaz, 2014). In the present study, adopting this comparative method encouraged reflection on differences and

similarities between different parents' responses to stigma and the influence of contextual factors.

One key aspect of constructivist grounded theory is symbolic interactionism (Charmaz, 2014). Symbolic interactionism is the view that interpretation and actions are a reciprocal process in which the shared meaning of language and actions play a central role in developing a shared understanding (Blumer, 1969). The researcher's position of what stigma is, what autism is, what parenthood is like, were explored and revisited throughout the research. Moreover, to develop a shared language with participants, the researcher asked them about their own interpretation of the word "stigma" and what terminology they use to describe their child's diagnosis of autism prior to beginning the interview. Charmaz (2014) highlighted the need to wrestle with preconceptions, particularly when analysing data encouraging reflexivity throughout the research.

### ***Researcher's position and reflections***

I approached and conducted this research from the perspective of a 27-year-old, middle class, white British female. I am not a parent and do not have any family member with autism. I have a specific learning disability and have experienced stigma at various points in my life. Due to my own personal journey in resisting stigma, I was aware of the challenges this may entail. My journey into clinical psychology began when I worked as a carer in a day centre for young adults with learning disabilities and autism. I noticed throughout my work with the young adults and their families how frequently they experienced stigma in various ways within their local community. I also saw how resilient the young people and their families were and how they often stood up to those that were stigmatising them, including organisations and wider social systems. Whilst conducting this research, I was a trainee clinical psychologist working in a range of clinical settings. Notably, I completed a year long placement in a Child and Adolescent Mental Health team for children and young people with learning

disabilities, where conversations around stigma and autism were often part of my clinical work. I did not have any prior contact with any of the participants of the study.

It is important to acknowledge that I hold a social constructivist epistemological position. I hold the belief that humans are neurodiverse, and society should be working towards inclusivity and acceptance of all. However, I believe the current society holds fixed negative beliefs around difference, and society continues to categorise and group individuals. I feel this, in turn, leads to in-group bias and leads to a context which fosters stigmatisation and discrimination. I personally advocate for society to become more inclusive, and I aim to challenge stigma particularly around disability both in my clinical work as a trainee clinical psychologist but also as a research in the field of stigma.

In light of my strong personal views, I found it particularly helpful to work within a constructivist grounded theory framework. Furthermore, I used the strategies shared by Charmaz (2014) and Reinharz, (1997) to help reveal my preconceptions and which facets of my identity may be interacting with the research process. Charmaz (2014) suggests reviewing ones' position throughout the design, procedure and analysis of qualitative research. Therefore, I asked myself the following questions throughout the research and used a reflective diary to take stock and notice any bias I held. I ensured to consider and address how this may impact the research process and my findings:

- What are my preconceptions?
- How does a code I assign to the data reflect the incident or described experience?
- Do my analytic constructions begin from this point?
- Have I created clear, evident connections between the data and my codes?
- Have I guarded against rewriting and recasting?

I also consulted experts by experience, namely three mothers of children with autism within the target age group, to ensure a broader range of positions, values,

actions, and priorities were held in mind throughout the research process. This is explored further in Part 3: The Critical Appraisal.

### **Ethical considerations**

Ethical approval was obtained from the UCL Departmental Ethics Committee (Ref: CEHP/2016/551). The study was registered with the data protection team (Ref: Z6364106/2019/04/06). Additionally, due to the interviews focusing on experiences of stigma, the researcher held in mind that the interviews might evoke strong emotions in participants. Therefore, informed consent and confidentiality were explained to participants both verbally and in written format (Appendix 2 & 3). Participants were told that they could pause or end the interview at any point without consequence. Support and reassurance were given to parents in the moment if they became distressed. Four participants became upset during the interviews; in these instances reassurance was offered and the interviews were paused for a few minutes. These participants were asked at the end of the interview if they felt they needed any additional support - all declined. All participants were signposted to support groups and local services following the interview, by providing an information sheet listing support services for parents with autism and/or other disabilities within their local area.

### **Consultation with experts by experience**

During the design stage of this study, the researcher advertised via local charities and online platforms to seek consultation from experts by experience on the research project. Three mothers of children with autism and/or learning disabilities responded to this advertisement and volunteered to consult on the study. Through group meetings, they contributed to the study design and methods by helping to develop the information sheets, consent forms, advertisement, semi-structured interview schedule, and recruitment ideas. They also proposed sharing information and lists of local services with participants to help parents connect with each other and support services. Additionally, following an initial phase of data collection, transcription, and initial analysis, the initial codes and memos were discussed with

this consultation group. This led to two additional questions being added to the semi-structured interview.

### **Recruitment procedure**

Participants were recruited through charities and carers groups. Social media and research platforms were also utilised to advertise the project and aid recruitment. Twenty-five parents contacted the researcher about the study. Of these, 17 parents met the inclusion criteria; however, only 12 parents went on to participate in the research. This study had two inclusion criteria: firstly, the child must have a formal diagnosis of autism spectrum disorder and must be at least one-year post-diagnosis. Immediately after a child is given a diagnosis, families are often still engaged with meeting their child's practical needs as well as developing their own narrative and understanding of their experiences. Crane et al. (2016) examined 1000 parents' experiences of their child receiving a diagnosis of autism and reported that 56% found the process very stressful. This highlights that even without any complications, this process is often very challenging for parents. Hence by holding this inclusion criterion, it was hoped that parents participating would feel able to reflect on their experiences without still being in the immediate process of trying to find answers. Secondly, the child with autism had to be aged ten years or under. This decision was made to narrow the focus of the study to a period of high parental involvement, prior to children reaching adolescence and potential increased independence upon moving to secondary school.

### **Participants**

Twelve parents of children with a formal diagnosis of autism (11 mothers and one father) took part in the study. The mean age of their children with a diagnosis of autism was 8 years 2 months, and 83% were boys. Although there is a clear gender disparity in this sample of children, it is representative of the wider population of children with autism. Cohort studies highlight within this age range there is a ratio of 5.5 male:1 female who receive a diagnosis of autism (Rutherford et al., 2016). Three



parents had more than one child with a diagnosis of autism; of these, two parents had more than one child who met the inclusion criteria. Cohort studies have highlighted that there is a high familial risk of autism, with sibling recurrence rates estimated to range from 6.1% to 18.7%, indicating that the present sample was broadly representative of the wider population (Grønberg et al., 2013; Palmer et al., 2017). Diagnoses were received on average 3 years 7 months prior to recruitment to the study, with the children's mean age at time of diagnosis 4 years and 4 months. Table 1 presents further demographic information about the participants.

Table 1. Participant demographics

Participant No.	Age range (yrs)	Parent's religion	Parent's ethnicity	No. of children with autism diagnosis	No. of children meeting inclusion criteria	Child's gender (F/M)	Child's age (yrs)	Child's ethnicity	Age at autism diagnosis (yrs)	Other diagnoses
1	31-40	Christian	White British	1	1	M	9	White British	7	ADHD, Anxiety Disorder
2	41-50	No religion	White British	1	1	M	10	White British	6	ADHD
3	41-50	Atheist	White British	1	1	M	5	Mixed - Asian and White	2	Speech delay
4	31-40	Christian	White British	1	1	M	10	White British	7	None
5	41-50	Muslim	Asian British-Pakistani	3	1	F	6	Asian British-Pakistani	5	Specific Learning Difficulties and *
6**	51-65	Christian	Mixed-other	2	2	M/M	8/ 8	Mixed-other	4 /7	*/ Cerebral Palsy and *
7	41-50	No religion	White British	1	1	M	10	White British	4	None
8**	21-30	Muslim	British Moroccan	2	2	F/F	5/9	Mixed-Moroccan/ Caribbean	3/8	Hearing Impairment/ None
9	31-40	No religion	White British	1	1	M	7	White British	3	Genetic condition

10	41-50	No religion	White British	1	1	M	10	White British	4	Language processing disorder
11	31-40	No religion	Chinese	1	1	M	8	Mixed-Asian/White	5	None
12	31-40	Christian	White British	1	1	M	10	White British	3	None

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\*Sensory Processing Difficulties

\*\*Parent with two children who meet inclusion criteria

## **Theoretical sampling and saturation**

Theoretical sampling is an abductive, specific, and systematic approach in developing theoretical categories and concepts (Charmaz, 2014). It involves starting with initial data, constructing tentative ideas about the data, then examining these ideas through further inquiry. Theoretical sampling can be particularly helpful if early data and codes raise more questions. Within this study at the initial stage four participants were interviewed. These interviews were transcribed, and initial coding was conducted. Then initial codes and memos were shared with the experts by experience and decisions made about the next steps in theoretical sampling. Following discussions, two additional questions were added to the semi-structured interview;

1. "Would you describe yourself as being part of a community, perhaps a cultural community or religious community?" If yes, follow-up questions:
  - a) "Within that community how have people responded to "X's" diagnosis and difficulties?"
  - b) "What do you think their understanding of "X's" diagnosis and difficulties are?"
  - c) "Can you give me an example? Have people's responses changed over time?"
2. "Have you experienced any situations with a co-primary carer (e.g. other parent of the child) where you have both feel stigmatised?" If yes, follow-up questions:
  - a) "How did you both react in this situation?"
  - b) "Is this normally how you both would react?"

Within a constructive grounded theory framework, saturation is viewed as the point at which "gathering fresh data no longer sparks new theoretical insights, nor reveals new properties of the core theoretical categories" (Charmaz, 2014, p.213). Moreover, Bowen (2008) notes that this sampling strategy is less focused on generalisability or

sample size, and instead focuses on sampling adequacy and richness of the data. This guidance was held in mind when recruiting, as well as the need to meet the requirements and time-constraints of completing this research as a DClinPsy thesis. This led to the researcher initially aiming to recruit for 10-12 participants. Following the interviews and analysis, it was felt that data collected from 12 parents were rich and detailed enough to construct an initial theory.

### **Procedure**

Semi-structured interviews were conducted with parents in a private room at University College London, private rooms at a London based charity, or via Skype. The interviewer checked participants' understanding of the information sheet (Appendix 2), gained informed consent (Appendix 3), and explained the process of confidentiality, data protection, and the participant's right to stop or pause the interview without any consequences. All participants were given the option of receiving a £10 gift voucher to thank them for their time, or to donate £10 to a charity of their choice before the interview began. Participants then completed a pre-interview questionnaire to collect demographic information about themselves and their child/children with a diagnosis of autism (Appendix 4). The interviews lasted between 55 and 96 minutes.

The semi-structured interview schedule was co-created with the experts by experience (Appendix 5). Open-ended questions were used to encourage unanticipated statements and stories to emerge; follow-up questions were used to gain greater clarity.

### **Data Analysis**

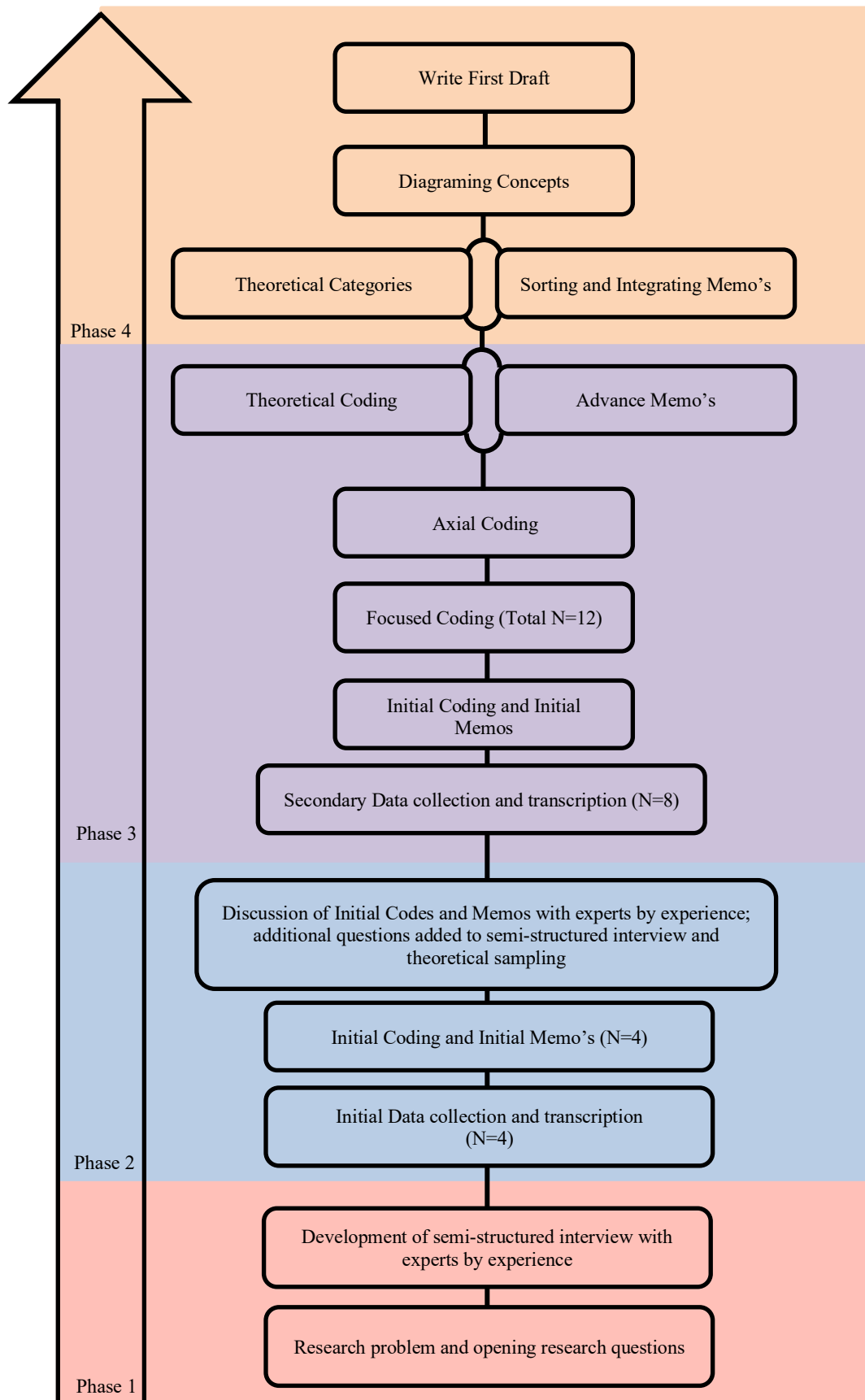
All interviews were recorded and transcribed. Transcription was completed by the researcher with the assistance of the transcription software Trint, followed by the researcher carefully checking each transcript prior to analysis. In keeping with a constructivist grounded theory approach, the analysis was conducted as outlined by Charmaz (2014). Figure 1. details the key phases of analysis performed in this study,

including the four stages of coding: initial coding, axial coding, focused coding, and theoretical coding.

Initial coding involved a line-by-line analysis of the data, specifically coding for actions, using gerunds. Gerunds are a heuristic device that ensures the researcher is focused on what is happening in the data, with the aim of reducing researchers' tendencies to add meaning to another's actions (Charmaz, 2014; Glaser, 1978). Focused coding was then used to develop the most salient initial codes, which categorise the data in an analytic way. During the process of focused coding, the researcher must be sure to examine how their own position may influence the way they see the data. Axial coding was conducted to re-establish context to the codes and give coherence to the analysis. Strauss and Corbin (1998) noted that this means reassigning codes to the 'when, where, why, who, how and with what consequences' actions occurred in.

Theoretical coding is the final stage of coding, where the researcher asks, "how do the substantive codes relate to each other as hypotheses to be integrated into theory" (p.72, Glaser 1978). The researcher must hold in mind their own preconceptions and their positions when drawing codes together. Memo-writing is a key aspect of developing and refining categories. Memos were kept throughout the analysis process and offered a train of thought which could be traced back through the data. Memos allow for comparison within data and highlight where categories and subcategories may fit together. An extract of analysis, including memos written, is presented in Appendix 6 (pseudonym used for this example extract). Additionally, at each stage of coding, one of the transcriptions was cross coded by a second independent researcher to ensure agreement, continuity, and reliability in the coding.

**Figure 1. Phases of Analysis**



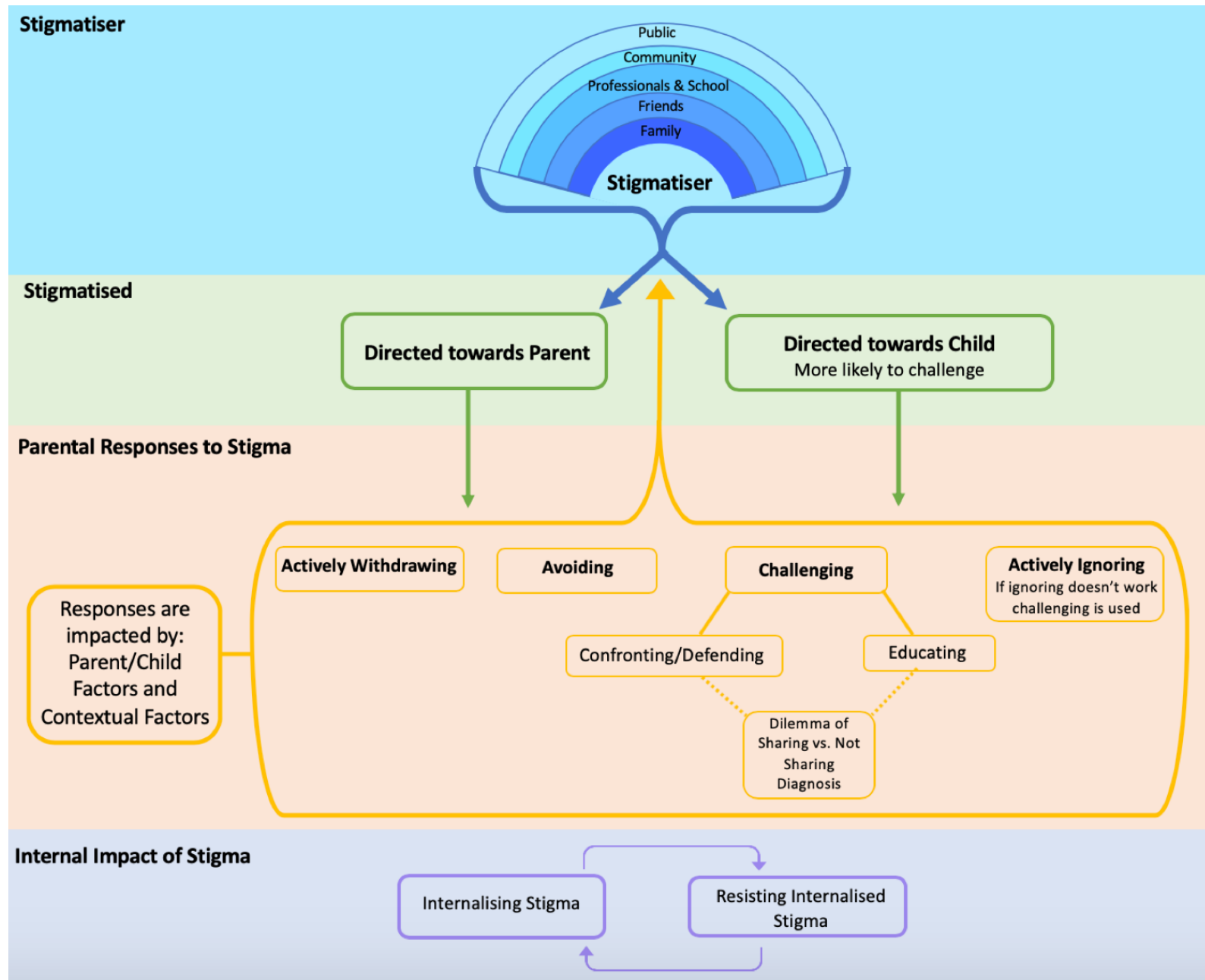
## Results

### Model Summary

Parents described the complex interplay between individuals who stigmatise them and their child with autism. The following section presents a theoretical model to understand how they respond to and manage the stigma they experience. A diagrammatic representation of the overall theory is presented in Figure 2. This model presents the four main responses parents in this study used to manage stigmatising interactions: 'avoiding', 'actively withdrawing', 'challenging' and 'actively ignoring'. Parents spoke about two aspects which influence how they respond to stigma: first, who the stigmatiser is, i.e. the source of stigma, and, secondly, who the stigma is directed towards, i.e. the stigmatised individual. Additionally, parents described internal processes involved in resisting stigma at a personal level. They also cited a range of contextual factors and parent/child factors which additionally contributed to their responses to stigma.



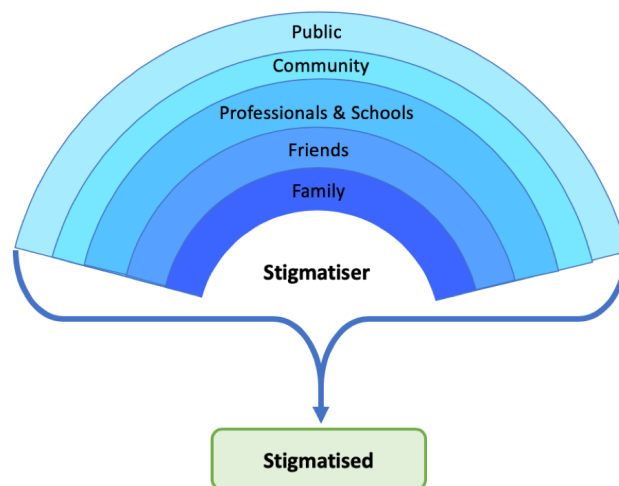
**Figure 2.**  
*A model to portray responses to stigma of parents of children with autism*



### **The Stigmatiser**

Parents' narratives showed that they experienced stigma from individuals within five different social systems, shown in Figure 3. Bronfenbrenner's Ecological Systems theory was used to understand the dynamic between parents and those stigmatising them (Bronfenbrenner, 1979). How individuals expressed stigma towards a parent, as well as how a parent responded to stigma, was found to differ based on the system the stigmatiser was located within and the closeness of this relationship.

**Figure 3.**  
*The stigmatisers' location within social systems*



Parents spoke about how those closest to them often expressed stigma in more subtle and complex ways. For example, one of the focused codes for family members stigmatising parents was; "*blaming parent for getting child diagnosed with autism*". In contrast, an example of a focused code for stigma from members of the public was "*staring and commenting on parent/child interaction*".

Furthermore, parents described responding differently depending on which social system the stigmatiser was associated with. For example, they were likely to respond by 'actively ignoring' with the general public, professionals and members of their local community. Yet, they were unlikely to respond to stigma from family and friends in this way. Differences in response depending on who 'the stigmatiser' was

are further discussed below; diagrams presenting these differences in responding is presented in Appendix 7.

### ***Direction of stigma***

One of the key influences on parental responses to stigma was whether the stigma was directed toward them or their child with autism. For example, a focused code relating to stigma directed towards a parent by a family member was “*judging parenting*”. In contrast, a focused code for child-directed stigma from a family member was “*viewed as being unable to achieve*”.

Consequently, if the stigma was directed towards their child, parents predominately responded by ‘challenging’ the stigmatiser, either by confronting/defending or educating. Six parents spoke about specific instances where members of the public negatively judged their parenting, particularly how they disciplined their child. One participant used the term “*global discipline*” to highlight this effect and how such moments can contain both child-directed and parent-directed stigma:

*"I remember one time it was this old man in the street. He said to my son "you're a very rude boy". I said, "no, you are very rude". I just couldn't help myself. I was just like "you don't understand what's going on here, please leave us alone." ...It was amazing because it's a child, and people feel like it is global disciplining. We can all discipline anyone else's children, but like you can't because you don't know what's going on...people feel they can kind of step in and they have the right to discipline, you know, without even knowing in the situation or the child." P10*

Parents described responding to “*global discipline*” in a range of ways due to the subtle difference in the direction of stigma. *Participant 7* described two examples of “*global discipline*”, one where stigma was directed towards them, and other towards their child. They responded by ‘actively ignoring’ when it was directed towards them, yet ‘challenging’ when directed towards their child.

*“You know, you get tuts, you get looks, you get people saying “control your child”. You know, criticisms for being a bad parent, we just try to ignore it”. P7*  
*“One man turned to him and said, “you are a very rude little boy aren’t you”. My son said, “I’m not little”, and I said, “actually, he is autistic”, and it was kind of slightly oblivious because he was fixated on the lift buttons. And he said, “oh, I didn’t know.” And I said, “no, you don’t know, so you shouldn’t make assumptions about people.”” P7*

### **Key parental responses**

Theoretical coding highlighted four key parental responses to stigma. These are outlined and illustrated with examples to highlight the context in which parents used these responses.

#### ***Challenging***

‘Challenging’ was defined as a direct response from the parent to the stigmatiser, whereby they challenge the stigmatiser’s negative beliefs about the parent or their child. ‘Challenging’ was used by parents in stigmatising encounters with individuals from all of their social systems. ‘Challenging’ was divided into two sub-responses: educating and confronting/defending.

#### **Educating**

Educating was defined as instances when a parent would seek to educate the stigmatiser about their child’s needs; this might include sharing the child’s diagnosis with the stigmatiser.

*“I think the thing that helped me most, I think, was having an autism card from the National Autistic Society. And when I’ve sort of seen people start to get all uppity, then I just sort of carefully show them that card, and then suddenly they say, “oh, my goodness. Oh, sorry, I’m sorry.” And quite often that’s diffused it. So, I’m not feeling like I have to defend my child or defend myself.” P7*

Another parent described their decision to describe their child’s needs to a member of the public who stigmatised their child, but not to state their diagnosis:

*“And they were all like, “Hey, father Christmas coming.” He wasn't interested. And they were like saying “he doesn't like us, he doesn't like us. He's really shy.” And what they're seeing is his coldness, apparent coldness ... They are putting all these demands on him... I used to say “he's shy”. Then I realize saying “he's shy” in front of him all the time, is not going to help him. Sometimes I say “he's autistic”. And then I think, well do you know what, he doesn't have to talk to these people. And then now I say, “he doesn't feel like talking just now”. Because that's true.” P3*

Despite family members, friends and professionals or school staff knowing a child's diagnosis, parents described still needing to educate stigmatisers to understand their child's difficulties and the impact these have on their family.

*One parent* described the challenge of educating their own parents about their child's needs in order to challenge their views:

*“Well, it's kind of difficult 'cause you rely on their help so much, so you don't want to cause an argument, cause a rift...sometimes I would be like “well he's not fine Mum, he's not the same as a kid his age.”” P9*

Parents spoke about one of the problems of managing stigma experienced from professionals and school staff as holding the belief that professionals are experts.

*“I'm imagining that they have the same understanding I do. And it's apparent. No, they really don't get it. I'm gonna have to spell out for you... even with professionals that are there to support your child. Making them understand his needs. This is a cry for help, behaviour. I'm not trying to make your life difficult, but they think I am.” P2*

### **Confronting and defending**

Confronting and defending are both 'challenging' responses directed towards a stigmatiser in the moment, yet they differ slightly. Confronting was defined as a response to a stigmatiser when they have made a generalisation or shared a

stigmatising view about the parent or child without it relating to a specific behaviour or action. Defending was defined as a response to a stigmatiser who has focused on a specific behaviour of a parent or child; the parent would then defend this behaviour and challenge stigma in the process. Both responses are illustrated in the following examples.

*"I had this friend who I'd open up to and then she sent me this thing, it was like a thing about curing him, you know, and I was like, "how dare you? You know?". I said, "I don't want you ever to think that this needs to be cured. And I don't want any children to say that to my son.""* P11 (Confronting)

*"Your son hit my daughter", I said "I'm so sorry." They said "what's the matter with him?" I was like "My son is autistic, you know that". And like I would have considered this person a friend, but they didn't get it...My friend was like "oh well you know, he's very nasty now." I was like "He's not nasty, he's autistic and doesn't want to share his stuff.""* P12 (Defending)

Parents spoke about the dilemma of sharing their child's diagnosis with members of the public and people within their local community. Interestingly, each parent spoke about different reasons why they might share their child's diagnosis in some situations, and not others, with no clear pattern found among parents.

*Participant 8* described their decision-making process when deciding whether to confront/defend or educate a stigmatiser. They linked this to their experiences of managing Islamophobia:

*"If somebody is coming across really ignorant and really just outright rude about it. Then no. I'm not exposing myself to people like that. So it's like the same thing for me with religion, if somebody you talk to has said "like all Muslims are terrorists and they go around bombing people, blah, blah." I'm not going to justify my religion to them. But if it was somebody that said something like, "oh, you know, but why do they do all of this stuff and is there anything to Islam," I'll happily sit there and have a conversation with you. Like even if you*

*have different views, I will correct you or educate you, it is not a problem. So, it just depends on the way you respond with me.”*

Seven of the parents expressed the view that they had learnt over time to only challenge stigma if they believed it will help their child. *“So, I chose not to fight that battle because I didn’t really see that there was much to be gained for him”*. P4

### **Actively ignoring**

‘Actively ignoring’ was defined as purposefully choosing to block out and not engage with a stigmatiser in the moment. Parents described ‘actively ignoring’ individuals from their wider social system; school staff, professionals, members of their local community and the general public.

*“And you do get those stares, what a parent said to me a while back is “what I do is called my ‘superhero cloak’. Say the child hits the deck, starts screaming, I go into that mode.” So now I do it too, my superhero ability is I don’t care about them staring, the only person that I have to serve is my child.”*

P3

One parent described ‘actively ignoring’ other parents in their religious community:

*“They’d get so annoyed that I didn’t have to do what the other parents did, and could sit with the children, so it did ‘cause a slight difference between us. But I would just ignore it because most of the people were good and would give him things to play with or try to distract him.”* P1

Another parent shared that if they experienced stigma from a staff member at their child's school, they chose to actively ignore:

*“So I became less defensive. And I let them talk down about me and my child, without fighting back. I told them, I know he’s bad, I know I am doing it all wrong. I became on their side...because that is the only way to do it. To get him the help he needs, I had to ignore all the stuff they said”*. P11

Notably, three parents described situations where they attempted to 'actively ignore' a stranger who was stigmatising them. Yet, due to the stigmatising individual becoming more confrontational parents then responding by 'challenging'.

*"He was looking and going "tut tut tut". I was just like 'whatever'. I was really ignoring him and just talking to my son, really trying to ignore him. Then he says "give him a slap", and I said "excuse me, what did you say", he said "give him a slap", I said "what do you mean, give him a slap?, you know what, I've got a better idea, why didn't I give you a slap and see how you feel?" P12*

### **Actively withdrawing**

'Actively withdrawing' was defined as the process whereby a parent makes the conscious decision to withdraw from an interaction or social relationship in response to a stigmatising experience. Parents spoke about 'actively withdrawing' from friends, family, school staff/professionals, but not with the general public or members of their local community. *Participant 2* described the moment they made the decision to withdraw their child from a school:

*"I just decided to take the power back because I can see the damage they are doing to my child and me. And I just said, "he's just not coming back to school because it is too damaging", it's quite extreme."*

Parents described 'actively withdrawing' from family and friends when other approaches proved ineffective.

*"I just won't go, like with extended family, I've tried to explain it, but they won't change anything. So, what's the point going to parties with them or anything 'cause you just feel watched. So, I won't go, I won't engage with them, and I will overcompensate for my kids and do something special at home". P5*

Likewise, another parent described that they chose to withdraw and end relationships with those who were not accepting of them and their child:



*“So now I don’t give a shit to be honest with you, I am totally accepting of my child, and if people can’t accept us, then “bye!”... I’ve cut off a lot of family and friends.” P12*

### **Avoiding**

Parents described 'avoiding' stigmatising situations with people from all social systems in their life. 'Avoiding' differed slightly depending on the social context. In general, 'avoiding' was defined as the process whereby the parent avoids any form of engagement in situations which may lead to a stigmatising interaction. Moreover, if they felt stigmatised, they would avoid engaging in an interaction with the stigmatiser. One parent described 'avoiding' talking about their child and their own difficulties with their friends and family:

*“And I've always had best friends who I've talked to about everything. And our family, we've always talked about everything. And now I realise I'm censoring my conversations with most people at most times, bar a very small number of people, 'cause I am worrying what they will say”. P3*

Another parent noted that they avoid certain public situations due to the fear of stigmatising interactions:

*“So if my child is hopping and skipping between the aisles, then some people will be like “take your child, why is your child doing that”. Then everyone will stare. Then I just tend to apologise. So now I just avoid things a lot, I just don’t take him shopping, because there is always drama.” P1*

Interestingly, *Participant 4* described 'avoiding' forming relationships with parents who do not have a child with a disability due to worries they would not understand their experiences:

*“I think we've kind of gravitated towards the families where there is a special needs child because we have that understanding. I think other families who we were closer to in that context we now spend less time with, because it's just like they might not get it.” P4*

Four of the parents' accounts of when they responded by 'avoiding' linked to their worries about what others might think of them and their child.

*"You know I've taken him out of the supermarket, when he's throwing a strop. I'm usually the one that says "all right, we'll get out" ... it depends on where you are but if you're not dealing with it, people are going to think, why aren't you dealing with this." P9*

### **Internalised Stigma**

*"I felt so useless and I felt so stupid and you know, when people say you're a bad mum, you're this, you're that, you start to believe it, and I took it in." P12*

Parents' narratives highlighted that despite using strategies to manage stigma, they often internalised others' stigmatising views. Similarly, six of the parents described feeling lonely and doubting friendships, due to others not understanding their experiences and their children's needs.

*"It feels a bit rubbish, because they know me, and they trust my judgement in other areas, so why don't they trust me in this? Why would they think that I'm making it up about my child? It makes me question myself and our friendship".*

P4

Participant 2 shared that at times they felt life would be easier if their child's disability was more visible so others would gain an understanding of the challenges:

*"It's awful to say this, I don't wish this, but sometimes I wish there was something visible because we might get sympathetic looks rather than judgement". P2*

Another parent noted the impact that others' views can have on how they manage and make sense of stigma:

*"You know I have a thing where I don't like people to think that I'm just letting my kid run wild, and I'm not paying attention to them and I'm not considering other people's feelings." P9*

These examples highlight the powerful impact that stigma can have on parents and how, over time, they may begin to believe stigmatisers' points of view.

### **Resisting internalised stigma**

Parents shared the ways that they had managed their internal battles with stigma. Three of the parents found humour to be key to helping them resist internalising others' stigmatising belief.

*"You just have to laugh, you have to find humour in it, just take it easy and take your time. And if people can't understand that then they're not people you need to know". P12*

Two parents noted the importance of reminding themselves that they are the expert on their child.

*"I do trust myself, at the end of it all. However much society might let us down. I'll make sure to do the right thing for us; I know him best." P2*

Two parents spoke about how becoming advocates for others helped them to challenge their own internal stigma.

*"I'd hate for people to go through what I've gone through... so I tell my story, it was good for me cause you hold onto the stress, but by helping others see it helps you see more about how hard it is". P4*

### **Broader parent/child and contextual factors**

Parents' narratives highlighted that additional contextual factors or parent/child factors could impact how they responded to stigma they experienced. Four specific factors were cited as affecting how they managed stigma: wellbeing, previous positive experiences with others, their relationship with a co-parent, and the passage of time since diagnosis.

#### ***Wellbeing***

Five parents noted that their mental state and wellbeing affected how they responded in stigmatising situations.

*“If you don’t look after yourself, if you don’t look after your mental state, something simple can send you into a deep dive. It could be that someone’s not looking at you, but it feels like they are, like everyone is looking at you, it’s a mind game.” P5*

Three parents felt that they were more reactive in their responses to stigma at times when they were feeling low in mood or exhausted.

*“I stood up, after four days of an exhausting trip, I’d lost it, I was screaming at her, but I lost my voice, I was just so angry but exhausted”. P10*

### **Positive experiences**

Parents noted that positive experiences helped them feel that they and their child were accepted and resulted in them feeling less stigmatised.

*“And [my sister] said to me “I didn’t realise that’s what it is like, it gave me a little taste of what your life is like every day.” So, I think she understands more, and she’s got it more now.” P2*

Five parents shared stories of members of the public spending time with their child or offering help during a crisis.

*“And I felt utterly shamed and the staff sort of intervened, when I came back from the counter I burst into tears. Then this woman came up to me and said, “I saw what happened there, just so you know you’re doing a great job.” So that was so lovely.” P7*

Participant 12 shared an account of an empowering experience with a member of staff at their child’s school:

*“I asked them “What do you think? Because you’re obviously the experts” you know they said, “you’re the expert, you’re the parent”. And that’s how they made me feel, and that is why I feel strong...because you’re made to feel like that you did nothing wrong, you’re the expert.” P12*

### **Change in responses over time**

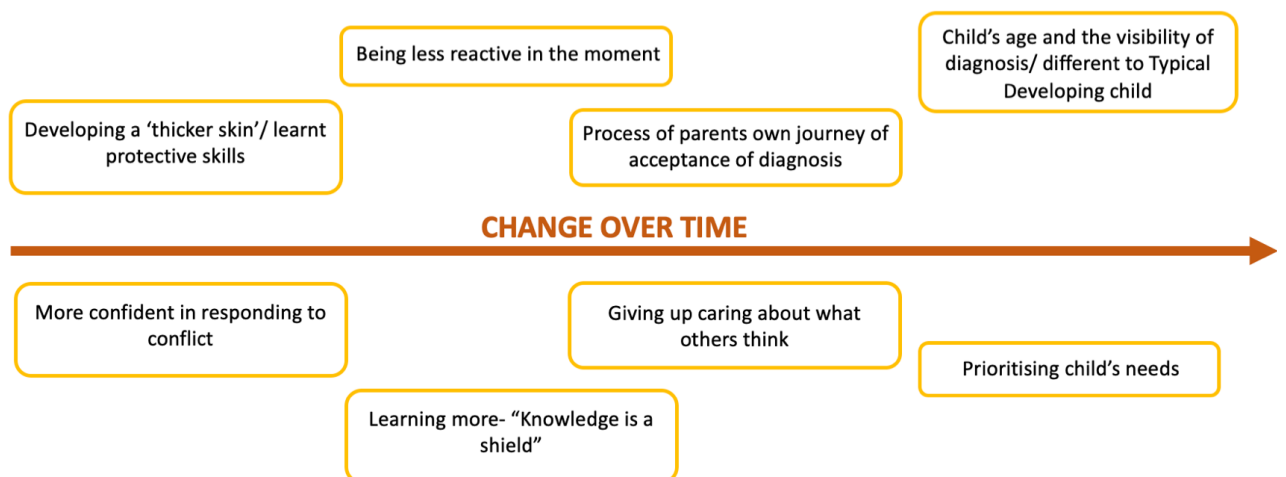
Focused coding highlighted eight recurring themes of how parents felt their responses to stigma changed over time (Figure 4). Notably, nine of the parents shared that developing their knowledge had led to them feeling more able to manage stigma:

*“the more you learn, the more power you have to challenge things which you don’t think are ok” P6.*

Seven parents also shared that over time they had learnt more skills to protect themselves from external and internal stigma:

*“But as you go through, you get a thicker skin, I guess you know [what responses to expect from people].” P10*

**Figure 4.**  
*Changes in parental responses to stigma over time.*



### **Co-parenting**

Parents noticed that the way they responded to stigma was impacted by their co-parent. Theoretical coding formulated five focused codes around co-parenting that fell into two overarching groups: impact on parental relationship and impact on responding to stigma in the moment (Figure 5).

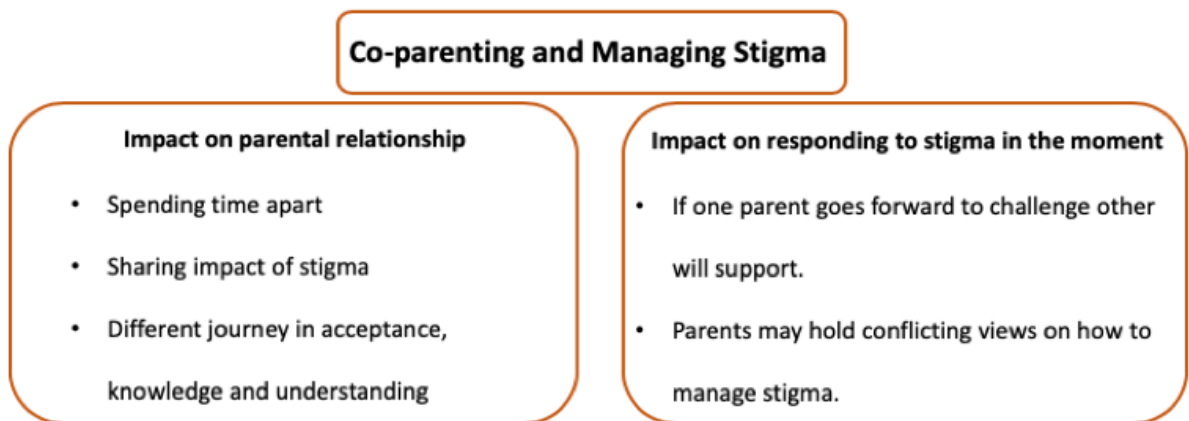
Four parents spoke about noticing that if one member of the parental unit challenges a stigmatiser, the other would support them.

*“You know we kind of balance each other... I wouldn’t say that one of us would react in a typical way and the other another way. You know, we’ve done our fair share of either supporting or giving someone an earful”. P7*

Yet parents noted the impact that stigma could have on their relationship with their co-parent. Five of the twelve parents felt that they could share the impact of stigma on their wellbeing with their co-parent. However, four of the 12 parents shared that due to their child's difficulties, they tended not to spend time with their co-parent leading to feeling more alone in managing stigma. Three parents noted that being at a different point in the acceptance of their child's diagnosis could impact how they shared their experiences of stigma:

*“I’ve got a thick skin and he’s definitely the one who has felt it more... like something was missing, he’s felt the loss pretty profoundly, so he notices other people more”. P8*

**Figure 5.**  
*Co-parenting and Managing Stigma.*



**Parents’ advice for others**

Parents were asked two questions at the end of the interviews: (1) Do you have any advice you would give to other parents of children with autism to help them manage these types of experiences? And (2) What are some of the positives of parenting a child with autism that you would want to share with others? The key advice, ideas and benefits that parents shared are presented in Figure 6.

**Figure 6.**  
*Parents' advice and ideas to share with others*

Wellbeing	Social Support	Your child	Stigma Resistance Advice	Benefits
<ul style="list-style-type: none"> <li>• Take Time-out for yourself</li> <li>• Have something of your own- nurture your own identity</li> <li>• Remember each situation will pass</li> </ul>	<ul style="list-style-type: none"> <li>• Join the SEN Community</li> <li>• Choose your friends carefully, you may have to let some go</li> <li>• Ensure to have one person who you can share experiences with</li> </ul>	<ul style="list-style-type: none"> <li>• Adapt the environment not your child</li> <li>• Learn coping skills</li> <li>• If people are curious don't be afraid to be honest</li> <li>• You are the expert about your child</li> </ul>	<ul style="list-style-type: none"> <li>• You don't have to fight every battle</li> <li>• Challenge stigma if it will benefit your child</li> <li>• With strangers/ other children remember they may not be judging you – it may only be your interpretation of the situation</li> </ul>	<ul style="list-style-type: none"> <li>• Being less judgmental of others</li> <li>• Being more confident as a person</li> <li>• Having a deeper understanding of your child/ deep relationship</li> <li>• Becoming more resilient to life's challenges</li> <li>• Meeting people from all walks of life</li> </ul>

### Discussion

This study aimed to develop a theoretical model to understand how parents of children with autism respond to and manage the stigma that they experience. The model constructed from parents' narratives helped to identify subtle differences in responses to stigmatisers. Responses were primarily dependent on two variables: who is being stigmatised and who the stigmatiser is.

#### Reflections on the model

Building upon Firmin et al.'s (2017) model of stigma resistance, the model presented in this paper goes further in thinking about the relationship between the stigmatised individual and the stigmatiser. Firmin et al. (2017) found that participants tended to use challenging or deflection as responses, depending on whether the stigmatisation was happening at a person-level, peer-level or public-level. Similarly, the model presented here identifies that parents' responses differ depending on which social system the stigmatiser is located within. This model includes a broader classification of the 'levels', or social systems stigmatisers may come from. Friends

and family are presented as separate levels. Additional levels were added to include local or religious community, the child's school, as well as the general public.

Parents' accounts revealed that if their child was directly stigmatised, they were likely to respond by 'challenging', regardless of which social system the stigmatiser belonged to. Six parents described 'challenging' when responding to strangers stigmatising their child. However, when the stigma was directed towards the parent, they responded differently e.g. 'actively ignoring'. This finding was inconsistent with Harandi and Fischbach's (2016) research, who found that some parents of children with autism responded to stigma using 'passive response strategies' like avoidance, regardless whether the stigma was directed at them or about their child. However, their study did not clearly define whether parents' responses differed if the stigma was directed towards the child, for example "you're a naughty child", it only alluded to the stigma being about the child.

The model presented shares similarities with Thoits' (2011) model, which used the terms 'deflecting' and 'challenging' to encapsulate responses to stigma. It identifies that 'actively withdrawing', 'actively ignoring' and 'challenging' are responses which involve the parent making a conscious decision to acknowledge and respond to stigma. These responses could map onto Thoits' (2011) definition of 'challenging'. In contrast, 'avoiding' could be deemed to map onto Thoits' (2011) definition of 'deflecting', as it involves cognitively separating from the experience while still maintaining stigmatising beliefs.

The majority of participants in Firmin et al.'s (2017) study disagreed with the term 'deflection', as they felt it had connotations of passivity to stigma. In light of this finding, the model presented here does not use 'deflection' or 'passive strategies' as its terminology, instead choosing to use the more active term 'avoiding'.

### **Key parental responses to stigma**

In this study it was found that parents' responses to stigma varied depending on who the stigmatiser was. Parents did not, for example, actively ignore stigma



encountered from family and friends. This may be linked to the closeness of their relationships with family and friends, as 'actively ignoring' may be seen as likely to be ineffective. Instead, parents spoke about using more guarded responses when they experienced stigma from those closest to them, such as 'actively withdrawing', such as withdrawing from conversations or ending contact with certain family members or friends. Notably, parents did not respond by 'actively withdrawing' from the general public or within their local or religious community. This may be due to not having a close relationship to withdraw from.

The decision of when to respond by 'challenging' was considered by many of the parents. One parent shared their view that they would decide to respond to stigma by educating vs confronting/defending, based on whether the stigmatiser was open to a conversation. Other parents said they would only respond by challenging if they believed this would benefit their child and ensure their child's needs are met. These findings highlight that choosing not to challenge can be a conscious decision on the behalf of a parent in order to protect their child and themselves. Interestingly, these findings contradict Harandi and Fischbach's (2016) conclusions that only parents using 'active response strategies' are more accommodating of their child's behaviours by proactively educating those stigmatising them, when compared to parents who use 'passive response strategies'.

Parents in the present study spoke about the dilemma of when to share a child's diagnosis of autism with others. Each parent held slightly different perspectives about when and with whom they would share their child's diagnosis of autism. Some parents described finding sharing their child's diagnosis defused stigmatising situations and resulted in them feeling less blamed, whilst others did not want to have to explain their child's difficulties, particularly to strangers. This finding indicates the need for parents to think about their own decision of when and with whom they feel comfortable sharing their child's diagnosis. This finding mirrors the mixed conclusions across the research field. Harandi and Fischbach (2016) noted that parents who used

'passive response strategies' with strangers who stigmatised their child, tended to feel more uncomfortable sharing their child's diagnosis of autism to the general public, than those parents who used 'active response strategies'. Whilst Manago et al. (2017) found that parents sometimes used a medical label to challenge stigma, and sometimes acknowledged disabling social structures, whilst deflecting stigma. Similarly, Farrugia (2009) found that when parents tell the general public about their child's diagnosis of autism they often deploy medical knowledge, as a way to preserve how they and their child are viewed by others, ensuring they aren't viewed as bad parents and their child is viewed as having a medical reason for atypical behaviours. Scior, Connolly and Williams (2013) found that attaching the label of 'learning disability' to a vignette reduced stigma among members of the public in contrast to presenting the same vignette without a diagnostic label. This would seem to suggest that for some conditions or attributes, providing the label may have the effect of reducing the stigma in the moment. Congruently, studies with adults with a diagnosis of autism found that members of the public were more positive about an individual with autism if they were aware of their diagnosis (Brosnan & Mills, 2016; Butler & Gillis, 2011). The findings discussed, alongside this study's findings, support the notion that using a medical label or sharing a diagnosis is a personal preference which research has not yet clearly linked to affiliate stigma. But sharing a diagnosis with the general public may have benefits in reducing stigma in the moment. Future research could explore in more detail whether increased levels of affiliate stigma link to parents disclosing their child's diagnosis of autism when they and their child are stigmatised.

### **Affiliate stigma associated with autism**

Theoretical coding of parents' narratives identified that many of them continually experienced affiliate stigma. Mitter et al. (2018) noted that there are three aspects to affiliate stigma: the cognitive dimension, the negative emotional impact, and the behavioural dimension. In this study, parents described the emotional and cognitive aspects of affiliate stigma vividly and noted the impact on their own

wellbeing and mental health. Parents did not explicitly link their experiences of internalising stigma to how they responded to stigmatisers. Those who spoke about responding by 'avoiding' observed that this was often due to their fears and anxieties around experiencing stigma. It is conceivable that they responded in this way due to having internalised stigma, in line with Mitter et al.'s (2018) behavioural dimension of affiliate stigma. Harandi and Fischbach (2016) similarly found that parents using 'passive response strategies' were more likely to experience raising a child with autism as very difficult and to struggle to manage stigma.

Parents described the range of strategies to manage internalised stigma from using humour, reminding themselves that they were the experts on their child, to becoming advocates for other parents of children with special educational needs. Firmin et al. (2017) similarly found that people with mental health difficulties who were able to resist stigma both internally and externally held a strong sense of identity, empowerment and viewed resisting stigma as an on-going process.

### **Additional contributory factors to managing stigma**

Parents cited contextual and parent/child factors that influenced how they responded to stigma. Some parents noted that the lower in mood they felt, the more reactive they were in their responses to stigma. Whilst some parents described how feeling that they and their child were accepted by their family, friends, and community, resulted in them feeling more able to cope with stigma.

Parents also reported that their responses to stigma had changed over time. They described that having acquired more knowledge and skills in parenting a child with autism, as well as their own acceptance of their child's diagnosis, impacted how they respond to stigma. This finding corresponds with the conclusions from previous research; parents of children with autism appear to become resilient and self-confident in their dealings with the public through experience over time, as they develop more emotion-focused strategies to manage stigma (Gray, 2006; Ryan, 2010).

Interestingly, parents' descriptions of managing stigma jointly with a co-parent highlighted that they might have different responses during a stigmatising experience. If one parent challenged stigma, the other would support them. Some parents described the impact that stigma and their child's difficulties had had on their relationship with a co-parent. Correspondingly, Saini et al.'s (2015) scoping review into the impact of raising a child with autism has on co-parenting relationships stressed the risk of increased discord in relationships, and the need for services to support co-parenting relationships.

### **Limitations and clinical implications**

This study is one of the first attempts to conceptualise and develop a theoretical model regarding how parents of children with autism respond to and manage stigma. Parents' narratives gave a rich and detailed understanding of how they responded to stigma they or their child faced. However, the model should be viewed tentatively and tested with a larger and more diverse sample of parents of children with autism. Despite attempts to recruit a diverse sample, only one father participated in the research. Although there was some ethnic diversity within this study's sample, it is important to further understand the degree to which the model presented in this paper fits with fathers' experiences and with the experiences of parents from a broader range of cultures, communities and ethnicities.

On reflection, it could have been beneficial to formally measure participants' levels of perceived associate stigma and affiliate stigma. Future research could use self-report measures such as the Family Stigma Instrument (Mitter et al., 2018) to assess if the model presented in this study maps onto self-reported data of experiences of associate stigma and affiliate stigma. It is possible that parents who report higher levels of associate and affiliate stigma respond to stigma in certain ways, such as being more likely to respond by 'avoiding'.

The scope of this research focused primarily on parents of children with a diagnosis of autism, aged 10 and under. Future research could build upon this model

and explore what extent it maps onto the experiences of parents of older children with autism and other disabilities. Future studies could also investigate whether the type of school a child attends (mainstream or specialist) affects the level of stigma experienced by parents or indeed children with autism. Additionally, research needs to be conducted with children and young people themselves to see if this model is also representative of how they manage stigma and resist stigma.

It is hoped that on dissemination, the model presented in this research can be reflected upon with parents of children with autism in clinical settings, for example, post-diagnostic parenting groups and in CAMHS LD services. The model presented may help parents see the range of responses and strategies they could use to manage stigma in different contexts. Moreover, it may be helpful to highlight that whether to share a child's diagnosis with strangers and people within one's community is a common dilemma among parents of children with autism and a matter of personal choice. This model may also help parents reflect on whether they respond to stigma by 'avoiding', perhaps due to having internalised stigma. This model may be particularly helpful to integrate into some of the current trials being completed around psychosocial stigma protection interventions, focusing on improving the mental health of parents of autistic children (Lodder et al., 2020).

Finally, although this study focuses primarily on the experiences of parents, it is essential to acknowledge how this study emphasises the need for change in policy at a national-level. In particular, this study stresses the importance of reviewing the current support in place for parents of children with autism and the need for national level education focusing on reducing stigma around neurodiversity and working towards an inclusivist society.

## **Conclusion**

The origins of this research emerged from concern for parents of children with autism and the impact that stigma has on them. The research question was developed from the desire to understand how parents respond to and manage these experiences

with the hope that a detailed understanding may highlight how parents resist stigma. A novel theoretical model was developed by using constructivist grounded theory to analyse rich, in-depth qualitative interviews with parents of children with autism. Two key aspects were presented in this model: responses were dependent on who the stigmatiser was and who was being stigmatised. The model also highlighted the four typical responses parents use to respond to stigma in the moment; avoiding, actively ignoring, actively withdrawing and challenging. This model can be integrated into clinical interventions for parents who experience stigma around their child's autism, as it offers parents an overview and a different lens on stigmatising situations they experience. Clinical services specialising in autism can use this model with parents to further understand the range of responses, and subsequently, strategies can be developed to manage stigma parents experience in different contexts. Researchers and clinical services could benefit from exploring whether this model maps onto the experiences of parents of children with different disabilities and families with different sociodemographic characteristics.

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### **Part 3: Critical appraisal**

## **Introduction**

This appraisal reflects on the process of working with experts by experience. It examines the value of co-developing research and how to ensure that the ideas shared by experts by experience are put into action. Reflections are made on some of the challenges faced during the completion of this project, such as whose voices were not heard in this study.

### **Conducting research with experts by experience**

Literature highlights the importance of consulting experts by experiences when conducting research (Braye & Preston-Shoot, 2005; Preston-Shoot, 2007; Telford & Faulkner, 2004). The inclusion of experts by experience perspectives and first-hand accounts can help direct studies towards researching concepts which are meaningful to those in the population being researched (Preston-Shoot, 2007). Often researchers have been given the discretion to determine whether it is possible to involve experts by experience in the design, analysis and reporting of research. This can lead to researchers often choosing to not involve experts by experience due to the time and cost associated with doing so (Braye & Preston-Shoot, 2005; Telford & Faulkner, 2004).

Experts by experience have been involved in co-developing research studies in various settings and populations, for example, research exploring the experience and impact of different mental health (Simpson & House, 2002). Co-developing research with experts by experiences can add value and efficacy to research, particularly in relation to getting their support around developing reliable methods of data collection (Telford & Faulkner, 2004). Moreover, researchers have noted that co-producing research can have a positive impact on experts by experience and result in them feeling empowered and that their opinion is valued (Horgan et al., 2018; Mayer & McKenzie, 2017).

This research project focused on how parents of children with autism manage and respond to stigma. When developing the proposal for this research, it was

considered integral to work with experts by experience to hear their perspectives about the hypotheses and proposed research methods.

### **Reflections on working with experts by experience in this project**

Experts by experience were recruited through social media platforms and local charities. The advertisement can be found in Appendix 8. The title of the advert, “Researching Together”, was chosen to emphasise that this would be a joint venture between researchers and experts by experience. Five parents contacted me stating their interest in being part of the experts by experience consultation team. However, due to prior commitments, two parents were unable to consult on this research project. Subsequently, the consultation team was made up of three mothers of children with autism and/or learning disabilities, who were from a range of ethnic and cultural backgrounds. We met on two occasions in person for three hours each time.

De Geeter, Poppes, and Vlaskamp (2002) found that in clinical settings parents of children with multiple disabilities can struggle to fulfil the role of ‘the expert’ despite their wide depth of knowledge based on their own experiences. Belam et al. (2005) highlighted the importance of addressing power differentials when co-producing research to help experts by experience feel able to share their knowledge and perspectives. In this project, I decided to address the power imbalance in three ways. Firstly, when we initially met as a group, I invited the experts by experience to join me in having breakfast at the university. This helped to create a welcoming space for the three experts by experiences to talk openly, as we shared food together. Secondly, I shared my background and what had led me to be interested in researching stigma and the experiences of parents of children with disabilities. I reflected on my first job as a carer in a day centre for young adults with disabilities, and my own first-hand experiences of witnessing the stigma these young people and their families experienced. Thirdly, we spent time together thinking about their experiences of stigma as parents of children with disabilities and the impact it has had on their lives. From an early stage, it was clear that each parent had their own unique

experiences of parenting a child with a disability. They each linked their experiences of stigma to their background, circumstances and own belief systems.

I went on to share my research proposal with the consultation team, explaining what research had been done in the field so far and what I hoped to understand further by conducting this study. I presented them with a basic outline of an interview schedule I had developed. They shared their ideas and perspective on the interview schedule (Appendix 5). They suggested that it would be important to ensure to use the terminology and language that each participant preferred, for example, 'child with autism' or 'autistic child'. Hence, I added a question at the start of the interview to find out which terminology parents preferred. They also stressed the importance of referring to the child by name throughout the interview to ensure that the experience did not feel dehumanising. We also thought about the importance of understanding more about the child and parent before asking questions around experiences of stigma. Accordingly, we added a section focusing on finding more about the child's strengths and difficulties, and about family life in general. In our discussions the experts by experience recalled finding it hard to talk to family and friends about the stigma they had encountered, describing how at times it affected them as a parent and as a person. To reflect this, we added questions to explore this in the interviews. The experts by experience spoke about how often parents of children with disabilities want to offer advice and support to others; additional questions were added to try to capture this.

We then worked together on reviewing the information sheets, demographic questionnaires and consent forms. The experts by experience highlighted the importance of leaving a section for parents to describe their child's disability, instead of it being a 'tick box exercise', as often a child will have multiple diagnoses, for example, sensory processing disorder and autism.

They shared helpful ideas around recruitment and supporting participants. Co-produced flyers are presented in Appendix 9. Additionally, they proposed sharing lists

of local services and parent groups with participants to help parents connect to services. This was one of the most valuable ideas that we put into practice. Prior to interviews, I collated a list of services near each participant's home. An example is present in Appendix 10. This was shared with participants at the end of the interview. This list helped highlight ways for them to connect with others and seek help and support if they needed it, as many participants described feeling isolated and lonely.

Following the preliminary phases of analysis, I met with the experts by experience to share the initial codes and memos. Two additional questions were added to the semi-structured interview. The experts by experience noticed that the questions asked were not capturing parents' experiences of stigma at a broader level, particularly within parents' local communities. They also reflected their own experiences of how they often respond differently to stigma from strangers when with a co-parent. The following questions were added to try to capture these experiences.

3. "Would you describe yourself as being part of a community, perhaps a cultural community or religious community?" If yes, ask follow-up questions:
  - a) "Within that community, how have people responded to "X's" diagnosis and difficulties?"
  - b) "What do you think their understanding of "X's" diagnosis and difficulties are?"
  - c) "Can you give me an example? Have people's responses changed over time?"
4. "Have you experienced any situations with a co-primary carer (e.g. other parent of the child) where you have both feel stigmatised?" If yes, ask follow-up questions:
  - c) "How did you both react in this situation?"
  - d) "Is this normally how you both would react?"

Working with experts by experience added insight and value to this project. It helped me navigate complex dilemmas, for example, what terminology around diagnoses to use with parents. The experts' perspectives ensured that the participants were able to gain something from taking part in the research. In particular, their

suggestions helped to create space within the interviews to truly understand parent's experiences. The suggestion to share a personalised list of local services, brought forward by the experts by experiences, enabled me to feel like I could support and connect participants to services and local parent groups. Unfortunately, due to the coronavirus pandemic, I was not able to meet with the experts by experience prior to submitting this thesis. I hope to meet with them again over videoconferencing to share the results and hear their opinions, prior to examining this project at the viva.

### **Whose views this project does not capture**

One of the key limitations of this project is whose voices were not captured. Only one father participated in this research, despite my hopes and efforts to try to recruit more fathers. The experts by experience encouraged and supported me to get in touch with a range of charities. I attended a support group for fathers with children with disabilities in North London. However, it was difficult to seek out fathers who wanted to take part in the research and those who had time to do so.

Donaldson et al. (2011) highlighted that literature could often position fathers as the 'peripheral parent', resulting in their views often being missed out or minimised. It is important to hold in mind fathers' roles in the family; when fathers struggle to manage with the caregiving burden, it can be even more challenging for them to support other family members (Dardas & Ahmad, 2015). Research conducted by Gray (2002) captured both mothers' and fathers' experiences of stigma. Their results indicate that both parents experienced stigma, but that mothers were more likely to do so than fathers. In this study only a minority of fathers said they had experienced 'enacted stigma', for example, hostile staring and rude comments from others. This finding highlights the importance of listening to fathers' perspectives about how they manage stigma. Whilst it was not possible in the present study to hear about multiple fathers' experiences of stigma, future research could specifically look into how fathers manage and respond to stigma, and whether their experiences maps onto the model developed.



This study attempted to listen to the experiences of stigma from a range of participants, diverse in race and culture. However, it failed to hear the experiences of black mothers and fathers of children with autism. Intersectional stigma has only recently begun to be explored in research. Participants have reported feeling that cultural, ethnic and religious sensitivities are often ignored by white professionals (Kandeb et al., 2020). Additionally, experiences of stigma are reported as common amongst people with autism, yet Kandeb et al. (2020) found that participants felt that these were not well understood in people identifying as belonging to an ethnic minority in the UK. A mother described her experiences of being a black British mother to her daughter with an autism diagnosis:

*“What is different is how cultural and religious perspectives shape each community’s response to autism. Families of autistic children from BAME communities can easily become isolated in their community bubble.”* (Bobb as cited in Carpenter et al., 2019, p.44).

In the United Kingdom 73,017 children were reported to have a diagnosis of autism as their primary need on their SEN statement or EHCP, in the Special Educational Needs School Census (Department of Education, 2019). A section of the national data is presented in Table 1, the number and percentage of pupils with statements or EHC plans due to diagnosis of autism, by ethnic group (DfE, 2019).

**Table 1.**

*National data of the number and percentage of pupils with statements or EHC plans with a diagnosis of autism, by ethnic group (DfE, 2019).*

	Ethnicity of Child						
	Total	Any other ethnic group	Asian (Indian/Pakistani/Asian Other)	Black (Caribbean/African/Black Other)	Chinese	Mixed (Black African-White/Black Caribbean-White/Asian/White/ Mixed other)	White
Number of Children with Autism Diagnosis	71,783	1,447	7,300	6,854	407	4,850	50,925
Percentage	100%	2%	10%	10%	1%	7%	71%

Unfortunately, no data is available for parents' ethnicity. Moreover, there is no comparative data for primary school aged children, comparing local authority, number and percentage of pupils with statements or EHC plans, by ethnic group and primary type of disability. Therefore, based on the data I have access to I can only crudely predict what a nationally representative sample of ethnicity would have been for parents of children with autism in a sample size of 12 (Table 2).

**Table 2.**  
*Divergence between the ethnicity of the research sample and ethnicity of national population of children with autism.*

	Ethnicity of Participant						
	Total	Asian-Pakistani	Black	British Moroccan (Any other ethnic group)	Chinese	Mixed other	White British.
No. Participant	12	1	0	1	1	1	8
Percentage of Sample	100%	8%	0%	8%	8%	8%	67%
Percentage of national population of children with autism		10%	10%	2%	1%	7%	71%
Percentage Variance		-2%	-10%	6%	6%	8%	-4%
Sample variance		No sample impact	1	No sample impact	No sample impact	No sample impact	No sample impact

Table 2. shows that in this study four participants in the study identified as ethnic minorities in the UK, none of the participants identified as black. The divergence between the research sample and the ethnicity of the national population of children with autism highlights that in sample size of 12 ideally one parent would have identified as black. This makes me wonder how my recruitment strategies did not enable me to recruit black parents of children with autism and leads me to reflect on my own ethnicity as a white professional. I wonder how this may have blocked me from thinking more about how to ensure ethnic minorities experiences were captured in this study. I wonder whether due to the isolation that Bobb (2019) describes black parents many not be linked into some of the parent groups and charities where I

advertised. This led me to reflect further on the relationships that need to be formed with communities to help ensure that participants from all backgrounds have the opportunity to choose whether to participate in research. More research is needed to explore experiences of stigma for parents of children with autism who identify as an ethnic minority in the UK. Yet, it is important for this to be done thoughtfully and for researchers to build relationships with communities to ensure that all voices can be heard.

I personally do not feel that the phrase 'hard-to-reach populations' is appropriate, as 'hard-to-reach' places the onus on the participants, failing to acknowledge the systemic barriers that block their involvement in research. Instead, I hold myself and the academic world accountable to amplify seldom heard voices. In this study, the unheard voices were those of parents of children with intellectual disabilities, fathers, and ethnic minorities, particularly black parents. In reflection, I could have done more to contact and build relationships with communities to ensure that more parents heard about the project and could choose whether to participate.

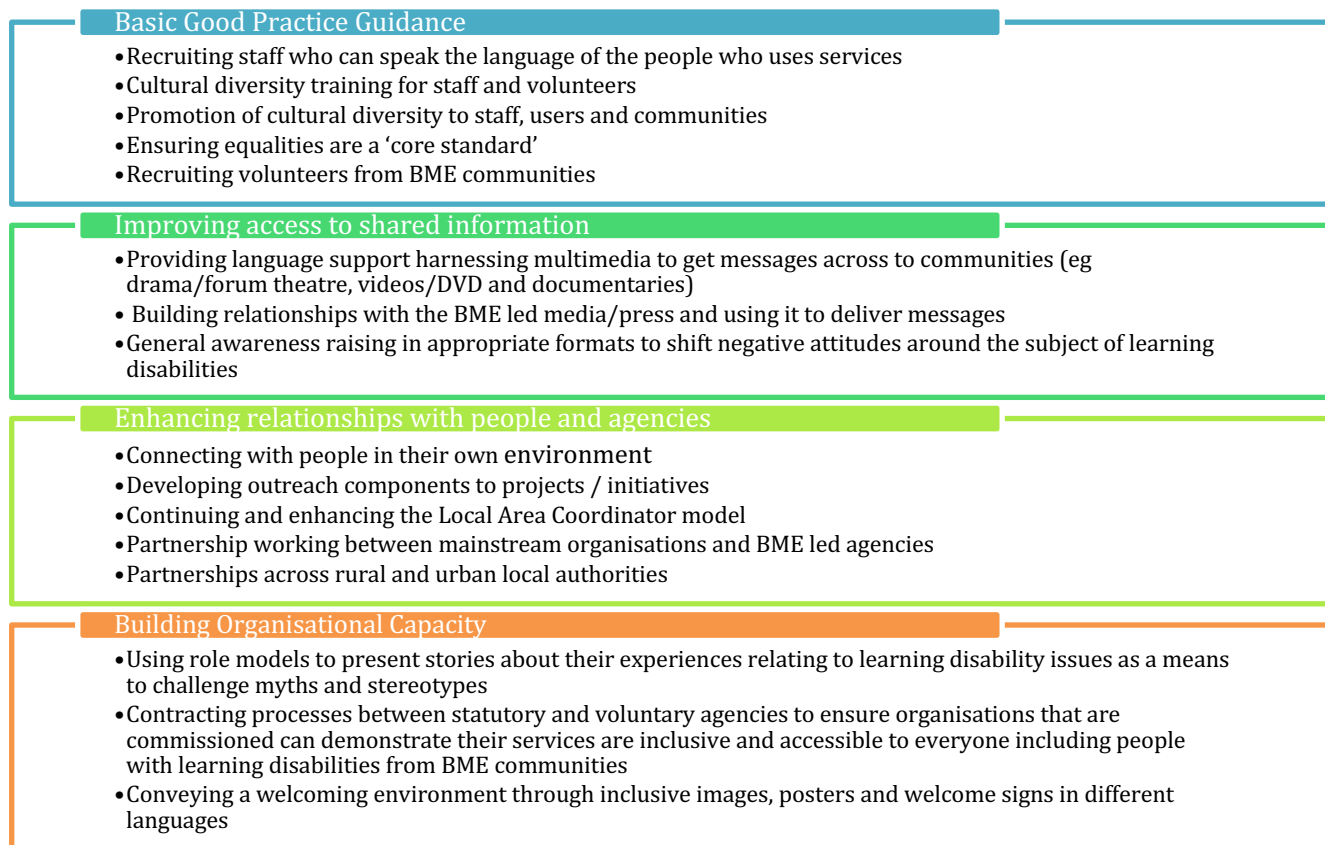
This study originally proposed to hear from parents of children with autism and/or intellectual disabilities about their experiences of stigma. This relied on me being able to conduct interviews with parents of children with intellectual disabilities. Unfortunately, no parents of children with intellectual disabilities were able to participate. This resulted in me adapting this research to focus purely on parents of children with autism. On reflection, this helped me develop a clearer understanding of the experiences of parents of children with autism but resulted in the perspectives of parents of children with intellectual disabilities being unheard. Werner and Shulman (2015) reported that parents of children with autism or intellectual disabilities report experiencing more stigma than parents of children with physical disabilities. They also found that parents of children with autism were more likely to internalise stigmatising experiences. The authors linked this to feelings of embarrassment about the child's behaviour, which in turn led parents to reduce going out with the child, reduced

contact with friends and relatives and avoid telling others that the child had autism. Their research highlights the importance of finding how parents of children with intellectual disabilities manage and respond to stigma, as it would be helpful to understand what reduces the likelihood of them internalising stigma. I hope that future research will explore if the model developed with parents of children with autism maps onto the experiences of parents of children with intellectual disabilities, or if they use any additional resources and strategies to respond to stigma.

The Scottish Consortium for Learning Disability (2010) conducted the “What’s out there?” project to find out about support services for people with learning disabilities and their families from black and minority ethnic communities. Following this project, they shared ideas on how to develop good practice. These can be adapted to a research setting, see Figure 1. In reviewing these ideas, I can see how I could have worked towards building better relationships with communities.

In particular, I used social media to advertise for both the recruitment of experts by experience and participants. However, I did not specifically look into developing a relationship with charities and media outlets that were led by members of ethnic minorities, fathers or parents of children with intellectual disabilities.

**Figure 1.** Scottish Consortium for Learning Disability (2010) “What’s out there?” Project recommendations.



## Conclusion

The issues considered in this appraisal highlight the importance of building relationships with communities and amplifying the voices of the populations we are researching into. Experts by experience can offer valuable and integral perspectives on research methodology. Their insights can ensure that research is developed and conducted in a way which feels valuable to participants.

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## Appendices

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## Appendix 1

**Table 2.**  
*QualSyst Ratings*

<b>Study</b>	<b>Rater 1 x/total</b>	<b>Rater 2 x/total</b>	<b>Observed agreement</b>	<b>Mean rating x/total</b>	<b>Mean % Rating</b>
Bennett et al. (2017)	19/20	19/20	100%	19/20	95%
Chen & Shu (2012)	19/19	19/19	100%	19/19	100%
Chiu et al. (2017)	20/22	21/22	95%	20.5/22	93%
Christensen et al. (2012)	39/41	39/41	100%	39/41	95%
Cooney et al. (2006)	21/22	21/22	100%	21/22	95%
Forte et al. (2011)	39/41	40/41	97%	39.5/41	96%
Hatton et al. (2018)	19/22	19/22	100%	19/22	86%
Iglesias et al. (2019)	35/40	35/40	100%	35/40	88%
Rose et al. (2015)	16/22	13/22	86%	14.5/22	66%
Sabornie & Kauffman (1987)	19/22	17/22	90%	18/22	82%
Starke (2011)	18/19	19/19	95%	18.5/19	97%
Sullivan et al. (2012)	18/22	17/22	95%	17.5/22	80%
Sullivan et al. (2015)	15/22	15/22	100%	15/22	68%
Tipton-Fisler et al. (2018)	40/41	39/41	97%	39.5/41	96%
Zeedyk et al. (2014)	15/19	14/19	95%	14.5/19	76%
Zic & Igrić (2001)	20/22	19/22	95%	19.5/22	89%

## Appendix 2



### Participant Information Sheet For Parents

UCL Research Ethics Committee Approval ID Number: CEHP/2016/551

#### **YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET**

#### **Experiences of stigma among parents of children with autism &/or intellectual disabilities**

##### **Department:**

Research Department of Clinical, Educational & Health Psychology, University College London, 1-19 Torrington Place, London WC1E 7HB

##### **Name of the Researchers:**

Rachel Ransley (Trainee Clinical Psychologist), supervised by Dr Katrina Scior.

You are invited to participate in a research study, which seeks to understand how parents of children with additional needs (specifically autism &/or intellectual disabilities) respond to and manage stigma they may experience. Before you decide whether to take part, it is important for you to understand why the research is being done and what participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

#### **What is the project's purpose?**

This project aims to understand parental experiences of negative attitudes and unfair treatment (jointly referred to as 'stigma' hereafter) in relation to their child's disability. It is hoped that by exploring parents' perspectives we will be able to develop our understanding of how parents resist stigma they may experience and that our research may go on to inform support for parents.

#### **Why have I been chosen?**

You have been invited to take part in this study, as you are a parent of a child with additional needs relating to autism &/or intellectual disabilities. Your child will be aged 10 or under. Your child will have also received a diagnosis relating to autism and/or learning disabilities over a year ago.

#### **Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. You can withdraw at any time without giving a reason and without it affecting any benefits that you are entitled to. If you decide to withdraw you will be asked what you wish to happen to the data you have provided up that point.

#### **What will happen to me if I take part?**

Should you choose to take part you will first be asked to complete a consent form and a general demographic questionnaire. We will then begin the interview. The interview will last approximately one hour. You can take breaks if needed. You can also stop the interview at anytime and your data will be removed from the study and

deleted. All your data will be kept securely and anonymised. Your data will also be deleted within 18 months of the interview. We will offer you a voucher for your time or we can donate to a charity of your choice if you prefer.

**Will I be recorded and how will the recorded media be used?**

The audio recordings of the interview made during this research will be used only for analysis for this research project. No other use will be made of them without your written permission, and no one outside the project will be allowed access to the original recordings. The audio recordings will also be deleted within 18 months of completing the interview.

**What are the possible disadvantages and risks of taking part?**

The investigator does not perceive more than minimal risks from your involvement in this study (that is, no risks beyond the risks associated with everyday life). However, we understand that this can be a sensitive topic and talking about it may cause some distress. If you feel upset you can immediately withdraw from the study. The researcher will also advise you where you can seek help if you would like some further support

**What are the possible benefits of taking part?**

Whilst there are no immediate benefits for those people participating in the project, it is hoped that this work will towards advancing our understanding of how parents of children with disabilities manage stigma that they may experience and what may help them in managing and resisting it.

**What if something goes wrong?**

For questions about your rights as a research participant or to discuss problems, complaints, or concerns about a research study, or to obtain information, or offer input, contact the research supervisor, Dr Katrina Scior, Research Department of Clinical, Educational & Health Psychology, University College London, 1-19 Torrington Place, London WC1E 7HB. You can contact Dr Scior by email at [k.scior@ucl.ac.uk](mailto:k.scior@ucl.ac.uk)

However if you feel that your complaint has not been handled then you can contact the Chair of the UCL Research Ethics Committee – [ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk)

**Will my taking part in this project be kept confidential?**

All the information that we collect about you during the course of the research will be kept strictly confidential. You will not be able to be identified in any ensuing reports or publications. Only the key researchers on this project will have access to your data. The main researcher on the project will transcribe the data and is the only person who will be able to identify you.

**Limits to confidentiality**

In certain exceptional circumstances where you or others may be at significant risk of harm, the researcher may need to report this to an appropriate authority and confidentiality will be broken, in accordance with the Data Protection Act 2018. This would usually be discussed with you first.

Examples of those exceptional circumstances when confidential information may have to be disclosed are:

- The researcher believes you are at serious risk of harm, either from yourself or others
- The researcher suspects a child may be at risk of harm
- You pose a serious risk of harm to, or threaten or abuse others

### **What will happen to the results of the research project?**

The result of the research project will be presented to peers and other professionals, as well as part of the researchers doctoral thesis. We also aim to publish the results of this study in a scientific journal, if you wish we could send you any published articles that are written from the findings of this research project.

### **Local Data Protection Privacy Notice**

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk)

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice; <https://www.ucl.ac.uk/legal-services/privacy/participants-health-and-care-research-privacy-notice>

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The categories of personal data used will be as follows:

Your child's ethnicity	Your ethnicity
Your child's gender	Your gender
Your child's age group	Your age group
Your child's disability	Your marital status
Your child's religion	Your religion

The lawful basis that would be used to process your *personal data* will be performance of a task in the public interest.

The lawful basis used to process *special category personal data* will be for scientific and historical research or statistical purposes.

Your personal data will be processed so long as it is required for the research project, approximately 18months. We will anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk).

### **Contact for further information**

For questions about the study, contact the lead researcher, Rachel Ransley, Research Department of Clinical, Educational & Health Psychology, University College London, 1-19 Torrington Place, London WC1E 7HB. You can contact Rachel by email: [rachel.ransley.14@ucl.ac.uk](mailto:rachel.ransley.14@ucl.ac.uk)

For questions about your rights as a research participant or to discuss problems, complaints, or concerns about a research study, or to obtain information, or offer input, contact the research supervisor, Dr Katrina Scior, Research Department of Clinical, Educational & Health Psychology, University College London, 1-19 Torrington Place, London WC1E 7HB. You can contract Dr Scior by email at [k.scior@ucl.ac.uk](mailto:k.scior@ucl.ac.uk)

**Thank you for reading this information sheet and for considering taking part in this research study.**

### Appendix 3



#### CONSENT FORM FOR PARENTS IN RESEARCH STUDIES

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

#### Experiences of stigma among parents of children with autism &/or intellectual disabilities

**Department:**

Research Department of Clinical, Educational & Health Psychology, University College London, 1-19 Torrington Place, London WC1E 7HB

**Name of the Researchers:**

Rachel Ransley (Trainee Clinical Psychologist), supervised by Dr Katrina Scior.

**Name and Contact Details of the UCL Data Protection Officer: [ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk)  
This study has been approved by the UCL Research Ethics Committee: Project ID number: CEHP/2016/551**

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

**I confirm that I understand that by ticking/initialling each box below I am consenting to this element of the study. I understand that it will be assumed that unticked/initialled boxes means that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element that I may be deemed ineligible for the study.**

		Tick Box
1.	I confirm that I have read and understood the Information Sheet for the above study. I have had an opportunity to consider the information and what will be expected of me. I have also <i>had the opportunity to ask questions, which have been answered to my satisfaction an individual interview.</i>	
2.	I understand that I will be able to withdraw my data up to 18months after the interview.	
3.	I consent to participate in the study. I understand that my personal information (general demographic data) will be used for the purposes explained to me. I understand that according to data protection legislation, 'public task' will be the lawful basis for processing.	
4.	I understand that my data gathered in this study will be stored anonymously and securely. It will not be possible to identify me in any publications.	

5.	I understand that my information may be subject to review by responsible individuals from UCL for monitoring and audit purposes.	
6.	I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason, without the care I receive or my legal rights being affected. I understand that if I decide to withdraw, any personal data I have provided up to that point will be deleted unless I agree otherwise.	
7.	I understand the potential risks of participating and the support that will be available to me should I become distressed during the course of the research.	
8.	I understand the indirect benefits of participating	
9.	I understand that the data will not be made available to any commercial organisations but is solely the responsibility of the researcher(s) undertaking this study.	
10.	I understand that I will not benefit financially from this study or from any possible outcome it may result in in the future.	
11,	I understand that I will be compensated for the portion of time spent in the study (if applicable) or fully compensated if I choose to withdraw.	
12.	I agree that others may use my anonymised research data for future research. No one will be able to identify you when this data is shared.	
13.	I understand that the information I have submitted will be published as a report and I wish to receive a copy of it.  Yes/No	
14.	I consent to my interview being audio/video recorded and understand that the recordings will be destroyed within 18months of recorded. During the 18month period all recordings will be stored anonymously, using password-protected software.	
15.	I hereby confirm that I understand the inclusion criteria as detailed in the Information Sheet and explained to me by the researcher.	
16.	I hereby confirm that:  (a) I understand the exclusion criteria as detailed in the Information Sheet and explained to me by the researcher; and  (b) I do not fall under the exclusion criteria.	
17.	I agree that my GP may be contacted if any unexpected results are found in relation to my health.	
18.	I have informed the researcher of any other research in which I am currently involved or have been involved in during the past 12 months.	

19.	I am aware of who I should contact if I wish to lodge a complaint.	
20.	I voluntarily agree to take part in this study.	
21.	I understand that other authenticated researchers working on the project will have access to my anonymised data.	

**If you would like your contact details to be retained so that you can be contacted in the future by UCL researchers who would like to invite you to participate in follow up studies to this project, or in future studies of a similar nature, please tick the appropriate box below. YES /NO (please circle)**

\_\_\_\_\_

Name of participant                      Date                      Signature

\_\_\_\_\_

Researcher                      Date                      Signature

## Appendix 4



### Experiences of stigma among parents of children with autism &/or intellectual disabilities

#### Pre-Interview Questionnaire

This questionnaire asks about demographic information about you and your child with autism and/or learning disabilities, as well as more information about your child's disability.

**We would like to create a unique identification code to ensure that your details stay anonymous.**

**Please write down:**

**The first two letters of your surname** \_\_\_\_\_

**The month of your date of birth** \_\_\_\_\_

**About you:**

**Gender:** Female  Male  Prefer to self-describe: \_\_\_\_\_  
Prefer not to say

**Age:** 16-20  21-30  31-40  41-50  51-65   
66+

**Vocation/ Employment:** \_\_\_\_\_

**Marital Status:** Married  Living with partner  Separated   
Divorced  Single  Other: \_\_\_\_\_

**Religion:** No religion  Hindu  Sikh   
Christian  Jewish  Buddhist   
Muslim  Prefer not to say  Atheist   
Any other religion: \_\_\_\_\_



**Ethnicity:**

*White*

British

Irish

Any other White background  
\_\_\_\_\_

*Asian/Asian British*

Indian

Pakistani

Bangladeshi

Any other Asian background  
\_\_\_\_\_

*Chinese and other ethnic background*

Chinese

Any other ethnic background  
\_\_\_\_\_

*Mixed*

Black Caribbean and White

Black African and White

Asian and White

Any other mixed background \_\_\_\_\_

*Black/British*

Caribbean

African

Any other Black background \_\_\_\_\_

**About your child:**

**Child's Gender:** Female  Male  Prefer to self-describe: \_\_\_\_\_  
Prefer not to say

**Child's Age:** \_\_\_\_\_

**Child's Religion:** No religion  Hindu  Sikh

Christian  Jewish  Buddhist

Muslim  Prefer not to say

Any other religion: \_\_\_\_\_

**Child's Ethnicity**

*White*

British

Irish

Any other White background  
\_\_\_\_\_

*Asian/Asian British*

Indian

Pakistani

Bangladeshi

Any other Asian background  
\_\_\_\_\_

*Chinese and other ethnic background*

Chinese

Any other ethnic background  
\_\_\_\_\_

*Mixed*

Black Caribbean and White

Black African and White

Asian and White

Any other mixed background \_\_\_\_\_

*Black/British*

Caribbean

African

Any other Black background \_\_\_\_\_

Type of disability/special needs (e.g. Autism, epilepsy, ADHD, learning disabilities):

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

How old was your child when their disability was diagnosed? \_\_\_\_\_

## Appendix 5



### RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL AND HEALTH PSYCHOLOGY

#### Experiences of stigma among parents of children with autism &/or intellectual disabilities

#### Semi-Structured Interview Schedule

##### Introduction

The following points will be discussed with participants:

- Informed Consent.
- The structure and length of the interview.
- Note taking and use of recording device.
- Confidentiality and data storage.
- What language/terminology participants would prefer the interviewer to use in reference to their child's autism or intellectual disabilities? Where \_\_\_\_\_, insert the parents preferred terminology.
- Introduce concept of stigma; what terms/ language does the participant use? Use this term throughout the interview.

**1) Tell me a bit about you and your family, and your life right now?**

**2) Before we think a bit about your experiences as a parent, could you tell me a little bit about "X" so I get a sense of who they are?**

- a. Strengths and difficulties? Personality?
- b. At what point in their journey through life did you wonder if they developing differently to other children their age?
- c. Would you describe their \_\_\_\_\_ as visible or noticeable?
- d. Does your child prefer to communicate? (verbally/sign language)
- e. Does your child experience what some people might describe as 'challenging behaviour' or 'unusual behaviour'?
- f. What do you think your child's understanding of their \_\_\_\_\_ is?

**3) Before having "X", how much did you know about people with \_\_\_\_\_?**

- a. Before having "X", did you know anyone with \_\_\_\_\_? How close were you to them?

**4) Did having "X" change your views about people with \_\_\_\_\_?**

**5) How have your (friends/ family) responded to X's \_\_\_\_\_? (Repeat for both friends and family).**

- a. What do you think their understanding of \_\_\_\_\_ is?

- b. Can you give me an example? Have their responses changed over time?
- c. (Follow-up to ensure that answers given for both friends and family)

**6) Would you describe yourself as being part of a community, perhaps a cultural community or religious community? (If “no” move to question 7) Within that community how have people responded to “X’s” \_\_\_\_\_?**

- a. What do you think their understanding of \_\_\_\_\_ is?
- b. Can you give me an example? Have people’s responses changed over time?

**7) How do strangers respond to you and “X” when you’re out and about with them?**

- a. Describe your most memorable best/worst experience with a stranger
- b. Has this changed over time?

***(Repeat what stigma is and our specific focus on Stigma Resistance!)***

**9) Do you feel as though your child faces negative attitudes, prejudice or discrimination (what some call ‘stigma’) from others due to their \_\_\_\_\_?**

- a. Can you give me an example?

**10) Do you feel as though you as a parent of a child with \_\_\_\_\_ have experienced negative attitudes, prejudice or discrimination (what some call ‘associate stigma’)?**

- a. Can you give me an example? *(Look for examples at different levels; personal, family, peer, public and organisational).*
- b. *For each example, ask;*
  - a) What was it that specifically felt stigmatising?
  - b) How did you managed in the moment? What did you do?
  - c) After a few hours how did you feel? What did you do?
  - d) Looking back now is there anything you would have done differently?
  - e) Range of experience and is this how you would generally react

**11) Have you experienced any situations with a co-primary carer (e.g. other parent of child) where you have both feel stigmatized?**

- e) How did you both react in this situation?
- f) Is this normally how you both would react?

**12) Do you feel like you have the space to, and are able to, speak about these experiences with your friends, family or other people?**

- a. Can you give me an example?

**13) How have these experiences affected you, as both a parent and as a person?**

- a. How you manage your own wellbeing?

**14) What enables you or supports you, to manage these experiences?**

- a. What is it about you? (Personality? Skills? Experience?)
- b. What is it about the people around you?

**15) Do you have any advice you would give to other parents of children with \_\_\_\_\_ to help them manage these types of experiences?**

- a. Both in the moment and after the event. (*Look for examples at different levels; personal, peer, public and organisational*).

**16) What are some of the positives of parenting a child with \_\_\_\_\_ that you would want to share with others?**

**We have now come to the end of the interview. I would now like to ask you if there is anything else you would like to tell me about you, your family or your child's experiences that you think is important?**

**Thank you again for sharing your experiences and talking with me today.**

Appendix 6

Pseudonym "Helen" used

do. So I walk away, and then go "damn, I should have said something."

*Helen - Strangers - Now*  
leaving situation  
*Helen - Strangers - Now*  
7  
regretting not challenging stigma

R [00:23:49] Yeah. How do you manage that with strangers?

HF [00:23:51] Like I said early on the tube I feel able to be like "autism awareness", but when it's one on one, it's much trickier.

*Helen - Strangers - past*  
Trying to help ppl understand but not apologies  
*Helen - Strangers - Now*  
Finding it harder with Strangers 1:1

R [00:24:00] And does it ever feel stigmatizing to you as a parent?

HF [00:24:02] Oh, definitely, because I feel judged okay. Because they look and tutting, but not just about him. I don't think. They are also tutting because I'm not doing the discipline they think I should be doing. I remember when S was about four and he really just started asking for things, maybe even five years old. It was very late. And he said, "can I have some water", which was massive. This lady went "Excuse me, say please, what kind of behaviour is that". I was like "oh my god".

*stranger - feeling judged parenting*

*Helen - Strangers - Now/past*  
Being judged & tutted at as a parent  
*Helen - Strangers - Now/past*  
Viewing her as not parenting / disciplining child  
*S - past*  
Meeting milestone / achieving goal

R [00:24:33] What did you do in that moment?

HF [00:24:35] I just I just ignored it. But now you see, I'd say something. I would be like "actually he has got autism, and this is a massive deal he asked for something, and I want to high five him, not tell him off." But at the time I was mortified, I was like "why would you say that?".

*Stranger - Ignoring*

*Being criticised stranger and punished*  
*ignoring it*  
*Helen - Strangers - past*  
Reflecting that would now respond differently  
*Helen - Strangers - past/Now*  
Being embarrassed at Strangers response

R [00:24:50] Yeah. And do you think that in those moments you're someone who tends to confront? Or would you be someone who tends to sort of deflect?

HF [00:25:04] I am definitely conflict averse. I either ignore it or I go, "well, you know..." But sometimes I've just gone no enough.

*Helen - Now*  
being conflict averse  
*Helen - Strangers*  
Ignoring - Now  
*Helen - Strangers - Now*  
calling things out

R [00:25:12] What's led to you doing "no it's enough"? What do you think?

HF [00:25:15] I remember one time when that's happened it was an old man in the street. He said to S "your very, your very rude and very something", I can't remember exactly what it was. I said "you are very rude." I just couldn't help myself. I was just like, "you don't understand what's going on here. Please leave us alone."

*Stranger stigmatizing child*  
*Dependent child*

*strangers - S - past*  
stigmatizing child  
*Helen - Strangers - past*  
Responding with impulse  
*Helen - Strangers - past*  
Telling Strangers they have no understanding of situation

R [00:25:32] Yeah. What led you to have that reaction, do you think?

# HELEN

More impulse  
to confront  
if stigma  
towards child

feeling false sense  
of acceptance  
as ASD community  
so accepting & welcoming

Meeting "societal  
norms"  
↳ mother/daughter  
conflict

Learning over time  
how to manage  
stigma

Having to explain  
to friends children  
↳ maintaining stigma

Defusing situation  
"ASD awareness"  
↳ NOT apologising

More likely to  
engage in  
conversations  
with family

↳ Harder  
with strangers

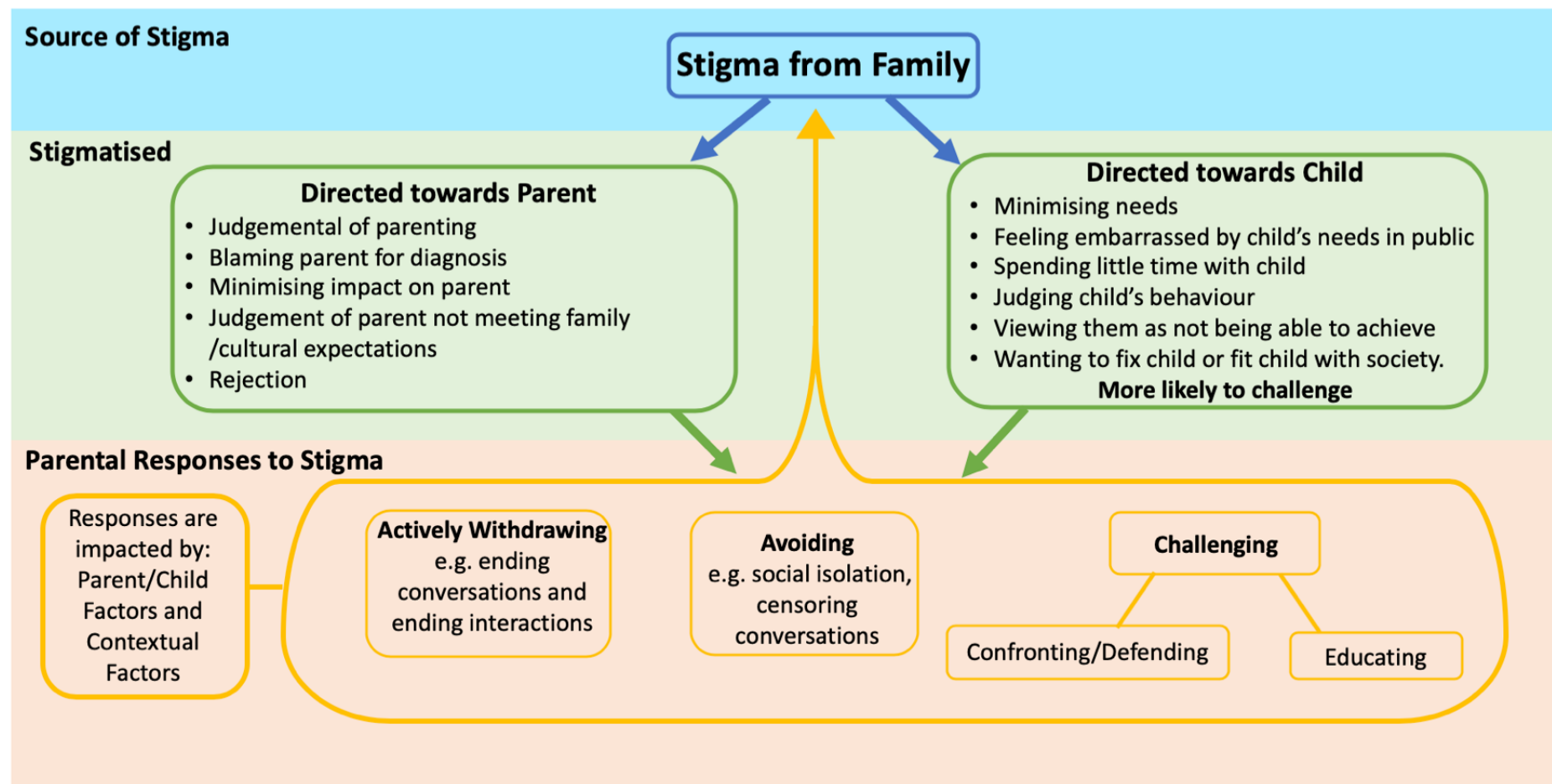
Mother - compare  
parenting →  
judging  
parenting

Having shared understanding  
with family/friends  
with autistic child.

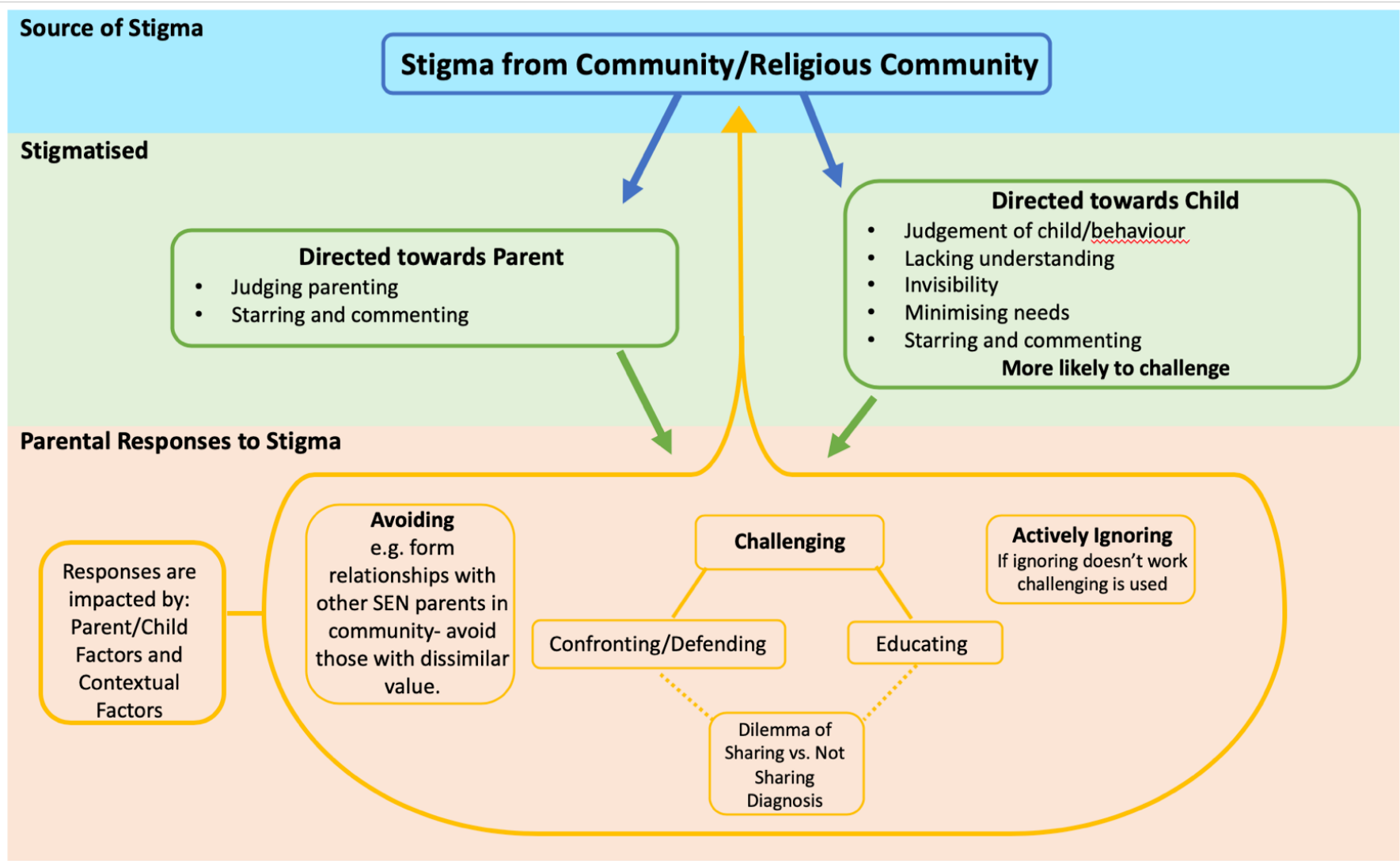
Defending / confronting  
stigma directed  
@ child.

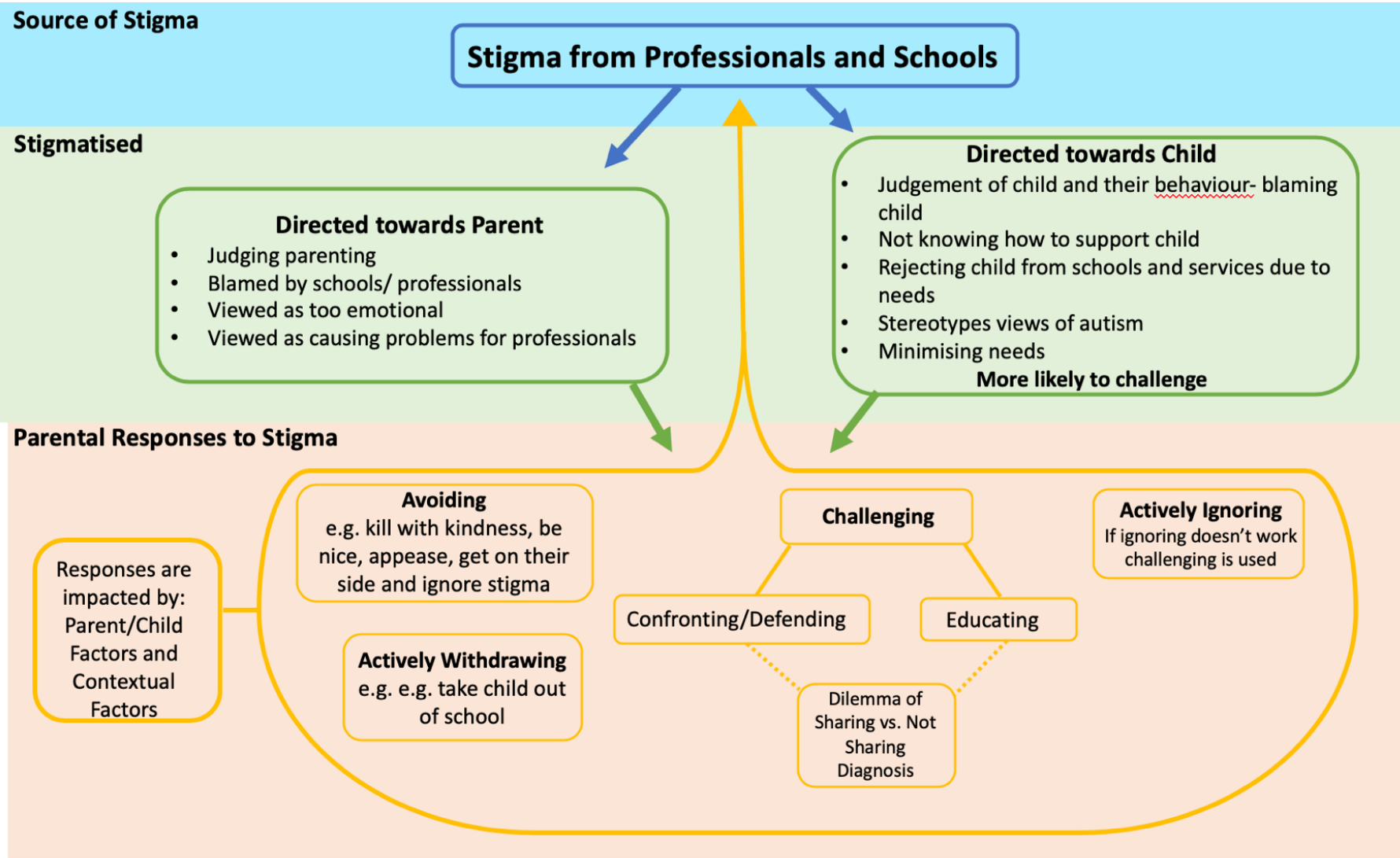
Accepting but  
minimising / lacking  
understanding

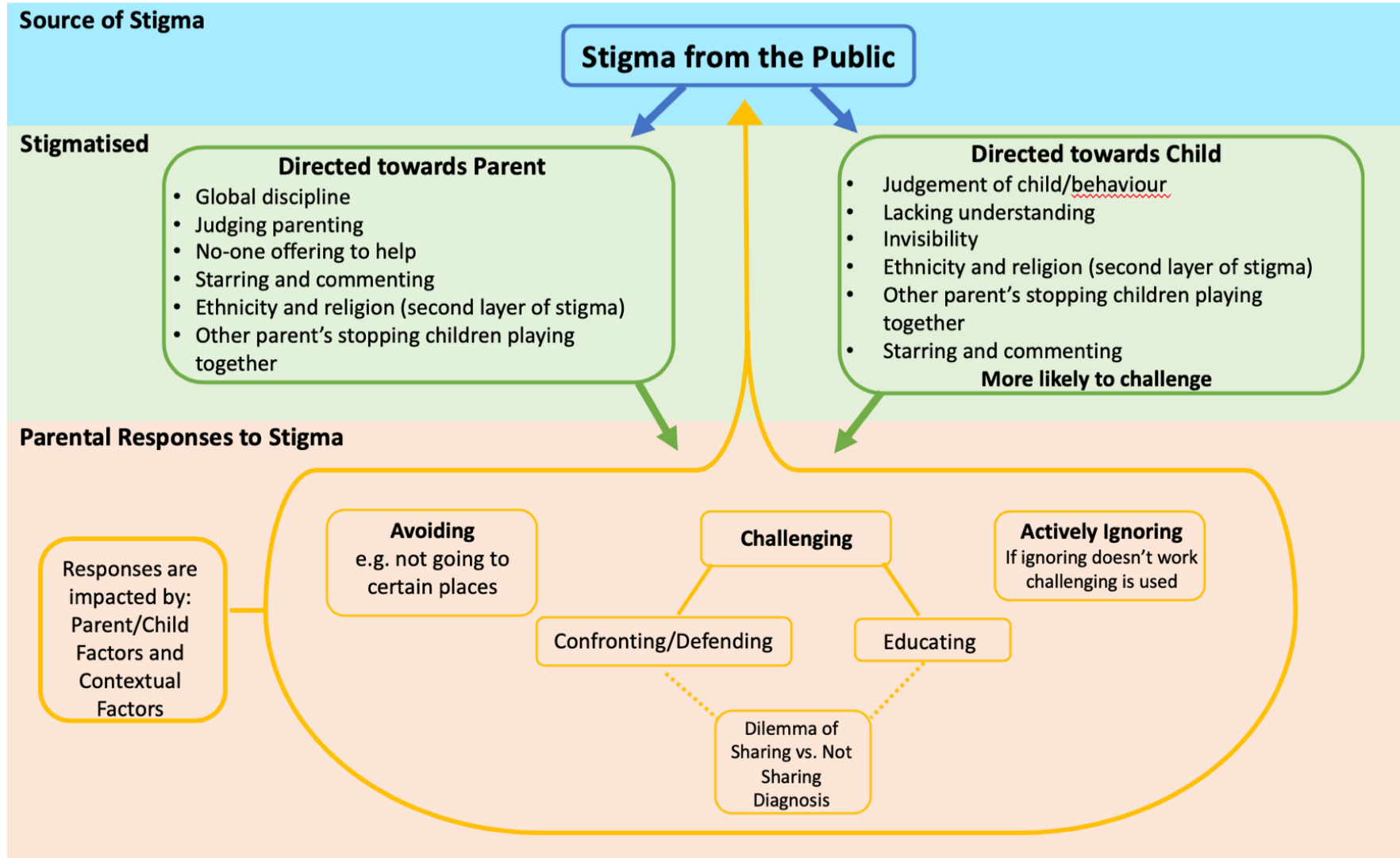
## Appendix 7

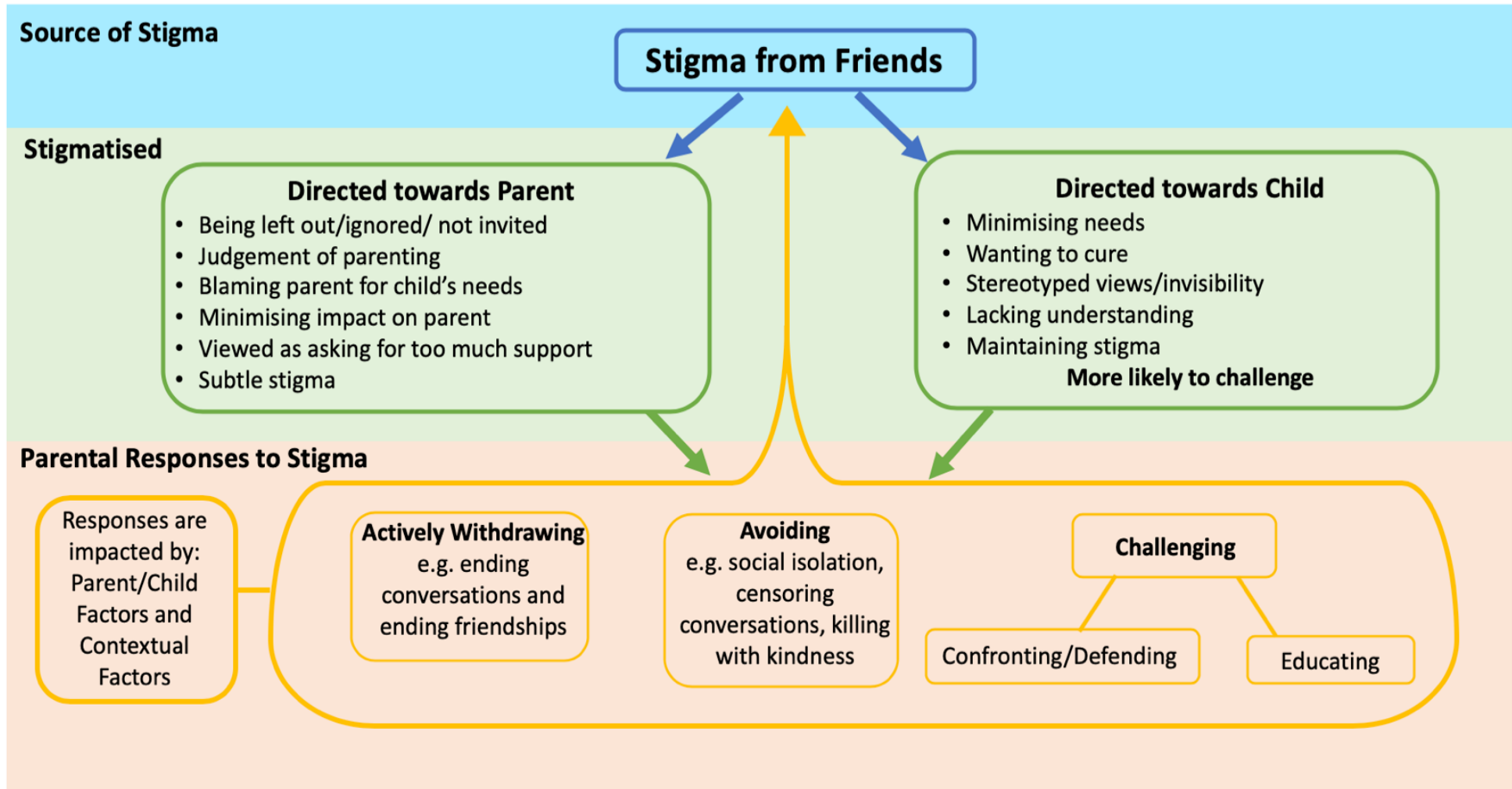




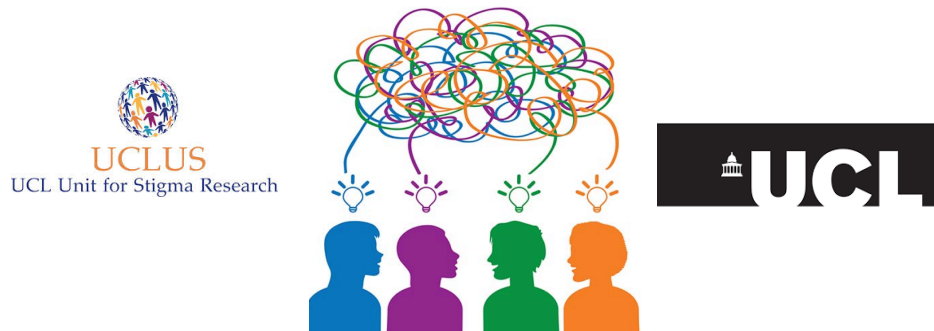








## Appendix 8



### Researching Together

**We are seeking parents of children (Aged 10 & under) with autism and/or learning disabilities to advise us on research.**

#### **What we are researching?**

We are researching how parents respond to and manage stigma they may experience in their daily lives related to their child's disability.

#### **Who are we?**

Researchers at the UCL Unit for Stigma Research (UCLUS) are conducting this research study

#### **How can you get involved?**

We are looking to recruit a small group of parents to advise us on the best ways to help parents speak about stigma they may have experienced. We will invite interested parents to meet with us in person or speak over the phone to hear their views on the research project and the materials we are developing for this study.

#### **Are you interested?**

If you are interested in advising us on this study and would like more information please contact the lead researcher at: [rachel.ransley.14@ucl.ac.uk](mailto:rachel.ransley.14@ucl.ac.uk)

## Appendix 9



**Are you a parent or carer of a child (aged 10 or under) with autism and/or learning disabilities?**

**Have you experienced stigma or discrimination in your daily life, relating to your child's difficulties?**

**Would you like to share your experiences with us?**



### **What the research is about:**

We are researching how parents and carers respond to and manage stigma or discrimination they may experience in their daily lives related to their child's difficulties.

### **How you can get involved:**

We are looking for parents and carers of children (aged 10 or under) with learning disabilities and/ or autism, whose child received a diagnosis over a year ago to take part in our research.

Participating in the research involves meeting with a researcher for a confidential hour-long interview to talk about your experiences of stigma as a parent or carer. You would be invited to visit UCL or a London-based charity, to carry out these interviews (home visits for the interviews may be possible in London locations). If you take part in the interview you will be compensated for your time as well as your travel expenses.

### **Who we are:**

Researchers at the UCL Unit for Stigma Research (UCLUS) are conducting this research study.

If you are interested in taking part in this study and would like more information please contact the lead researcher at:

[rachel.ransley.14@ucl.ac.uk](mailto:rachel.ransley.14@ucl.ac.uk)



## Appendix 10

### Support in Walthamstow

- **Waltham Forest Parent Forum -**  
<http://www.walthamforestparentforum.com/> Vanessa Moore - 07528 433640 - Carol Prideaux - 07794 298496 or  
[info@walthamforestparentforum.com](mailto:info@walthamforestparentforum.com)
- **Waltham Forest Parent Forum Dad's Group - e-mail:** [danny.herbert@me.com](mailto:danny.herbert@me.com)
- **Waltham Forest SENDIASS -**  
The Special Educational Needs Disability Information Advice and Support Service provided by Citizens Advice Bureau in Waltham Forest is a confidential service. [wfsendiass@walthamforestcab.org.uk](mailto:wfsendiass@walthamforestcab.org.uk) or call on 0300 330 1175
- **The Engine Shed – for train loving children- North London-**  
[theengineshed@hotmail.co.uk](mailto:theengineshed@hotmail.co.uk)
- **Picture-house cinema-** Autism friendly cinema showing  
- <http://pheducation.wixsite.com/pheducation/autism-friendly>
- **The Limes – Children Centre for children with additional needs-**  
[admin@thelimes.org.uk](mailto:admin@thelimes.org.uk)
- **Local Offer-** guide to all services available in Waltham Forest for children with additional needs. [localoffer@walthamforest.gov.uk](mailto:localoffer@walthamforest.gov.uk).  
<https://directory.walthamforest.gov.uk/kb5/walthamforest/directory/localoffer.page?directorychannel=1-2>
- **Independent Provider of Special Education Advice -**  
<https://www.ipsea.org.uk/>
- **SOS SEN -** Independent advice for special education need and disabilities –  
[www.sossen.org.uk](http://www.sossen.org.uk)
- **Waltham Forest Talking Therapies-** Adult Psychology/Counselling services- either self-refer at [wftalkingtherapies.co.uk](http://wftalkingtherapies.co.uk) or as GP for a referral, or call on 0300 555 1271
- **Kids Charity –** [www.kids.org.uk](http://www.kids.org.uk)
- **KEEN London –** one- to- one support at free sports and activity sessions for children with additional needs <https://www.keenlondon.org/>
- **Autistica Charity –** [www.autistica.org.uk](http://www.autistica.org.uk)